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Chronic Kidney Disease Services Planning Guideline

July 2023 NSW Ministry of Health



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The NSW Health Chronic Kidney Disease Services Planning Guideline (formerly known as "Guideline for Planning Renal Services") was written by Strategic Reform and Planning Branch.

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GLOSSARY

AKIAcute Kidney InjuryANZDATAAustralia and New Zealand Dialysis and Transplant RegistryANZSCAustralian and New Zealand Society of Nephrology	
, , , ,	
ANZSC Australian and New Zealand Society of Nephrology	
APD Automated Peritoneal Dialysis	
AusHFG The Australasian Health Facility Guidelines	
CALD Culturally and Linguistically Diverse	
CAPD Continuous Ambulatory Peritoneal Dialysis	
CaSPA Clinical Services Planning and Analytics Portal	
CIE Centre for International Economics	
CKD Chronic Kidney Disease	
District Local Health District	
DPE The NSW Department of Planning and Environment	
ESKD End-Stage Kidney Disease	
HD Haemodialysis	
Ibid. ibīdem ("in the same place") – refers to the work cited in preceding f	ootnote
KHA Kidney Health Australia	
Network Specialty Health Network	
NHMS National Health Measures Survey	
PD Peritoneal Dialysis	
RRT Renal Replacement Therapy (i.e. dialysis or transplant)	
RSC Renal Supportive Care	
Ministry NSW Ministry of Health	

1. INTRODUCTION

What is Chronic Kidney Disease?

Chronic Kidney Disease (CKD) is the occurrence of kidney damage and/or decreased kidney function for a period of three or more months. Clinically, CKD is classified into five stages from mild kidney damage with no loss of kidney function to severe loss of kidney function. Lower-stage CKD (stages 1 to 3) is less serious and patients often show no symptoms. End-Stage Kidney Disease (ESKD) is the final stage of CKD where kidney function has declined to the point that kidneys can no longer function on their own. See APPENDIX A for a description of each stage of the CKD care pathway.

Governance of CKD services

In NSW, and most other States and Territories, renal services (including CKD) are linked through informal hub and spoke networks. According to the <u>NSW Health Guide to the Role</u> <u>Delineation of Clinical Services</u>, hubs are typically level 5 or 6 services and spokes are level 3 and 4 satellite services.

Through their renal clinical network, NSW Health Local Health Districts ('Districts') and Specialty Health Networks ('Networks'), are responsible for planning, coordinating, delivering and evaluating renal services at the local level. The Ministry supports Districts and Networks by providing leadership, developing policy and overseeing the strategic direction of renal services.

Who is this guideline for?

This guideline will help NSW Health District and Network health service planners support effective planning for renal services over the medium to longer term (next five to ten years) for patients in the later stages of CKD. This is intended to assist in making health service planners aware of the breadth and complexity of contemporary renal services and engage more comprehensively with those services when undertaking local planning.

Why have we developed this guideline and what is the scope?

The initial version of the Guideline focused on adult patients with ESKD, particularly planning dialysis services. This remains a key focus, however this update includes broader, though still limited, guidance across other aspects of CKD services, including the <u>NSW Renal</u> <u>Supportive Care (RSC) Service Model</u> (defined overleaf). However, we acknowledge that to effectively manage demand for renal services, it is essential that Districts and Networks plan person-centred care for people across all stages of CKD and all treatment options, and that stages 3 and 4 also have resource implications, although not all stage 3 and 4 patients will go on to develop ESKD.

This guideline will help service planners:

- Identify and generate the data needed to plan renal services for CKD patients
- Estimate activity demand for ESKD patients on dialysis and related services
- Make evidence-based recommendations to inform capital and recurrent investment decisions
- Use a best practice approach that supports consistent planning for renal services across NSW Health.

Although the following should be considered in planning, this guideline does **not** provide advice on:

- Renal therapy delivered in an admitted overnight bed
- Renal services for diagnosis and early intervention, including health promotion activities
- How to estimate demand for dialysis driven by Acute Kidney Injury (AKI)
- Palliative care and other support services (e.g. rehabilitation) that may be offered alongside renal services
- Renal services for children.

To plan for future demand and optimise health outcomes and patient experience, planners will need to consult with district and network renal service clinicians and consumers.

What are the treatment pathways for this cohort?

Figure 1 overleaf shows the various treatment pathway options for patients in stages 3 and 4 of CKD and ESKD (see for detailed description of each). RSC is a service that supports CKD patients in Stages 4 and 5 with symptoms and/or suffering to live as well as possible and is offered as an adjunct to the treatment pathway (see pages 20 and 34 for more detail). These patients need special consideration because of factors such as age, complexity and comorbidities.

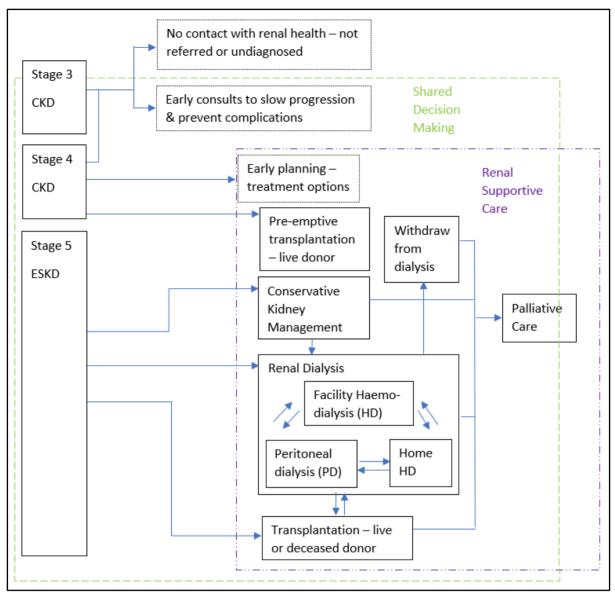


Figure 1: Renal services treatment pathways in NSW

When planning services, it is important to consider all treatment pathways (conservative kidney management, transplant and dialysis) and RSC services taking into consideration that patients will progress through these pathways in different ways. Patients waiting for a transplant are sometimes on dialysis in preparation for a living donor and usually on dialysis if waiting for a deceased donor (to be eligible), and a few may require dialysis if the transplant is unsuccessful. However, transplants have a half-life of around 15 years so even those who receive a successful transplant may require dialysis if their transplant fails.

