# Kidney supportive care:

Establishing a model of service delivery in Western Australia

# **Consultation DRAFT**

(September 2025)

Classification: Official

### Acknowledgement of Country and People

The Western Australian (WA) Department of Health acknowledges the Aboriginal people of the many traditional lands and language groups of WA. It acknowledges the wisdom of Aboriginal Elders both past and present and pays respect to Aboriginal communities of today.

#### 'Using the term Aboriginal'

Within WA, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of WA.

Aboriginal and Torres Strait Islander may be referred to in the national context and Indigenous may be referred to in the international context.

No disrespect is intended to our Torres Strait Islander colleagues and community.

#### Corporate acknowledgement

The WA Department of Health acknowledges the following documents as foundational guide for the development of this WA Kidney Supportive Care Model of Service:

- NSW Renal Supportive Care Service Model <sup>1</sup> and Implementation Strategy and Evaluation Plan. <sup>2</sup>
- Davison et al. Conservative kidney management and kidney supportive care: core components of integrated care for people with kidney failure. Kidney International. 2024. 3

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# Introduction

In 2012, the Western Australia (WA) Renal Health Network identified kidney supportive care (KSC) as a strategic priority and developed the *Pathway for Renal Palliative Care Services in Western Australia*. <sup>4.</sup> Since then, KSC has been recognised globally as an established core component of comprehensive kidney care. This shift has been driven by the significant burden of chronic kidney disease (CKD), its poor health outcomes, financial impact on healthcare systems, and under-utilisation of palliative care services. <sup>5</sup> Together with increasing engagement from the renal community, this evolving landscape highlights the need to update the 2012 policy to reflect and implement current best-practice KSC.

## What is kidney supportive care?

Kidney supportive care (KSC) is formally defined as 'an approach that aims to improve the quality of life for people for whom kidney disease, either directly or indirectly, substantially impacts their well-being, treatment options, or access to care, and their families, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.' <sup>3</sup> (p 38) Grounded in palliative care principles, KSC is a holistic, integrated, person-centred approach to support individuals and their families across all stages of kidney disease and the various treatment options such as conservative kidney management (CKM), dialysis, and transplantation. <sup>6</sup> KSC includes key components such as shared decision-making, advance care planning (ACP), symptom control, and end-of-life care.

## What is conservative kidney management?

Conservative kidney management (CKM) is an important patient-centred treatment alternative for individuals with advanced CKD who choose not to pursue dialysis or kidney transplantation. CKM focuses on maintaining quality of life through symptom relief, management of complications, slowing CKD progression and holistic supportive care. <sup>7</sup>

#### How do KSC and CKM differ?

While KSC and CKM have a shared focus on improving quality of life, they are distinct concepts that should not be used interchangeably. KSC is a comprehensive care approach that applies to all CKD patients, regardless of their treatment choices. § 9 In contrast, CKM is a specific treatment pathway for those with kidney failure who opt out of dialysis or transplantation. § In short, KSC provides an overarching philosophy framework of care, while CKM is a treatment option for kidney failure which sits within this framework.

#### How is KSC service delivered internationally and in Australia?

As part of the review of KSC in WA, both international and national models were examined, and various models were identified (refer to Appendix A). Below is a summary of the types of models currently being utilised: 8 10 11

- comprehensive regional or system-wide programs
- coordinated multidisciplinary team (MDT) model embedded within nephrology services
- separate multidisciplinary clinics
- renal clinicians providing simultaneous KSC and renal care services
- outreach model from visiting specialty palliative care team
- CKD case management models.

#### Current policy context

The KSC model of service delivery is informed by and aligned with both national and statelevel strategies, policies and frameworks. Key guiding documents include:

- WA Country Health Service Kidney Disease Strategy 2021–26 <sup>12</sup>
- WA End-of-Life and Palliative Care Strategy 2018–2028 <sup>13</sup>
- WA Health Renal Dialysis Clinical Governance Framework 14
- Sustainable Health Review: Final Report to the Western Australian Government <a href="#">15</a>
- National Strategic Action Plan for Kidney Disease <a href="#">16</a>
- Joint position statement from Palliative Care Australia and Kidney Health Australia on Palliative Care for Chronic and End-stage Kidney Disease (2018).

# Purpose and scope of the Kidney Supportive Care Model of Service Delivery in Western Australia

This document provides a strategic framework for the statewide implementation of a coordinated, best-practice KSC model of service delivery in WA. The model aims to improve equity, access, and quality of care for individuals with advanced CKD, through a holistic, person-centered care approach that integrates renal, palliative care and primary health care (PHC) services. This document also explicitly acknowledges the disproportionate burden of kidney disease experienced by Aboriginal peoples and supports development of Aboriginal-specific KSC services through genuine co-design processes. KSC is intended to complement and not replace standard renal care or specialist end-of-life services.

This is a foundational guide to policy development, service planning, and phased implementation of KSC services in WA. This model applies to adults (aged ≥18 years) with advanced CKD (eGFR ≤15 mL/min/1.73m²), including those on dialysis, those with a kidney transplant, and individuals who choose CKM. While providing a structured framework, the model is designed to be customisable to meet the needs of diverse communities and aligned with available resources in various health care settings.

#### Implementation considerations

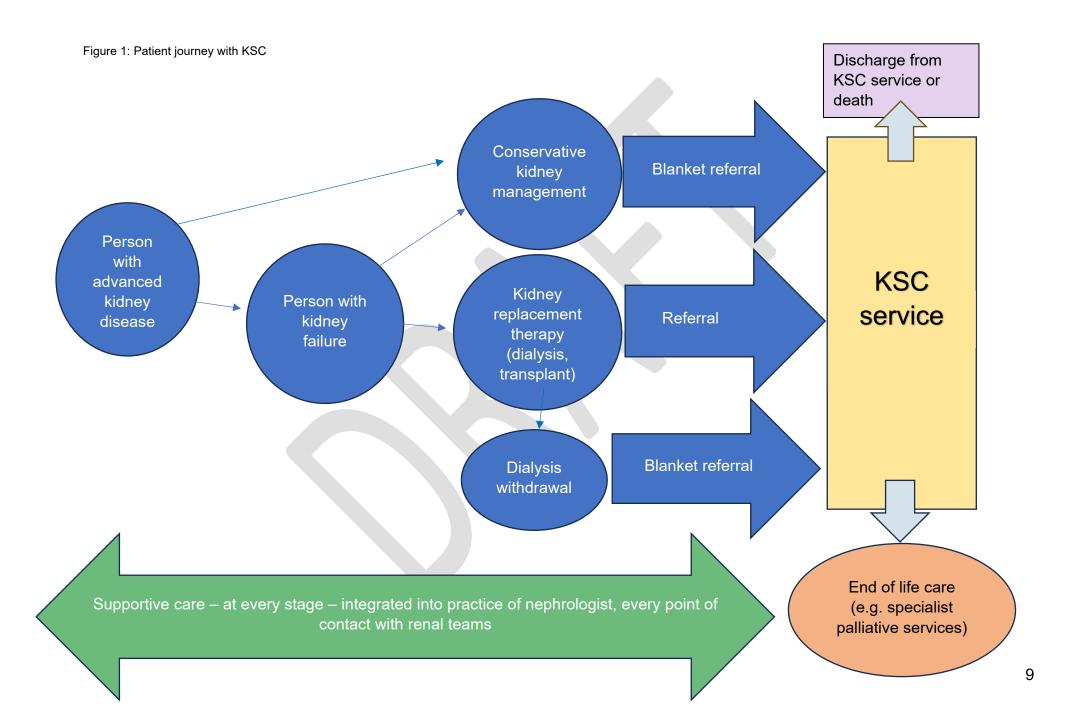
A key challenge identified is the integration of the private healthcare sector within a primarily public healthcare framework. Additionally, the absence of detailed implementation plan and adequate resourcing has historically limited the implementation of previous KSC initiatives.