Patients may also move between treatment pathways. For example, patients receiving dialysis may have a transplant; a few people on a conservative kidney management pathway may decide to undertake dialysis. Patients may move from one dialysis modality to another and patients on dialysis may elect to stop dialysis and undergo end-of-life care.

To continue to deliver high quality and sustainable renal services, a greater emphasis on integrating and coordinating care across all stages of renal disease is essential. This includes:

 Increasing patient awareness of risk factors with a focus on health promotion and prevention

- Increasing early detection and intervention of CKD
- · Ensuring access to all appropriate treatment pathways and services
- Ensuring access for all patients to appropriate end-of-life care.

The use of virtual care can maximise existing and new resources across NSW, and improve patient access to timely, equitable and effective care. Patients receiving dialysis in their home may be suitable for remote dialysis monitoring by hospital-based healthcare teams, saving both the patient and staff time and cost associated with travel. However, virtual care is a complementary service and may only be suitable for some aspects of service provision e.g. patients may need to be seen face-to-face to complete validated assessment tools as required and for specialised clinical review. In addition, some rural and regional areas may not currently have reliable internet and mobile services.

For further information about acute and chronic care for renal patients see APPENDIX A and APPENDIX B of this guideline. For information models for satellite dialysis in NSW see APPENDIX D.

How did we develop the guideline?

The NSW Ministry of Health ('the Ministry') engaged Deloitte Access Economics Pty Ltd to develop the initial version of this guideline and The George Institute and Predictive Analytics Group to produce the *ESKD Patient Dialysis Projections* referred to in this guideline and included on NSW Health's <u>Clinical Services Planning and Analytics (CaSPA) Portal</u>. Expert advisory groups were established to inform the development of the guideline and the projections. Members of the groups included renal physicians, health service planners and representation from the NSW Agency for Clinical Innovation. APPENDIX C acknowledges those who were involved in the latest update of the guideline.

2. CONTEXT

What is the prevalence of CKD and ESKD in Australia and NSW?

More than two million Australians were living with CKD in Australia in 2021 at a cost of \$9.9 billion in that year¹. Based on the National Health Measures Survey (NHMS), an estimated 11% of Australians aged 18 and over had biomedical signs of CKD in 2011–12². The total number of people with CKD in Australia increases rapidly with age, affecting around 44% of people aged 75 and over. However, only 6.1% of NHMS respondents who showed biomedical signs self-reported having the disease, indicating that CKD is a largely under-diagnosed condition.

ESKD is the final stage of CKD where kidney function has declined to the point that kidneys can no longer function on their own. Patients who are known to and managed within the health system are either provided with renal replacement therapy (RRT) i.e. dialysis or transplantation, or receive conservative kidney management. Nationally, around 50% of patients with ESKD receive RRT, and whether people with ESKD are treated with RRT varies with age³ (though this is not the only factor affecting the decision to start treatment). Before age 75, most new cases of kidney failure are treated with RRT; however, this trend reverses after age 75. In 2018/19, the total number of known ESKD patients in NSW was 9,151 and this number is projected to increase to 15,686 by 2029/30⁴. Between 2017 and 2019, 51% of ESKD patients known to NSW Health were receiving dialysis.

The incidence (number of new cases) of treated ESKD is projected to continue to rise over the next decade at the national and state/territory levels, for both sexes and across most of the age groups⁵. Diabetes is expected to contribute considerably to the increase in treated ESKD. The proportion of patients commencing treatment with diabetes is projected to increase to about 64% in 2020 from 45% in 2009.

What is the prevalence and incidence of ESKD patients on dialysis in NSW?

The number of ESKD patients receiving (or 'prevalence' of) dialysis each year from NSW continues to increase and is forecast to rise to nearly 6,000 patients by 2041 (see Figure 2 overleaf).

¹ Kidney Health Australia. Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment. Sydney: Deloitte Access Economics; 2023.

² Australian Institute of Health and Welfare (AIHW). Chronic kidney disease: Australian facts. Wed report; 2023. Available at: <u>https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-diseas</u>

³ Ibid. [*ibīdem* ("*in the same place*") – *refers to the work cited in preceding footnote*]

⁴ NSW Ministry of Health. Economic appraisal of ESKD modalities and patterns of care. Sydney: The Centre for International Economics (the CIE); 2021.

⁵ AIHW. Projections of the incidence of Treated end-stage kidney disease in Australia. Cat. No. PHE 150. Canberra: AIHW; 2011.

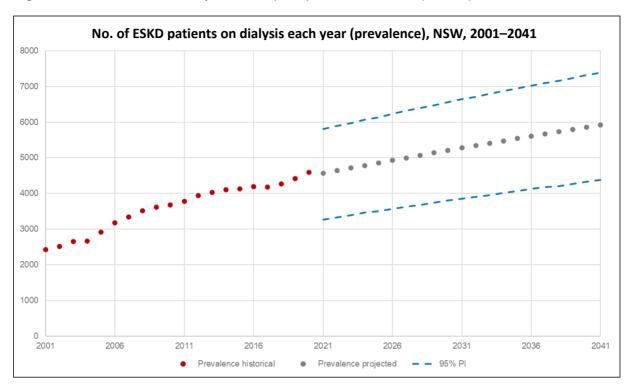


Figure 2: Source - NSW Ministry of Health (2023) ESKD Patient Dialysis Projections⁶

While the number of ESKD patients starting (or 'incidence' of) dialysis from NSW per year fluctuates, Figure 3 (overleaf) shows it is forecast to continue increasing over time to around 1,140 patients by 2041.

The dialysis prevalence rate is growing at a higher rate than incidence, which may be due to patients living longer on dialysis than previously. The growth in incidence and prevalence dialysis rates is projected to be slower than the historical growth that occurred between 2001 and 2008. Literature suggests this may be the result of a range of initiatives implemented at State and Federal levels between 2000 and 2010 to:

- support the early detection and management of kidney disease
- increase the transplantation rate⁷ which increased by 29.8% from 2013 to 2018 in Australia (see p10 for more information)⁸
- reduce risk factors like cardiovascular disease, hypertension and smoking.

More recently, clinical consultation, literature and analysis suggests that this may also be a result of stabilisation of practice supported by data on outcomes of older people receiving dialysis and availability of RSC as an adjunct to the conservative kidney management pathway⁹, which has been available in most NSW Districts and Networks since 2015 (and as early as 2009 in some)¹⁰. Changes in future treatment options may also impact on dialysis incidence and prevalence rates e.g. the use of dapagliflozin in patients with CKD.

⁶ Based on Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) 2001-2020 and NSW Department of Planning and Environment (DPE) 2022 Population Projections.

⁷ Australian Organ and Tissue Donation and Transplantation Authority. Progressing Australian organ and tissue donation and transplantation to 2020: The 2016 – 2020 Strategy. 2016.

⁸ ANZDATA Registry. 42nd Report, Chapter 7: Kidney Transplantation. Adelaide: ANZDATA Registry; 2019. Available at: http://www.anzdata.org.au

⁹ Keuskamp D et al. Projecting the future: modelling Australian dialysis prevalence 2021–30. Australian Health Review. 2023. Available at: https://doi.org/10.1071/AH22291

¹⁰ NB: RSC can be an adjunct to all treatment pathways (i.e. dialysis, transplant and conservative management)

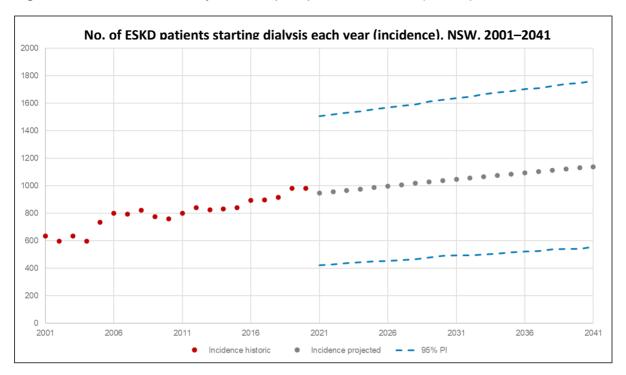


Figure 3: Source – NSW Ministry of Health (2023) ESKD Patient Dialysis Projections ¹¹

Figure 4 below shows that older Australians (aged 70 - 84) are a significant and increasing proportion of dialysis prevalence and a recent Australian study suggests that population ageing (rather than disease incidence) appears to be driving prevalence growth¹². The number of ESKD patients starting dialysis by age group is shown in figure 5 (overleaf).

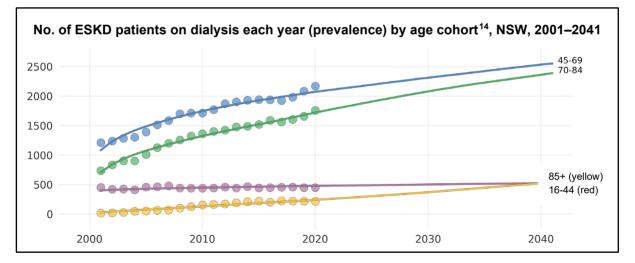


Figure 4: Source – NSW Ministry of Health (2023) ESKD Patient Dialysis Projections¹³

¹¹ ANZDATA 2001-2020 and DPE 2022 Population Projections (n 6) [n 6 - see footnote 6 for full refence].

¹² Keuskamp D et al. (n 9).

¹³ ANZDATA 2001-2020 and DPE 2022 Population Projections (n 6).

¹⁴ NB: Patients 0-15 years are excluded from graph due to low numbers.

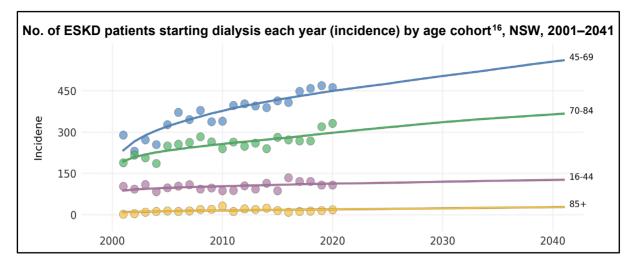


Figure 5: Source - NSW Ministry of Health (2023) ESKD Patient Dialysis Projections¹⁵

ESKD patients on a conservative kidney management pathway (i.e. those not receiving RRT) are projected to increase significantly from 2022 to 2030 (see Figure 6 below). Note: While this cohort includes some patients receiving RSC, it is not the same cohort as RSC includes patients on other pathways. Due to limitations in identifying conservatively managed patients in state-wide data collections, these numbers may include patients that are waiting for dialysis or a transplant and patients who are undecided on which treatment to pursue. For more information on the cohort definition and projections modelling, see footnote 17 below and 20.