#### Target patient population

Patients with advanced CKD, including those on dialysis, or with a kidney transplant may be appropriate for referral to the KSC team if they meet one or more of the following criteria:

- 1. need support in making decisions about kidney treatment options
- 2. have chosen or medically advised to pursue CKM
- 3. are experiencing significant symptom burden related to advanced CKD
- 4. are undergoing physical and functional decline from advanced age, frailty, or multiple co-morbidities
- 5. require assistance in making informed decisions about future care including ACP
- 6. are approaching end-of-life care.

Patients may engage with KSC services at various points during their care journey. See Figure 1 which illustrates the KSC patient journey. KSC services must be flexible and responsive to changes in health status, treatment goals and priorities as patients enter, pause or exit the KSC service.



# Considerations for priority populations

Some groups in WA face greater barriers to kidney care and experience worse health outcomes. Understanding their diverse needs and their intersectionality is key to delivering person-centred, equitable kidney care. Table 1 below summarised key considerations for priority populations.

Priority	Key considerations
populations	
Aboriginal people	Aboriginal people experience persistent disparities in access to kidney care, resulting in worse outcomes. These disparities are rooted in historical and ongoing impacts of colonisation, systemic racism, discrimination, and cultural bias within the healthcare system. To address these inequities, it is essential to build and maintain strong partnerships with Aboriginal Community Controlled Health Services (ACCHS) and Aboriginal communities. KSC services should be culturally safe, accessible and effectively communicated – particularly in relation to endof-life care discussions.  It is critical to include ongoing cultural safety training for staff and integrate Aboriginal workforce within KSC teams. There is also a need to validate existing KSC symptom burden assessment tools in Aboriginal populations to ensure they reflect the lived experiences, needs, and preferences of Aboriginal people receiving kidney care.
People living	Aligned with the WA Country Health Service (WACHS) Kidney Disease
in rural,	Strategy 2021–2026 $\frac{12}{}$ , the principle of right care, right time, right place is
remote and	essential to delivering kidney care for people living in rural and remote
very remote	areas. The following key priorities should guide KSC service:
areas	<ul> <li>access to care close to home to reduce need for relocation or travel.</li> <li>Telehealth and virtual support to reduce need for travel and improve continuity of care.</li> <li>transport and accommodation assistance to access specialist services</li> </ul>
	should be supported.
People from Culturally and Linguistically Diverse (CaLD) backgrounds	Effective engagement with people from CaLD backgrounds is required for the delivery of culturally safe, trauma-informed, and culturally sensitive KSC service. Health professionals must proactively connect with relevant staff or services to ensure that KSC is culturally appropriate, and care decisions are clearly and effectively communicated. This may include the use of accredited interpreters, multicultural liaison services, translated fact sheets and refugee services, as required (Please refer to the WA Department of Health mandatory <i>Language Services Policy</i> 18).

# People with disability

For a comprehensive guidance on supporting people with disability, refer to A Guide for hospital staff. 19 KSC staff should proactively discuss and implement care adjustments for people with disability following local site procedures. Staff training in the Hidden Disability Sunflower initiative is encouraged to enhance responsiveness to individuals with non-apparent ('hidden') disability. Supported decision making (see Glossary for definition) principles must be embedded in all aspects of clinical practice, staff training and organisational policy to ensure that informed consent is appropriately obtained. With the person's consent, active engagement with their support system is encouraged to enable meaningful participation in discussions about their care. Staff must have access to appropriate tools/resources required e.g. extended consultation time, use of information and consent forms in accessible formats. 20 For individuals with complex communication or behavioural needs, KSC staff should engage with someone who knows the person well to better recognise and respond to the signs of distress, pain, and other symptoms. If required, Augmentative and Alternative Communication (AAC) methods 21 should be consistently applied throughout the healthcare experience.

# LGBTQIA+SB people

LGBTQIA+SB individuals can experience distinct health risks and barriers to care arising from stigma, discrimination and limited access to inclusive, culturally safe healthcare services which can negatively impact on access to and engagement with KSC services. To address these health inequities, it is important that KSC services actively engage with LGBTQIA+SB consumers to identify service gap and ensure that staff receive education on delivering a KSC service that affirms individual identities, acknowledges experiences and support systems.

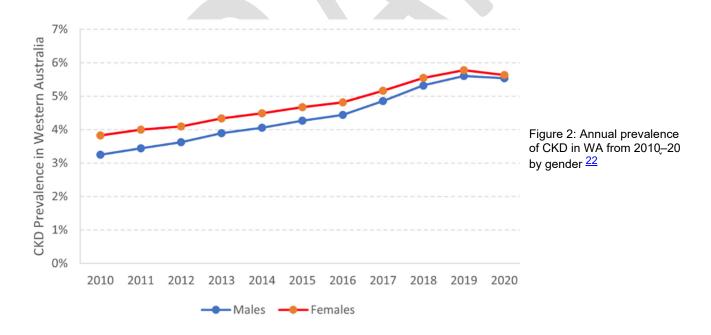
Table1: Key consideration for priority populations

# Why is there a need for a coordinated KSC service in WA?

KSC is increasingly recognised as a vital component of comprehensive kidney care and best-practice nephrology. <sup>3</sup> In WA, the need for a coordinated KSC services is in response to the rising prevalence of CKD, increasing complexity of patient care needs and persistent disparities in access to care for Aboriginal people and those living in rural and remote regions.

## Rising demand for kidney services

Consistent with global trends, a retrospective analysis of linked pathology data from over 2 million West Australians (2010–20) reported a **rising prevalence of CKD**, with a disproportionate impact on **older individuals**, those living in **rural and remote regions**, and individuals experiencing **socioeconomic disadvantage** (see Figure 2 and 3). <sup>22</sup> In addition, a recent Haemodialysis (HD) capacity survey identified Perth as having one of the highest HD patient-to-chair ratio in the country at 3.92 patients per chair, compared to the national average of 3.33. <sup>23</sup> National projections estimate that dialysis prevalence is expected to rise by 22.5 per cent to 30.4 per cent by 2030. <sup>24</sup> These findings highlight current and future demand on dialysis services and infrastructure in WA.



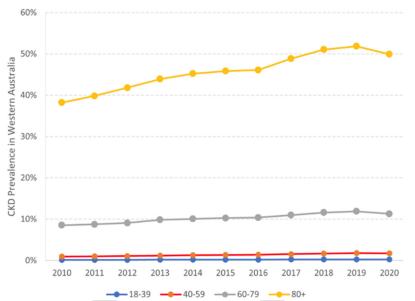


Figure 3: Annual prevalence of CKD in WA from 2010–20 by age 22

#### Complexity and vulnerability in dialysis patients

A 2020 survey in over 700 dialysis patients from tertiary incentre and satellite dialysis units in WA found that only 25 per cent met criteria for standard care, based on the Renal Dialysis Patient Dependency Classification Instrument HD acuity tool. <sup>25</sup> Notably, 8.4 per cent were classified as extremely frail, with Clinical Frailty Score greater than 7 (Cohen et al, abstract submitted to ANZSN 2025). Frailty is associated with poorer health outcomes, including higher rates of hospitalisation and increased mortality. <sup>26</sup>

# High symptom burden and reduced quality of life

Patients with CKD frequently experience poor quality of life with high symptom burden. <sup>27</sup> <sup>28</sup> Individuals living with kidney failure report worse self-assessed quality of life scores compared with other chronic conditions. <sup>29</sup> In addition to physical symptoms, many face difficult treatment decisions. In some cases, quality of life is prioritised over life-prolonging interventions, resulting in decisions to withdraw from dialysis and transition to end-of-life care. <sup>30</sup>

#### Economic burden of CKD

CKD places a substantial financial burden on the WA Health System with an estimated cost of \$704 million in 2019 alone. The primary cost drivers included hospitalisations, dialysis treatment and medication cost.  $\frac{31}{2}$ 

## Burden of kidney disease in Aboriginal People

Aboriginal communities show strong resilience in the face of significant health challenges, including CKD. WA has one of the highest incidence rates of kidney failure among Aboriginal

people, with rates at 5.8 times higher than for non-Aboriginal people, after adjustment for age. <sup>30</sup> A significant proportion of Aboriginal dialysis patients live in regional and remote areas (see Figure 4), <sup>32</sup> where access to culturally safe, locally led kidney services is critical.

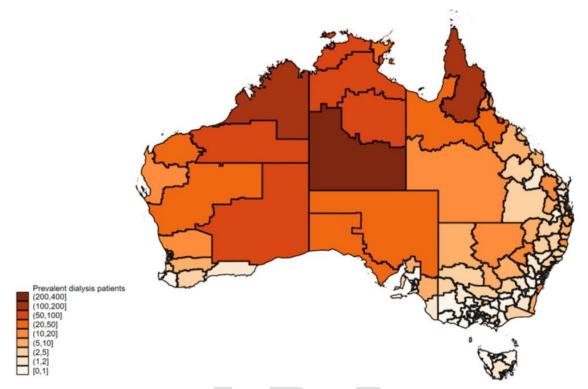


Figure 4: Prevalent Aboriginal and Torres Strait Islander people dialysis patients 2023 - by Statistical Area Level 3 32

#### Current KSC services in WA

The current care pathways for patients with advanced CKD in WA who are frail or seriously ill show significant service gaps. These deficiencies negatively impact on patient and family wellbeing and contribute to preventable hospital and intensive care admissions. Refer to Figure 5 for the current gaps in patients pathway through the CKD journey. § KSC services in WA remain limited in scope and show considerable variation in service models, workforce structures, referral pathways and access to care, driven by local resourcing and capabilities (Refer to Appendix B for summary of existing KSC services). Currently, there is no central oversight, no established quality benchmarks, no mechanism to assess service impact or patient outcomes, and no formal governance structure.

This fragmented approach poses significant risk of inconsistencies in quality of care and patient experience, inequities in access to care, inefficiencies and duplication in workforce and service planning, and limited capacity to expand services to meet demand.

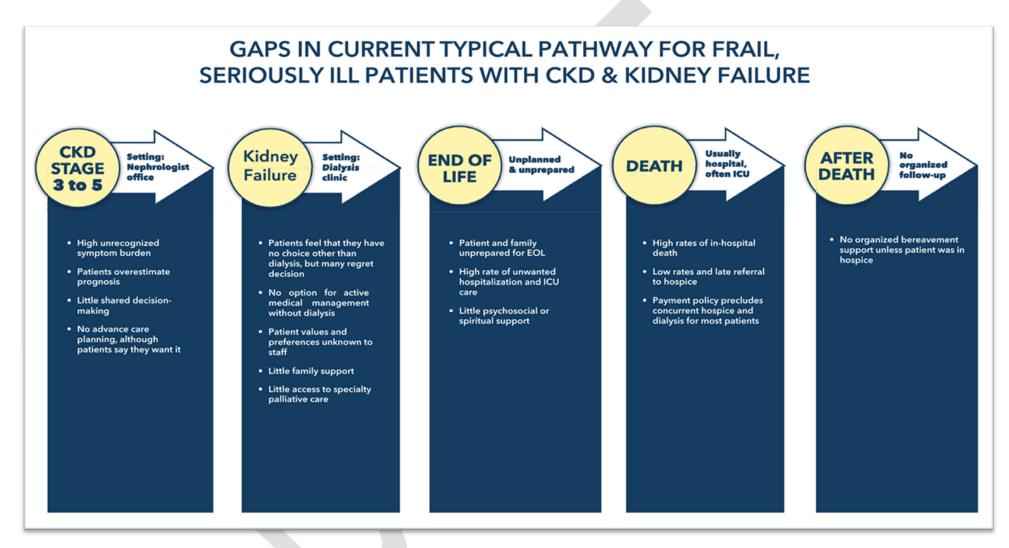


Figure 5: Gaps in current patient pathway through the chronic kidney disease journey

Reprinted from Lupu D, Moss AH. The Role of Kidney Supportive Care and Active Medical Management Without Dialysis in Supporting Well-Being in Kidney Care. Semin Nephrol. 2021;41(6):580–91 with permission from Elsevier 8

#### The need for action

The current fragmented approach KSC service is no longer adequate to meet the needs of WA's growing CKD population – many of whom are older, frail, and multimorbid with complex care needs. The time is now to strategically invest in establishing a coordinated, efficient, statewide KSC service that delivers standardised, culturally responsive, high-quality and patient-centred care across diverse healthcare settings and workforce capability.

# Key components of the WA KSC model of service

The following section outlines the core pillars of the WA KSC service, overarching objectives and suite of service activities to guide implementation.

## Core pillars of KSC

## Shared decision-making

Shared decision-making is the cornerstone of patient-centred care and is particularly important in advanced CKD, where individuals often face complex and life-altering treatment decisions. <sup>33</sup> Key components of effective shared decision-making include:

- establishing a strong therapeutic relationship based on trust, empathy and open communication
- providing clear, honest and comprehensive information about diagnosis, prognosis, and all available treatment pathways
- discussing estimates of prognosis including potential impact of treatment options on quality of life, functional status and symptom burden
- **collaboratively determining a care plan** that aligns with patient's values, life circumstances, goals, and preferences. 33

# Advance care planning (ACP)

Advance care planning (ACP) is a voluntary 'process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making in the future time when a person cannot make or communicate their decisions.' <sup>34</sup> (p 4) The 4 key elements of the ACP process are:

- **Think**: Initiate early, open and ongoing discussions about future care preferences.
- **Talk:** Engage in meaningful conversations in a supportive environment, informed by relevant clinical information and patient values.
- Write: Provide guidance on when and where to document ACP decisions.
- Share: Encourage individuals to share ACP documents with family members, carers and healthcare providers. 35

For further information, refer to WA-specific ACP documents resources are available at:

https://www.health.wa.gov.au/Articles/A E/Advance-Care-Planning/Training-and-resources (Health Professional Guide to Advance Care Planning in Western Australia 35) and www.healthywa.wa.gov.au/AdvanceCarePlanning.