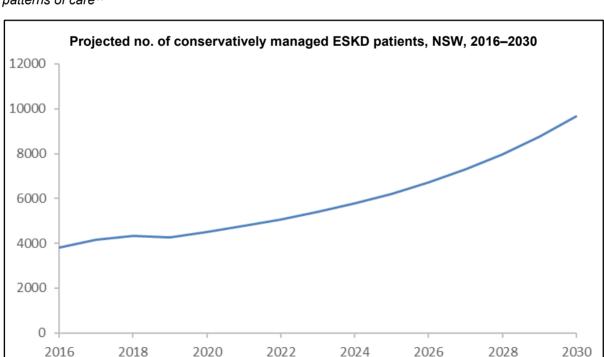


Figure 6: Source – NSW Ministry of Health (2021) *Economic appraisal of ESKD modalities and patterns of care*¹⁷

¹⁵ ANZDATA 2001-2020 and DPE 2022 Population Projections (n 6).

¹⁶ NB: Patients 0-15 years are excluded from graph due to low numbers.

¹⁷ Modelled from the DPE 2016 NSW Population Projections and NSW Health Admitted patient data collection – Patients with ESKD (i.e. those with an ESKD diagnosis code for at least 3 months) that were not successful transplant recipients nor on dialysis were classed as 'conservatively managed'.

In 2009, the Australian Government announced a target to increase the kidney donation rate¹⁸. In 2018 there were 1,149 kidney transplants performed in Australia¹⁹. The 29.8% growth in transplants from 2013 to 2018 parallels the increase in the number of deceased donors, whereas the number of live donors has remained unchanged. The number of prevalent patients in Australia with functioning kidney transplants also grew in the decade to 2018, increasing by 52.2% between 2009 and 2018 (from 8053 to 12,253 recipients). The proportion of first kidney transplant recipients in 2017 who had experienced acute rejection in the first 6 months was 19.1% (live donor) and 18.5% (deceased donor), with rejection rates remaining similar to the previous 5 years. There has been a decline in the number of deceased and living donor transplants performed in 2020 compared to the previous 5 years in Australia, with the lowest number of total transplants performed since 2013²⁰. The reduced transplant activity is likely due to the impact of the COVID-19 pandemic with an apparent greater impact in precincts with higher case numbers.

What are the renal service priorities for ESKD patients in NSW?

As with planning for all NSW Health services, equity of access for all NSW residents to the full range of ESKD treatment pathways, including transplant, should be a high priority. A literature review and consultation with NSW renal clinicians and other District and Network stakeholders was conducted to inform the original guideline (released in 2018). This, along with further consultation on the updated guideline in 2023, has identified the following renal service planning priorities:

Disease prevention and community education. Prevention and education needs to focus on kidney disease risk factors for the general population and high-risk patients (patients with diabetes, hypertension and cardiovascular disease)²¹. Patients who have had AKI are also at increased risk of developing CKD.

Multidisciplinary care. Holistic management of chronic diseases like ESKD benefits from support and specialist care from a range of healthcare professionals. This includes ensuring appropriate allied health and psychological support is available for patients with ESKD. In planning for ESKD services, Districts and Networks should consider the availability of a range of allied health professionals with both generalist and specialist renal expertise.

Education, support and shared decision making. Shared decision making is a process where clinicians and the patient (and their family, partner or carer) make health decisions together (note: it is not the same as 'informed consent'). Appropriate education for patients approaching ESKD is important and essential for shared decision making, however, this is not the only component. Shared decision making involves discussing the risks and benefits of each option available, taking into consideration the person's values, preferences and circumstances. More information on shared decision making and consumer enablement is available on the <u>ACI website</u>.

¹⁸ Australian Organ and Tissue Donation and Transplantation Authority. Progressing Australian organ and tissue donation and transplantation to 2020: The 2016 – 2020 Strategy. 2016.

¹⁹ ANZDATA Registry. 42nd Report, Chapter 7: Kidney Transplantation. Adelaide: ANZDATA Registry; 2019. Available at: <u>http://www.anzdata.org.au</u>

²⁰ ANZDATA Registry. 44th Report, Chapter 7: Kidney Transplantation. Adelaide: ANZDATA Registry; 2021. Available at: <u>http://www.anzdata.org.au</u>

²¹ Kidney Health Australia. CKD Management in General Practice. 3rd Edition. 2015.

Home dialysis. Evidence suggests that home dialysis is an optimal modality for treatment, both in terms of health outcomes and quality of life^{22,23}. Home haemodialysis (HD) is around a third the cost of facility haemodialysis and peritoneal dialysis (PD) is around 41% of the cost^[4]. There are challenges to providing home dialysis for an ageing population with increasing comorbidities and in some areas, particularly rural, due to home water quality (being unsuitable for dialysis) and many landlords not permitting plumbing changes required to install home machines and water treatments. However, Districts and Networks need to consider innovative approaches that increase the uptake of home dialysis as a first-line dialysis treatment option.

Equity of access. Ensuring equity of access to renal services for patients with CKD is a priority, in particular for transplant. Patients with CKD in rural areas²⁴, Aboriginal and/or Torres Strait Islander people and those from culturally and linguistically diverse (CALD) communities often face obstacles in accessing dialysis and transplant.

Virtual Care. Virtual care plays an important role in improving access to treatment and ongoing care across NSW. It is a complementary service, which supports face-to-face assessment of renal patients. Planning for a virtual care component within any service should be undertaken collaboratively with patients, clinicians and technical experts to ensure effective use of available virtual care options within the intended model of care. Noting that in some rural and remote areas, internet access may be limited.