#### Symptom assessment and management

Effective assessment and management of symptoms in patients with advanced CKD aims to optimise symptom control thereby improving patients' quality of life. Regular and systematic assessment using validated symptom assessment tools allows for timely identification and appropriate initiation of a management plan. 33

#### Holistic approach to care

Comprehensive KSC requires the routine assessment of spiritual and cultural beliefs that shape patient experiences and care preferences. KSC staff should respond appropriately to these multidimensional needs and ensure the delivery of holistic, patient-cared KSC. 33

#### Role of family and kin

Families and kin often serve as primary caregivers and are integral partners in the care of patients with advanced CKD. When engaged effectively in alignment with a patient's preference, they can play a critical role in enhancing well-being, facilitate shared decision-making, and improve overall care outcomes. <sup>33</sup> However, they can experience significant stresses, particularly as the patient's health declines. <sup>36</sup> To support them in their caregiving roles, KSC staff should screen for mental health needs and carer stress, and assist with referrals to appropriate support services, including bereavement support. <sup>33</sup>

# Objectives of the KSC model of service

- Align care with patient values in all treatment decisions.
- Provide clinically appropriate alternatives to dialysis, including CKM.
- Ensure comprehensive support for effective symptom management, including addressing psychosocial and mental health needs.
- Enhance quality of life through individualised care and patient-centred care.
- Improve accessibility of care, including delivery of care closer to home.
- Support informed and shared decision-making regarding dialysis initiation, withdrawal and other medical interventions.
- Facilitate advance care planning, including timely discussion and documentation. 2
- Support families and carers through counselling and referral to support services.

# Types of KSC service activities For the patient:

- assessing and managing physical symptoms related to CKD using validated patientreported outcome measures
- screening for psychological, mental health, social and spiritual needs, as well as, coordinating access to appropriate support services (e.g. aged care services)
- facilitating ACP and documentation
- conducting goals of care (GoC) discussions
- providing education for kidney replacement therapy options, including CKM
- delivering CKM
- supporting individualised dialysis treatment prescriptions
- · engaging in discussions regarding dialysis withdrawal, when appropriate
- screening and supporting transition to end-of-life care. 11

#### For families and carers:

- involving family members and carers in care planning and decision-making
- offering support to family and caregivers throughout the care journey
- utilising carer-reported outcome measures to guide care
- providing bereavement support for families and carers following the patient's death.

### KSC service: a networked service model

In line with international recommendation (ISN) <sup>3</sup> and the well-established New South Wales (NSW) KSC model, <sup>1</sup> a **networked hub-and-spoke model** is recommended as the statewide model of service delivery framework in WA to deliver integrated, patient-centred KSC services. The proposed framework designates a lead health organisation (the **hub**) to provide a comprehensive range of services including specialty care and access to a multidisciplinary team. Linked to the hub are associated (**spoke**) health organisations which deliver core KSC services locally. These spokes are distributed widely to enhance accessibility. Each component of the hub-and-spoke structure plays distinct complementary roles that contribute to a cohesive statewide system.

In accordance with the principle of non-abandonment, KSC services should be embedded within existing renal services as a component of comprehensive kidney care. <sup>2, 37</sup> The model endorses a nurse-led KSC service, guided by local nephrology leadership, and supported by strong collaborative relationships between renal, palliative care and primary care services. Importantly, this model is scalable, allowing for the addition of hubs and spokes as required, to meet future service demands and growth. Refer to Figure 6 for a visual representation the model, including potential hub and spoke configurations.

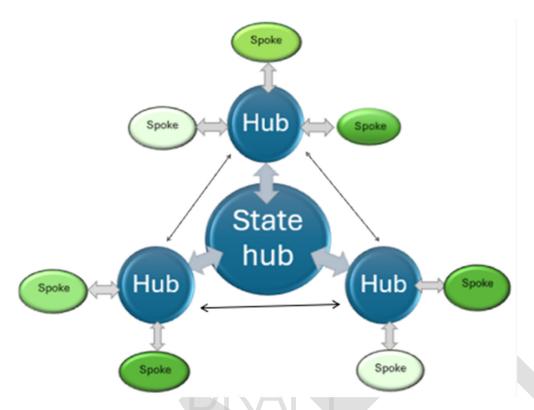


Figure 6: Visual representation of the WA hub and spoke model. Optional numbers of hubs and spokes.

#### Roles and functions of the hub and spoke components

Clearly defining the key roles and responsibilities of the hubs and spoke components is essential to ensure accountability, efficiency and minimise service gaps.

# KSC State Hub (Centre of Excellence)

The KSC State Hub will be coordinated within the Department of Health. It serves as statewide hub for leadership, coordination, innovation. It will play a pivotal role in driving the statewide phased implementation and oversight of the WA KSC services.

#### Key roles and responsibilities:

- 1. **System coordination:** Provide strategic leadership, oversight and ensure engagement with government, health department, clinicians and other key stakeholders.
- 2. **Statewide capacity building:** Lead workforce development initiatives, including delivery of education, training, mentoring and clinical supervision.
- 3. **Centralised resources:** Develop, manage and disseminate statewide clinical guidelines, assessment tools, patient and health professional education resources, clinical pathways, and culturally appropriate resources.
- 4. **Quality and safety oversight:** Establish key performance indices (KPIs), service delivery standards, conduct regular audits, monitor service performance across service levels.



5. **Research and evaluation:** Lead and coordinate research initiatives to evaluate the impact of KSC, validate clinical tools and interventions, and generate evidence to inform future service improvements and innovation.

#### KSC hubs

KSC hubs provide advanced clinical expertise to support affiliated spokes services, assist with workforce capacity building, and implement evidence-based KSC practices within their catchment.



#### Key roles and responsibilities:

- 1. **Clinical leadership:** Provide specialist renal and palliative care clinical leadership, accept referrals for complex case management from the spokes, support integrated care planning, clinical escalation pathways and coordination across its network.
- 2. **Capacity building:** Support workforce development within the network through targeted education, training, mentoring and clinical supervision for affiliated staff.
- 3. **Implementation of clinical guidelines:** Support dissemination and implementation of standardised clinical guidelines, assessment tools, patient and health professional education resources, and culturally appropriate resources within the network.
- 4. **Quality and safety oversight:** In collaboration with spokes, contribute to statewide quality assurance processes, including audits and monitoring of service performance to ensure adherence to clinical standards and drive continuous improvement.
- 5. **Research and e valuation:** Lead and contribute to KSC research initiatives, service evaluations, development and validation of tools and interventions to inform future service improvements and innovations. <sup>1</sup>

# Spokes (satellite sites and regional partners)

Spokes serve as the first point of contact for delivering KSC service



locally with strong connections with local palliative care service and primary care providers. Spokes have clearly defined referral pathways to the hubs for patients who require specialist input.

#### Key roles and responsibilities:

- 1. **Delivery of best practice KSC service:** Provide locally delivered KSC services in partnership with local palliative care, primary care and other healthcare providers, with clear referral pathway to hub for complex symptom management or specialist input.
- **2.** Participation in education and training: Actively engage in statewide training and professional development opportunities coordinated by the hub.
- Contribution to research, audit and service improvement: Contribute to and participate in collaborative research, shared data collection for routine service audits and outcome monitoring.

#### Interaction between hubs and spokes

Effective inter-hub collaboration through shared-training initiatives, streamlined communication, and knowledge exchange is essential to building system wide capacity. Figure 7 highlights the dynamic interactions between the hubs and spokes, demonstrating how the model supports workforce development and delivery of a flexible responsive KSC service.

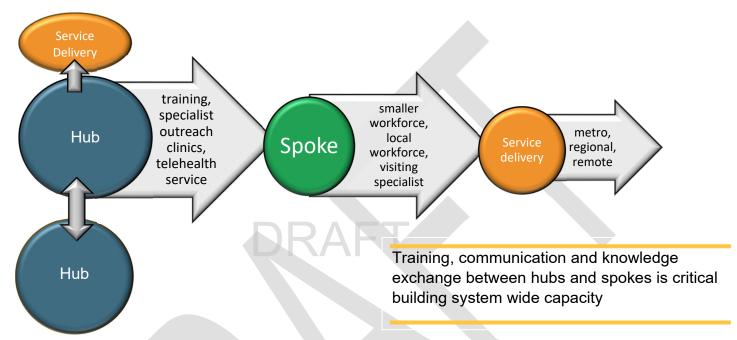


Figure 7: Interaction of KSC Hubs and spokes system

## Limitations of hub-and-spoke model for KSC service delivery

While the networked hub-and-spoke model offers clear advantages, it also has some important limitations the must be considered. A key concern is the reliance on a single, central hub to provide to provide leadership, coordination and provision of specialty services to multiple spokes. This centralisation can create vulnerability within the network should the hub become overstretched or under-resourced. Concentrating expertise and funding at the hubs may lead to inequitable distribution of resources, potentially disadvantaging spoke sites. Additional challenges include risk of bottlenecks at the hubs due to capacity constraints, difficulties in managing overly large or geographically distant spokes, and complexity of coordinating care and communication across the network.

# KSC service designs and operational arrangements

Within the broader networked model, health organisations may establish hubs and spokes (excluding the KSC State Hub) based on local patient demand and available resources.

# Service designs

The service design options outlined below are adapted from the well-established KSC organisational configurations implemented in New South Wales (NSW). 38 These options offer proven, evidence-based framework that can be tailored to suit the WA context.

#### Coordinated multidisciplinary team service

This service design is based on a KSC-nurse led multidisciplinary specialist team providing a comprehensive range of KSC services in a centralised location ('one-stop-shop) – embedded within existing nephrology services. It facilitates early and coordinated access to specialist services for patients with complex care needs and supports continuity of care across the patient journey. While this service design offers high level of care coordination and clinical oversight, it is resource intensive, requiring specialist staffing and dedicated clinical space. Services can be delivered through a range of settings (refer to Table 2 for service delivery settings options).

#### Outreach service (KSC nurse-led)

This model is led by a KSC nurse with specialist training in renal and palliative care principles. It is particularly well-suited to areas with limited access to multidisciplinary specialist team. Success relies on maintaining strong, ongoing connections with specialist services with clear referral pathways and supported by robust clinical governance. This service design is less resource-intensive, easier to implement and can also be delivered across a variety of service locations (refer to Table 2 for service delivery settings options).

# Service delivery settings

Health organisations have the flexibility to deliver KSC services across a range of settings, guided by the principle of delivering the **right care**, in the **right place**, at the **right time**. The service should be aligned with clinical need, patient preference and available resources. The service delivery settings shown in Table 2 are informed by review of literature,  $\frac{10}{10}$ ,  $\frac{11}{10}$  and learnings from the NSW KSC model  $\frac{1}{10}$  and Metro North Hospital and Health Service KSC Services.  $\frac{39}{10}$ 

Table 2: KSC Service Delivery Settings options

Service location	Description and key features
Inpatient services	<ul> <li>Facilitates shared decision-making and access to multidisciplinary (MDT) team.</li> <li>Offers integrated care for admitted patients with complex needs.</li> <li>Involves participation in ward rounds, inpatient review, and team meetings.</li> </ul>
Outpatient clinics	<ul> <li>Ideal for face-to-face review of new referrals and non-admitted patients.</li> <li>May be located in hub or spoke outpatient clinics.</li> <li>Hubs may offer a 'one-stop-shop' model with full MDT access.</li> <li>Structured environment supports teaching and training.</li> <li>Requires dedicated clinical space.</li> <li>Clinic frequency based on local demand.</li> </ul>
Dialysis unit clinics	<ul> <li>Delivered in in-centre, satellite, and home dialysis units.</li> <li>Suitable for new referrals and ongoing follow-up of dialysis patients.</li> <li>Enables real-time communication with dialysis nurses.</li> </ul>

	<ul> <li>Reduces transport burden (face-to-face reviews before, during, or after dialysis).</li> </ul>
	<ul> <li>Requires dedicated clinic space in dialysis units.</li> </ul>
Home visits	<ul> <li>Provides face-to-face care in the patient's home.</li> <li>Ideal for those with frailty, mobility, or transport issues and those from outer metropolitan, regional and remote areas.</li> <li>Ideally suited for follow up of patients known to the service.</li> <li>Enables assessment in home environment and engagement with family/carers.</li> <li>Opportunity for delivery of coordinated care with community palliative care and primary care services.</li> </ul>
Telehealth / telephone services	<ul> <li>Flexible and accessible option for follow-up or initial KSC introductions.</li> <li>Supports those unable to attend clinics due to distance, illness, or transport barriers.</li> <li>Enhances care continuity across locations.</li> <li>Limitations include no physical exam and loss of visual cues.</li> <li>Requires phone/internet access and device literacy.</li> </ul>
Multidisciplinary case conferences	<ul> <li>Allows for early identification and collaborative case discussion of complex patients or those at transition points.</li> <li>Involves MDT (nephrology, palliative care, nursing, allied health etc.)</li> <li>Conducted in person or via teleconference.</li> <li>Enables engagement with spokes and support for rural/remote staff.</li> <li>Enhances care coordination across multiple service settings.</li> </ul>

# Examples of operational arrangements and service settings

The following table illustrates how KSC services can be structured using 2 service designs (Table 3). Each service design is described in terms of key elements such as target population, workforce requirements, resources intensity, service location settings and implementation considerations.