Renal Supportive Care. RSC is an adjunct service that integrates renal medicine and palliative care to support CKD patients in Stages 4 and 5 with symptoms and/or suffering to live as well as possible (see pages 19 and 34 for more detail). RSC is predominantly accessed by patients on a dialysis or conservative kidney management pathway. Following pilots in select Districts, broader roll-out of RSC across NSW began in 2015.

All service planning needs to consider how any relevant Key Performance Indicators (KPIs) and targets can be met. Given the benefits RSC has provided both patients and the health system to date in terms of patient outcomes (patient experience and survival) and financial savings²⁵, an RSC enrolment target for ESKD patients (KPI22-03) was introduced in the 2022-23 District and Network Service Agreements to support further expansion of the initiative.

Environmental impact. Dialysis facilities have a large environmental impact including the need for large quantities of water, high power demand and significant amounts of waste. Districts and Networks should consider options to reduce the environmental impact of dialysis units such as re-cycling water to reduce wastage.

²⁵ NSW Ministry of Health (n 4).

²² Kidney Health Australia. A model for home dialysis in Australia. ISBN: 978-0-9808596-5-2. 2012. Available at: <u>https://kidney.org.au/</u>

²³ NSW Agency for Clinical Innovation: Home First Dialysis Model of Care. 2014

^[4] Kidney Health Australia. Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment. Sydney: Deloitte Access Economics. 2023.

²⁴ Scholes-Robertson N et al. Perspectives on Access to Dialysis and Kidney Transplantation in Rural Communities in Australia. Kidney International Reports, Volume 7, Issue 3 pp591-600; 2022. Available at: https://doi.org/10.1016/j.ekir.2021.11.010

3. PLANNING RENAL SERVICES

What sources of information inform health services planning?

Commonwealth and state government health policy directions and service priority areas provide a framework for delivering services in NSW. Service planning activities in the health sector are informed by, and aligned with, strategic plans that are linked to relevant system-wide policies, plans and programs.

A comprehensive environmental scan of relevant national, state and local frameworks, policies and plans should be undertaken prior to commencing any service planning process to ensure consistency and a contemporary approach. This should include, but not be limited to, the following key documents.

The NSW Health <u>Future Health</u> Strategy provides the strategic framework and priorities for the NSW Health system from 2022 to 2032. The strategic outcomes and key objectives outlined in this strategy need to be reflected in local service planning. *Align infrastructure and service planning around future care needs* is a key objective (2.5). The strategy emphasises that infrastructure and service planning must be agile and responsive to changes in demand and future healthcare needs, and accommodate emerging trends in care, particularly supporting digitally enabled care. Key priorities for service and infrastructure planning are:

- To be strongly informed by data and analytics
- To engage with clinicians and patients early in the process
- To drive collaborative whole-of-system optimisation early in the planning process.

The <u>NSW Regional Health Strategic Plan 2022-2032</u> details the strategic priorities and objectives when planning for health services for regional, rural and remote communities. These strategic priorities and objectives need to be reflected in local service planning. *Align infrastructure and sustainable service planning around the needs of staff and communities and to enable virtual care* is a strategic objective (2.6).

The Ministry's *ESKD Patient Dialysis Projections* provide information on the historic and forecast number of patients starting and receiving dialysis each year by District. The projections are modelled on age, sex and District cohorts and combined to provide NSW-level forecasts. See user notes for further information, which are available with the projections to health service planners on the <u>CaSPA Portal</u>.

The *NSW Department of Planning Environment (DPE) Population Projections* series has been endorsed by the NSW Government for use by public sector organisations. The latest DPE projections are available on the <u>CaSPA Portal</u>.

The <u>NSW Health Guide to the Role Delineation of Clinical Services</u> describes the minimum support services, workforce and other requirements for safe clinical services delivery for renal medicine. When planning renal services, refer to Section B19 - Renal Medicine.

A four-step approach to planning renal services

To help you plan clinical renal services for the later stages of CKD, this section outlines the four key steps, their objectives and main outputs.

Any service planning activity should include consideration of new and emerging treatments, generally via clinical consultation and horizon scanning, and adjust future demand projections accordingly.

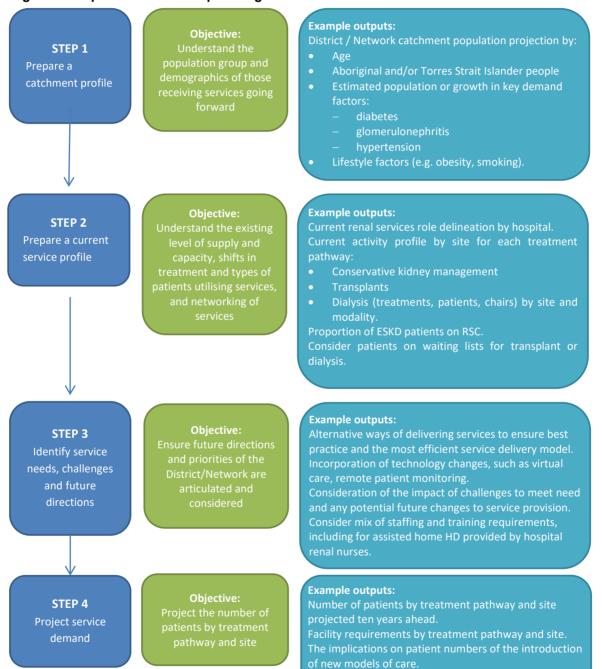


Figure 7: Steps to follow when planning renal services

Step 1: Develop a catchment profile

A renal service plan for each District and Network must consider the resident population, incidence of stages 3 and 4 CKD and ESKD as well as cultural factors.

Demographics: In your plan, include details of the size and characteristics of the resident population, including demographics and socioeconomic status.

Incidence of ESKD: ESKD is more common in certain patient groups (see Table 1). These characteristics may also influence the choice of treatment pathway. Any analysis must therefore also include the location of high-demand populations within the catchment.

Cultural factors: Cultural values and preferences of the catchment population should also be considered as this may influence how people view and use renal services.

Easter Description		
Factor	Description	
Number of patients aged over 55	 Over 70% of patients receiving renal replacement therapy are aged over 55 in Australia²⁶ Some evidence suggests increasing incidence in younger adults, and local data and consultation should identify any trends of significance in younger age groups 	
Number of Aboriginal and/or Torres Strait Islander people	• The prevalence rate of Aboriginal and/or Torres Strait Islander people on dialysis is almost five times as that of people without Aboriginal and Torres Strait Island ethnicity ²⁷ .	
Number of other high risk population groups including Pacific Islander people	Aside from Aboriginal and/or Torres Strait Islander people, some other population groups may also have higher prevalence rates, for example Pacific Islander people	
Number of patients with other co- morbidities, such as diabetes, coronary artery disease, peripheral vascular disease, cerebrovascular disease and chronic lung disease	 Diabetes is the leading cause of ESKD in Australia. In 2015 51% of new patients had either type 2 (45%) or type 1 (6%) diabetes²⁸ Glomerulonephritis is the second most common primary disease affecting 21% of new patients²⁹ Hypertension is a major contributor to ESKD affecting 13% of new patients³⁰ 	
Lifestyle factors such as smoking and obesity increase the risk of ESKD ³¹	 In 2015, 48% of new patients had smoked (11% were currently smokers)³² Obesity – BMI ≥30 kg/m² 	

Table 1: Demographic considerations

 ²⁶ ANZDATA Registry. ANZDATA Registry 45th Annual Report. Chapter 2: Prevalence of Kidney Failure with Replacement Therapy. Adelaide: ANZDATA Registry; 2022. Available at: <u>http://www.anzdata.org.au</u>
 ²⁷ Ibid

 ²⁸ ANZDATA Registry. ANZDATA Registry 39th Annual Report. Chapter 2: Prevalence of end-stage kidney disease. Adelaide: ANZDATA Registry; 2016. Available at: <u>http://www.anzdata.org.au</u>
 ²⁹ Ibid.

²⁰ Ibid.

³¹ <u>http://kidney.org.au/your-kidneys/prevent/risk-factors</u>

³² AIHW. Dialysis and kidney transplantation in Australia 1991-2010. 2010. Available at:

https://www.aihw.gov.au/reports/chronic-kidney-disease/dialysis-and-kidney-transplantation-in-australia/summary

Step 2: Prepare a current service profile

The purpose of the current service profile is to identify the need (demand) for renal services by the local resident population as well as the supply of renal services by local facilities in the public and private sector. The profile should specify the service elements available within the service being planned for (e.g. dialysis chairs, outpatient clinics, supportive care, transplant services).

Outline in your profile the service type and location, as well as the current volume of services delivered and the facility capacity at both public and private services. The profile also needs to include the potential capacity of infrastructure compared to the amount actually used and any hidden waiting lists. Demand can ebb and flow as patients move between modalities (particularly in satellite dialysis units and rural areas), move out of area or die.

To understand the demand and local appropriateness for each modality, consider each ESKD treatment pathway (transplant, dialysis modalities and conservative kidney management). When estimating the demand for renal services by the local resident population consider:

- Current activity including the number of patients from the catchment population currently receiving treatment
- Patient outflows (the number of patients treated by other Districts, Networks or Interstate)
- Private provision (the number of patients treated by private operators)
- The number of occasions of service
- Dialysis type HD or PD and modality e.g. home, facility and satellite (including self-care units / community and multi-purpose centres)
- ESKD Patient Dialysis Projections
- Assessment of any changes in the demand patterns over the past ten years by service type and modality
- Estimate of the infrastructure used (e.g. plumbed stations, chairs, dialysis machines, reverse osmosis systems)
- Transport options and carparking for dialysis patients.

Also consider dialysis demand for acute renal services, including AKI patients and other inpatient activity.

As well as assessing current District or Network health promotion and prevention activities, consider opportunities for early detection and treatment in high-risk populations. Consulting with primary health providers may provide additional information and strengthen networking opportunities.

Step 3: Identify service needs, challenges and future directions

New models of care and/or technologies may change the way renal services are delivered. Emerging evidence on new and novel treatments may slow or prevent disease progression to ESKD. Search the literature for new and emerging technologies and models of care and talk to other providers, such as Districts and Networks, about how they deliver services. The <u>ACI Renal Network</u> is a good source of information and provides several resources that can support effective service planning.

Seek specialist advice and local context from local clinicians such as nephrologists, renal surgeons, specialist nurses and allied health professionals. Consumers themselves should also be engaged in the consultation process to provide valuable information about their preferences.

Finally, consider the potential impact of strategic priorities for the District or Network, such as home dialysis and RSC enrolment rates.

Step 4: Project service demand

To help you plan future demand for workforce, infrastructure, budget allocations and other local issues, consider the treatment pathway (dialysis, transplant and conservative kidney management), place of treatment and modality (facility, satellite, home) and whether RSC will be provided.

Although in this guideline we have proposed a separate methodology for each treatment pathway, these pathways will interact. For example, increased demand for one pathway reduces demand for another pathway. Patients may also need to access more than one type of service as their disease progresses and their health status changes.

Dialysis

When projecting demand for dialysis, consider:

- The number of patients requiring treatment
- Whether PD or HD is required
- Where treatment may be delivered (e.g. facility or home)
- Consider the demand for dialysis for patients with AKI, home dialysis patients requiring
 respite care or in-patient admission for an acute illness, and the need/demand for holiday
 dialysis.