Table 3: Examples of operational arrangements and service settings

Features	Coordinated MDT Service	Outreach service (KSC nurse-led)
Service setting	Centralised 'one-stop-shop' embedded within nephrology services (e.g. tertiary hospitals, secondary or regional hospitals)	Hospital or community-based with flexible delivery across metropolitan, rural and remote settings
Service location	Outpatient clinic, inpatient, home visits, phone/telehealth consultations, multidisciplinary case conferences (MCC)	Outpatient clinic, home visits, phone/telehealth consultations, (MCC)
Target population	Patients with complex needs requiring coordinated specialist input	For all patients including those with limited access to care (e.g. rural and remote communities)
Staffing requirements	Multidisciplinary team: KSC nurse-led, renal physician, palliative care physician, and allied health professionals	KSC nurse-led with access to specialty support through referral and collaboration

Levels of care	High level of coordination and clinical	Moderate level, with reliance on external
coordination	oversight	support and strong referral pathways
Other	Dedicated clinical space	Access to reliable telecommunications
requirements		
Resource	High—requires investment in workforce and	Lower-cost effective and easier to scale,
intensity	infrastructure	particularly in under-resourced settings
Accessibility	Enhanced access at central sites;	High accessibility for regional and remote
	supported by telehealth and outreach	patients through outreach clinics and virtual
	services	care options
Sustainability	Suitable for metropolitan and large regional	Ideal for outer metropolitan, rural and
for WA	centres	remote WA and Aboriginal Community
		Controlled Health Services
Implementation	Requires significant planning, specialist	Success depends on strong links with
considerations	staff recruitment and clinical space	tertiary renal services, clear referral
	allocation	pathways and robust clinical governance

#### Roles of the multidisciplinary team members

High-quality KSC relies on a patient-centred, well-coordinated multidisciplinary team as illustrated in Figure 8. Team composition should be flexible and responsive to patient needs and adapted to local healthcare setting. The section below describes the key roles of the KSC team members, adapted from the NSW KSC model of care. <sup>1,2</sup> For detailed role descriptions, refer to Appendix C.



Figure 8: Representation of the patient-centred approach in KSC service delivery 4

KSC clinical nurse consultants (CNC), nurse practitioners (NP), or equivalent play a key leadership role in the KSC service. Training in both renal and palliative care principles, they provide direct clinical care, act as case managers and coordinates care with different health care providers. In the hubs, they lead service coordination, provide education, and support spoke services.

**Renal physicians** provide clinical leadership and governance for the KSC program within the renal unit, overseeing the management of CKD-related complications. They work in close collaborate with the rest of the MDT. In the hubs, they also lead education, research and service development.

**Palliative care specialists** – including physicians, nurses or general practitioners (GPs) with a special interest in palliative care – play a vital role in delivering integrated KSC. They provide direct clinical care with expertise in symptom management and end-of-life care and contribute to workforce development through education on palliative care principles and practices.

**Renal dietitians** play a pivotal role in maintaining nutritional health and preventing complications of advance CKD and its treatments. They assess individual nutritional needs, provide tailored dietary advice and deliver education on appropriate nutrition strategies to optimised health and well-being.

**Social workers** play vital role in providing emotional and psychological support for patients, family and carers. They assist with ACP, offer bereavement counselling, and coordinate referrals to appropriate support services.

**Aboriginal workforce** (Aboriginal health workers and liaison officers) play a vital role in ensuring that KSC programs are culturally safe and responsive to the needs of Aboriginal people, their families and kin.

**Renal pharmacists** play a critical role in ensuring the safe and effective use of medications in patients with advanced CKD.

**Administrative officers** provide essential operational and administrative support to ensure smooth functioning of KSC service.

**Data management officers** within the hubs and spokes assist with data collection and management of key KPIs.

**Quality improvement officers** based at the KSC state hub will ensure program evaluation and development.

Other members to consider depending on need and availability:

- renal/palliative care trainee
- psychologist/ counsellor
- palliative care nurse
- physiotherapist
- occupational therapist
- religious representative
- · cultural representative
- geriatrician

- psychiatrist
- research nurse/ coordinator
- navigator
- transport / driver for visits
- community links
- country links
- integration with health and community care system

#### Collaboration between KSC and specialist palliative care services

Delivering comprehensive person-centred KSC requires strong, coordinated, collaborative partnerships with palliative care providers. Effective interdisciplinary collaboration benefits not only the patients but also the kidney and palliative care teams (See Table 4). 33

Table 4: Benefits of collaboration between KSC and palliative care services

Stakeholder	Key benefits / outcomes
Patients, families, carers	<ul> <li>Improved quality of life via effective symptom management</li> <li>Timely access to specialist palliative care service</li> <li>Reduced avoidable hospital presentations</li> </ul>
Kidney care team	<ul> <li>Enhanced knowledge, skills, and confidence in supportive care</li> <li>Opportunities for shared learning and interdisciplinary collaboration.</li> </ul>
Specialist palliative care team	<ul> <li>Better understanding of kidney-specific palliative care complexities</li> </ul>

#### Strategies to support effective partnership

To strengthen collaboration and to build trusting relationships between kidney and specialist palliative care services, the following approaches are recommended:

- Provision of joint interdisciplinary care involving both KSC team and specialist palliative care providers.
- Integration of specialist palliative care clinicians within kidney care team.
- Capacity building and upskilling of kidney care clinicians in core palliative care competencies.
- Co-facilitation of joint education sessions and workshops between the teams to foster mutual understanding and skills development.
- Use of palliative care screening tools (e.g. SPICT™, clinical deterioration) by kidney care team to support timely identification and referral to palliative care. <sup>33</sup>

# Collaboration with primary health care

Primary health care (PHC) providers play a critical role in the successful integration of KSC services across WA. As CKD is increasingly managed within primary care settings, <sup>40</sup> it is essential to establish strong and structured collaboration between KSC teams and PHC providers. This collaboration should be guided by the following key strategies:

- Recognition of the critical role of PHC especially for individuals living in rural, remote, and very remote areas where access to specialist services is limited.
- Effective 2-way communication between KSC, renal and PHC providers.
- **Timely and accurate information sharing** of patient progress, care decisions and changes to treatment plans in shared electronic health records, if available.
- Clearly defined roles and communication protocols support shared care planning, minimise duplication and address gaps in care.
- Engagement PHC providers in care planning to leverage on their local knowledge and community connections.
- **Joint education and networking opportunities** to foster shared understanding and improve inter-service coordination.

#### Aged care services

CKD is significantly more prevalent in older populations. In WA, nearly half (49.9 per cent) of individuals with CKD in 2020 were aged 80 or older. <sup>22</sup> Given the complex needs of older adults with CKD, KSC services can play an important role in helping patients and their families navigate the aged care pathway, especially during stressful and challenging times.

# System leadership and strategic oversight for a coordinated KSC in WA

The principles of a statewide hub-and-spoke model, as highlighted in the *Sustainable Health Review*, <sup>15</sup> is applicable in the delivery of KSC service given that specialist renal-palliative care expertise is essential but unevenly distributed across the state.

Delivering an effective and sustainable hub-and-spoke KSC model in WA will require strong leadership, clearly defined governance structure and shared accountability across the health system. Establishing a statewide governance framework led by a statewide KSC hub will be critical in delivering a sustained, transparent, evaluated and continuously improved KSC service with system oversight across WA's complex health system.