Figure 8 overleaf shows that the proportion of patients receiving home dialysis (i.e. home HD and PD) in NSW has decreased from 44% in 2004 to 33% in 2021. Modality information on a District and Network basis (for public and private facilities) can be found in the *ESKD Patient Dialysis Projections*.

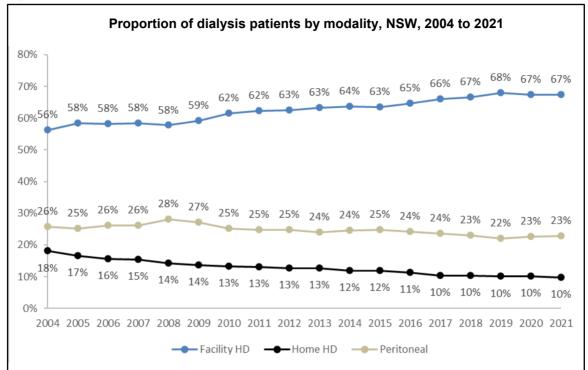


Figure 8: Source – ANZDATA 45th Annual Report 2022

When planning the future service profile for dialysis by modality (facility, satellite or home), consider the following for each network:

- Any NSW renal targets as outlined locally or in service agreements with Districts and Networks
- Appropriate alternative treatments (transplant or conservative kidney management) to dialysis
- Home dialysis as a first priority if clinically appropriate
- Population profile including age and geographical dispersion of the resident population
- Population prevalence of comorbidities such as diabetes, hypertension and cardiovascular disease which may limit options for care and impact projected dialysis requirements (particularly where rates are changing)
- Socioeconomic, rurality, CALD status etc. which may restrict access to some treatment options
- Psychological and social support services for patients and carers
- Staffing to include renal physicians, nurses, dietitians, social workers and consideration
 of other health professionals such as nurse practitioners, physiotherapists, occupational
 therapists, clinical psychologists, podiatrists, audiologists, pharmacists and exercise
 physiologists
- Infrastructure requirements including water quality for facility and home dialysis, recycling facility wastewater, etc.
- Costs of different options
- Environmental impact of different options.

As discussed below, you will also need to consider the number of patients who receive a transplant and those on a conservative kidney management pathway, as this will reduce the number of patients who require dialysis (see APPENDIX B for more detail on treatment modalities and models of care).

Table 3: Steps to forecast the number of ESKD patients on dialysis and treatments by	
modality^	

Step Action		Action
1.	Calculate the demand for dialysis in the district or network	 ESKD Patient Dialysis Projections are available through CaSPA The projections are available at District level (based on patients' District of residence) and account for local demographics Unless there is evidence that local factors or other relevant conditions will change over the projection period, you do not need to adjust for this The ESKD Patient Dialysis Projections file also contains historical information to enable analysis of: District and site of treatment (to support analysis of Inter-District/State inflows and outflows and to the private sector) Modality Local demographics e.g. Indigenous status, age group, gender, diabetes status
2.	Consider inter-District and Network flows and private sector provision	 Use supplementary information (e.g. historical flows data in the <i>ESKD Patient Dialysis Projections</i>) to estimate the number of patients who will receive treatment: in another District or Network by the private sector Adjust demand accordingly as these patients may not receive treatment in the district or network
3.	Determine the demand by modality	 Use the supplementary historic information in the <i>ESKD Patient Dialysis Projections</i> on CaSPA to determine the potential demand for: facility-based dialysis home-based dialysis (home HD and PD) Consider current activity and any local, national/state targets for each modality Consider local population preferences and cultural values when projecting demand for service modalities
4.	Convert the number of patients to treatments delivered	 Convert the projected number of patients who will access dialysis (from steps 1–4) to the number of treatments delivered annually See figure 9 (p23) for formula and worked example.

^ The effects of COVID-19 should be considered for each step, including whether any resulting impacts are likely to be seen in the short, medium or longer term. For example: impacts to flows due to Local Government Area and interstate boarder closures, including potential delays to patients in commencing dialysis where dialysis services are provided across State boarders.

Renal transplant

Several hospitals in NSW offer renal transplant services with referral networks for all NSW patients. Planners and clinicians should consider how best to ensure equity of access for patients from non-transplant sites.

Transplant activity is largely dependent on the availability of viable organs from live and deceased donors. Following national and state strategies between 2000 and 2010 to improve organ donation rates, an increase the number of kidneys available for transplant was seen between 2009 and 2018 (page 9 details recent and historic transplant levels, including the impact of COVID-19). Approaches to assessing kidney quality to improve post-transplant outcomes is an area of continuing research. All service planning should consider emerging technologies and advances in treatment that may impact service delivery over the planning horizon. See APPENDIX B for more detail on renal transplant.

Planning for transplant services will require additional considerations and clinical consultation. Due to the corresponding reduction in the need for other treatment options, understanding the proportion of patients eligible for transplantation is important for projecting demand for dialysis and conservative kidney management. To support planning for dialysis services, consider the number of patients likely to be suitable for a transplant in the catchment area. Based on historic data, determine:

- 1. The number of people in the catchment area who are suitable for a transplant
- 2. How many patients are currently on local waiting lists.