In the *WA Health Strategic Intent 2015–2020* <sup>41</sup>, WA Health acknowledges its duty to uphold transparency in clinical and corporate governance, implement robust risk management and ensure effective performance oversight. The *Independent review of WA health system governance* report 2022 (IGR report) further recommends that 'WA should evolve its devolved governance into an alliance governance model so that collaboration, information sharing and networking are the norm.' <sup>42</sup> (p 9)

# Strategic future priorities for the implementation of KSC in Western Australia

Extensive consultation with subject matter experts in the development of this document identified two transformative, system level priorities essential for implementing a coordinated, system-wide KSC service in WA.

#### 1. Establishment of a KSC state hub

A centralised KSC state hub is a critical foundational enabler for delivering a statewide KSC service – particularly in a geographically vast and demographically diverse state where health delivery often occurs in silo. The key functions of the hub would include:

- developing standardised care pathways or protocols
- ensuring accountability through the development and implementation of KPIs
- building capacity through education
- providing system governance and strategic oversight.

#### 2. Co-design of an Aboriginal specific KSC model

Addressing disparities in kidney outcomes for Aboriginal people requires structural system-level reform and investing in an Aboriginal-specific KSC service that is codesigned with Aboriginal communities and their advocates. This aligns with commitments and recommendations made in the *National Agreement on Closing the Gap*, <sup>43</sup> WA Aboriginal Health Executive Roundtable 2023, <sup>4</sup> and Recommendations for culturally safe clinical kidney care for First Nations Australians. <sup>44</sup>

#### Conclusion

The above strategic priorities are foundational for improving efficiency and care coordination, reducing service fragmentation and enabling a cohesive, accountable and culturally safe approach to KSC delivery across diverse health settings in Western Australia. These actions require strong coordinated leadership, cross-sector collaboration, targeted investment and commitment to equity and sustainability to meet future demands.

# **Appendices**

# Appendix A: Examples of Australian and International KSC Models of Service Delivery

Health Service/Country	Location	Service Model and Structure	Clinical Resource
New South Wales, Australia State-based Approach <sup>1</sup> commenced 2016 (Original: St George Hospital, NSW, KSC program commenced 2009)	Renal units in metropolitan hospitals (hubs) and renal units in outer metropolitan or regional areas (spokes)	State-wide networked coordinated MDT model. Hubs provide support to affiliated renal units (spokes) within their network. Outreach model (spoke)	<ul> <li>Nurse-led, embedded within existing renal services</li> <li>Strong collaboration with palliative care services</li> <li>Nephrologist provides local leadership</li> </ul>
Metro North Hospital and Health Service, Brisbane, Queensland 39 commenced 2016	Renal unit based in metropolitan hospital.	Health service provider (HSP) based coordinated MDT model	<ul> <li>Nurse-led, embedded within existing renal services.</li> <li>Strong collaboration with palliative care services.</li> <li>Evolved from a visiting team model, which are based on specific dialysis catchment area.</li> </ul>
University of Calgary Calgary, Canada <sup>11</sup>	Renal services in major metropolitan, smaller cities and rural areas	HSP based visiting service to specific catchment by nephrologist trained in palliative care	<ul> <li>Nephrologist led with support from nurses, social worker, dietitian</li> </ul>
Hammersmith Hospital London, United Kingdom <sup>11</sup>	Metropolitan peritoneal dialysis and haemodialysis centre	Hospital based; nurse led service	<ul> <li>Nurse with geriatric training provide referral-based service for dialysis patients</li> </ul>
Alive Hospital Nashville, Tennessee, USA	Urban hospice/ palliative care	Dialysis corporation engaging hospice leader	Offers communication training for dialysis unit staff

# Appendix B: Current KSC services in WA

Health Service/service commenced	Organisational Model	Team members	Care Settings	Access to separate funding for KSC service
Sir Charles Gairdner Hospital Commenced 2024	Metropolitan Health Service Provider (HSP) based Coordinated Multidisciplinary team	Renal CNC led Renal Specialist Palliative Care specialist Renal dietitian Social Worker	Outpatient clinic Dialysis Nurse initiated referral from G65 incentre and Joondalup satellite HD units Targeted shared review for country patients with local renal team via telephone	Partial
Royal Perth Hospital Commenced 2024	Metropolitan HSP based Outreach model	Palliative care nurse practitioner led Access to specialist palliative care physician and social worker by referral Close liaison with renal service	Outpatient clinic	Nil
Fiona Stanley Hospital (commenced at Fremantle Hospital 2024 and transitioned to FSH 2025)	Metropolitan HSP based Coordinated Outreach model	Medically led by Renal Physician (with Renal CN) and Palliative Care Specialist (with CNC) Access to social worker and pharmacist by referral	Outpatient clinic Multidisciplinary case conference	Nil

#### Appendix C: Roles of the KSC team members 1.2

#### KSC Clinical Nurse Consultant (CNC), Nurse Practitioner (NP) or equivalent

- Pivotal role in coordinating, triaging referrals and effectively communicating outcomes with the broader interdisciplinary team.
- Demonstrate advanced clinical expertise in both renal and palliative care principles.
- For the CNC based in the 'hub', provide clinical leadership and coordinate education programs for associated 'spoke' services.
- Function as case manager to ensure continuity and coordination of care across care settings.
- Provide direct clinical care for patients with complex or advanced care needs. Facilitate
  integration of interdisciplinary components of care to ensure patient-centred holistic
  care.
- Act as key liaison between patients, their families and health care teams.

#### **Renal Physician**

- Provides clinical leadership for the KSC program within the renal unit.
- Provide medical oversight to manage CKD related complications.
- Liaise with the hub to ensure consistency and integration of care.
- Collaborate closely with KSC nurse and palliative care physicians to deliver comprehensive care.
- KSC nephrologist at the hub assumes additional leadership, education and research and service development role across the network.

#### **Palliative Care Specialists**

- Service can be delivered by palliative care physicians, palliative care nurse practitioners or general practitioners (GPs) with special interest in palliative care.
- Collaborate closely with KSC CNC and nephrologist to ensure integrated care.
- Deliver direct clinical care and offer expertise in symptom management and end of life care for patients with advanced CKD with emphasis on quality of life.
- Provide education and support to other health care professionals on symptom management and broader palliative care principles and approaches.
- Offer consultation-liaison service or outreach services to spokes, if required.

#### **Renal Dietitian**

- Plays a pivotal role in maintaining nutritional health and preventing complications of kidney disease and its treatments.
- Assess nutritional needs and provide tailored dietary advice to support overall health and symptom management.
- Provide education for patients, their families and carers on appropriate nutrition strategies.

#### **Social Worker**

- Deliver essential psychological support and guidance to patients and their families.
- Provide counselling to support informed decision-making regarding dialysis initiation or withdrawal.
- Offer emotional support for patient, family and carers during periods of distress or significant change.
- Facilitate access to appropriate social services, financial assistance and community resources.
- Assist with ACP discussions and documentation.
- Provide bereavement support and counselling for families and carers following the death of a patient.
- Coordinate and facilitate support groups for patients and carers to foster connection, education and shared experience.

#### **Aboriginal workforce**

- Play a vital role in ensuring that any KSC program is culturally safe and responsive to the needs of Aboriginal people and their families.
- Acts as important conduit to improving access, engagement and health outcomes for Aboriginal people and their communities.
- Should be actively integrated into KSC services.

#### Renal Pharmacist

- Plays a critical role in ensuring safe and effective medication use in patients with advanced CKD.
- Conduct comprehensive medication review to ensure appropriate drug-dosing and minimise risk of adverse drug interactions.
- Act as liaison with community pharmacies to ensure continuity and accuracy of medication supply and administration.
- Support medication rationalisation to reduce polypharmacy and align treatments with patient goals of care.

#### **Administrative Officer**

- Provide essential operational and administrative support to ensure smooth functioning of KSC service.
- Support coordination of educational activities, including online training and ongoing professional development initiatives.
- Facilitate effective communication within KSC interdisciplinary team and external health care providers and services.
- Assist with staff coordination, including rostering and human resources administration to support efficient service delivery.

 Contribute to overall service organisation, documentation and administrative functions critical to success of the KSC service.

#### **Data Management Officer**

- Will be based within the hubs and/or spokes to assist with data collection and management of key KPIs.
- Contribute to ensuring evaluation of service delivery occurs.
- Contribute to success and sustainability of KSC program through robust data management and research support.

#### **Quality Improvement Officer**

- Will be based at the KSC state hub to ensure program evaluation and development.
- Support investigator-initiated research initiative including health services research and quality improvement projects.
- Assist researchers with ethics and governance applications, participant recruitment, data collection and management.
- Manage data extraction and analysis to support service monitoring and improvement.
- Contribute to success and sustainability of KSC program through robust data management and research support.

# Appendix D: Glossary of Terms

The model of service uses definitions and terms which encompass a range of services and disciplines. The following is an explanation of these terms.

Term	Definition
Aboriginal	'AHWs provide both clinical health care delivery and health education
<b>Health Worker</b>	to Aboriginal patients with kidney disease.' 45
Aboriginal	'ALOs provide emotional, social and cultural support to Aboriginal
Liaison Officer	patients with kidney disease and their families. ALOs also provide
(ALO)	cultural education and support to health service staff. ALOs are a
	valuable source of cultural education for non-Aboriginal staff.' 45
Augmentative	'Augmentative and alternative communication (AAC) is when a person
and alternative	uses something other than speech to communicate. They might use
communication	body movements or gestures. They might use sign language or a
(AAC)	computer or device. They might use communication books or other
	printed material.' 21
Carer	'A person who provides ongoing care, support and assistance to a
	person with disability, a chronic illness (which includes mental illness)
	or who is frail, without receiving a salary or wage for the care they
	provide.' 46
Chronic kidney	'Abnormalities of kidney structure or function, present for a minimum of
disease (CKD)	3 months, with implications for health.' 47
Conservative	A treatment option for kidney failure that does not include dialysis or a
kidney	kidney transplant. Instead, care focuses on managing symptoms
management	through medications, dietary adjustments, and other supportive
	measures to help the individual live as well as possible for as long as
	possible. <sup>7</sup> (also called comprehensive conservative care)
Dialysis	'A treatment for kidney failure that removes waste products and excess
	fluid from your blood by filtering your blood through a special
	membrane.' 48
End-of-life	'The period when a person is living with, and impaired by, a fatal
	condition, even if the trajectory is ambiguous or unknown. This period
	may be years in the case of persons with chronic or malignant disease,
	or very brief in the case of persons who suffer acute and unexpected
F. J. CPC.	illnesses or events, such as sepsis, stroke or trauma.'49 (p 27)
End-of-life care	'Includes physical, spiritual and psychosocial assessment, and care
	and treatment delivered by healthcare workers. It also includes support
	of families and carers, and care of the patient's body after their death.
	People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is
	imminent (expected within a few hours or days) and those with:

	<ul> <li>advanced, progressive, incurable conditions</li> <li>general frailty and co-existing conditions that mean that they are expected to die within 12 months</li> <li>existing conditions, if they are at risk of dying from a sudden acute crisis in their condition</li> <li>life-threatening acute conditions caused by sudden catastrophic events.' 49 (p 27)</li> </ul>
Kidney failure	'The stage of kidney disease when your kidneys have stopped working, so treatment such as dialysis or a transplant is needed to sustain life.' 50
Kidney replacement therapy (KRT)	'Having a functional kidney transplant or receiving regular dialysis.' 30
Estimated Glomerular Filtration Rate (eGFR)	'Measures how well your kidneys filter the wastes from your blood and is the best overall measure of kidney function.' 50
Haemodialysis	'A treatment for kidney failure. Your blood is pumped through special tubing to a haemodialysis machine. The machine acts like a kidney, filtering waste products from the blood before returning it to your body.'
Palliative care	An 'approach that improves the quality of life of patients – adults and children – and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.' 51 (p 1) Palliative care:  • provides relief from pain and other distressing symptoms • affirms life and regards dying as a normal process • intends neither to hasten nor postpone death • integrates the psychological and spiritual aspects of patient care • offers a support system to help patients live as actively as possible until death • offers a support system to help the family cope during a patient's illness and their own bereavement • uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated • will enhance quality of life, and may also positively influence the course of illness

Peritoneal Dialysis	<ul> <li>is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. <sup>51</sup> (p1)</li> <li>'Treatment for kidney failure during which dialysis fluid is moved in and out of your peritoneal cavity to remove wastes and fluid from the</li> </ul>
	blood.' 48
Satellite Dialysis Unit (SDU)	'Provides haemodialysis away from a tertiary hospital site. This option is suitable for medically stable, relatively independent patients for whom Home Therapies is not appropriate.' 45
Satellite Outreach Service (SOS)	'Enables small numbers of medically stable and independent patients to receive dialysis treatment closer to home in smaller country hospitals. This option is for stable chronic patients who don't require acute treatment and for whom Home Therapies is not appropriate.'
Shared decision making	'Shared decision making involves discussion and collaboration between a consumer and their healthcare provider. It is about bringing together the consumer's values, goals and preferences with the best available evidence about benefits, risks and uncertainties of treatment, in order to reach the most appropriate healthcare decisions for that person.' 52 (p 1)
Specialist	Specialist palliative care is undertaken by a professional palliative care
palliative care	team or service with recognised qualifications or accredited training in palliative care. They provide direct care to people, and their family/carer with complex palliative care needs and/or provide consultation services to support, advise and educate specialist and non-specialist teams providing end-of-life care. While every Western Australian with life-limiting illness has a right to a quality palliative approach through end-of-life care, not everyone requires specialist palliative care. 49
Supported	A person with an intellectual disability may require supported decision
decision making	making to assist with making more of their own decisions about their own care. <sup>53</sup> It can help people take part in shared decisions when receiving health care. <sup>20</sup> A supported decision-making process is 'undertaken in collaboration with the person and their family, supporters or guardian, to provide the person with information in a way they can understand and the means of communicating their will and preferences in response.' <sup>20</sup> (p <sup>34</sup> )
Telehealth	'The use of telecommunication techniques for the purpose of providing telemedicine, medical education and health education over a distance.'

Terminal phase	'Where death is imminent and likely to occur within hours or days, or
	occasionally weeks.' 49 (p 26)

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