Step	Description	
1. Determine the current transplant rate	 Source the number of patients with a transplant in the district or network's catchment over time Divide the prevalence by the relevant year's total catchment population 	
2. Determine the target transplant rate	 Consider any trends in the NSW transplant rate over time as well as national targets for organ donation and equitable access to transplant sites 	
 Project the base case and target number of transplant prevalent patients 	 Multiply the base case target transplant rates by district or network population projections to determine prevalence of transplant patients by year The difference between the base case and the target is the increase in transplant prevalent patients 	

Table 2: Steps to calculate the projected number of patients suitable for transplant

Conservative kidney management

Conservative kidney management is a non-RRT treatment pathway for CKD. It is not the same as RSC, which is a supportive service that can be provided across all treatment pathways. Patients on a conservative kidney management treatment pathway receive medications and dietetic advice for fluid and electrolyte management, psychological support, lifestyle and other active interventions.

It is difficult to determine the number of patients on the conservative kidney management pathway as most sites do not keep a register of these patients (and it is challenging to accurately identify the cohort in NSW Health datasets using diagnosis and procedure coding). This was estimated in recent analysis of ESKD modalities and patterns of care³³ by counting patients with a principal or additional diagnosis code of ESKD (for at least 3 months), that were not successful transplant recipients nor on dialysis (based on admitted patient procedure/diagnosis codes and non-admitted patient establishment type codes).

In effect, any patients with ESKD not receiving renal replacement therapy (i.e. dialysis and transplant) are counted as on a conservative kidney management pathway, although they have not all actively chosen conservative kidney management as their treatment option. It therefore may include undecided patients, those waiting for dialysis or transplant or withdrawing from dialysis.

Renal Supportive Care

An important distinction is that RSC is not the same as conservative kidney management which is a treatment pathway. RSC provides support for patients on any renal treatment pathway.

Since July 2015 (and as early as 2009 in some), Districts and Networks have been establishing access to RSC services for people in their catchment (see APPENDIX B). Suitable patients for the RSC program include Stage 4 and 5, those who are older, have multiple co-morbidities and a high symptom burden along with a loss of functional independence and/or psychosocial issues. These characteristics can be used to identify a population within the catchment that may be eligible for referral to RSC regardless of their treatment pathway.

To address variation in RSC delivery the Value Based Healthcare Steering Committee agreed on the inclusion of a minimum 20% RSC enrolment target for the ESKD cohort beginning on an incremental basis in the 2022-23 Service Agreements. The <u>ROVE analytics</u> application³⁴ dashboards contain charts showing the:

- Number of unique patients with ESKD by financial year
- Number of unique ESKD patients in RSC clinic by financial year.

To identify the proportion of patients who may be eligible for RSC consult with clinical staff.

³³ NSW Ministry of Health (n 4).

³⁴ For question on or access to ROVE email: <u>MOH-Roveapp@health.nsw.gov.au</u>

Step	Actions	
 Determine the rate of use for each group and pathway 	 Profile current RSC use by pathway (e.g. conservative versus dialysis) and age Divide by the population profile (by age category). 	
2. Confirm expected utilisation rates of each group	 Determine utilisation of each group based on historic utilisation rates and consultation with clinical staff regarding the proportion of patients who might be suitable for RSC. Consider if there is excess unfulfilled demand for RSC services. Consider any KPIs for RSC. 	
3. Project demand	Multiply the expected service utilisation (profiled by age) by the population profile.	

4. PLANNING INFRASTRUCTURE

This guideline predominantly focuses on dialysis infrastructure needs for CKD patients. Transplant is more complex than can be explained in this document and planners should consult with transplant clinical staff. Planners should also consider any impact of dialysis for AKI on local infrastructure needs and consult with renal services staff on this and any other aspects of the local service profile not represented by the methods described in this guide. It is expected that reasonable evidence and planning assumptions underpinning the impact on local infrastructure requirements be documented.

It is important to note that clinic spaces are required for training and support for home dialysis patients, private interview rooms (e.g. psychosocial discussions), multidisciplinary team meeting spaces, and the management of CKD patients (including conservatively managed and transplant patients) and those with other renal disease such as glomerulonephritis. To determine the appropriate number of clinic spaces use the Guideline for Planning Non-Admitted Patient Services, available on the <u>CaSPA Portal</u>.

The Australasian Health Facility Guidelines (AusHFG) describes the operational, functional and design requirements for a dialysis unit, including satellite and in-centre services, as well as home dialysis training for selected units. This is found in <u>Health Planning Unit (HPU) 620</u>.

Types of dialysis

There are two primary forms of dialysis (HD and PD) which are performed in different locations or modalities. The HD modalities include hospital, satellite, self-care and home. PD is usually done at home and modalities include continuous ambulatory (CAPD) or automated (APD). See APPENDIX B for further information on types of dialysis, including a description of each modality in Table 5.

It should be noted that patient's suitability and preference for different pathways may change, and they can transition between different modalities over time as their circumstances evolve. Planners should consult with local renal clinicians regarding the proportion of patients on each pathway. Information on the proportion of patients on each pathway by District of residence (i.e. demand-based) and treatment centre (i.e. supply based) historically from ANZDATA is also included with the *ESKD Patient Dialysis Projections*.

Facility-based haemodialysis

A patient will dialyse in a chair three times a week for approximately five hours per session. A single chair can generally be used for two sessions, six days a week with the potential to perform 12 dialysis treatments a week to four patients.

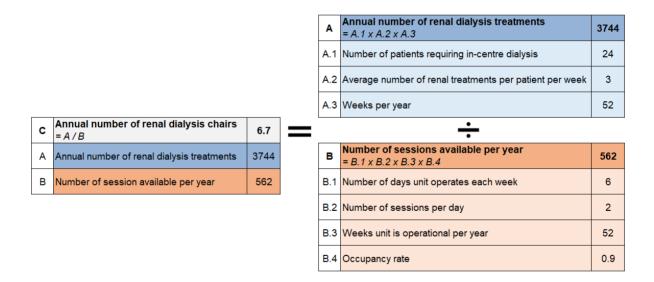
If there is the demand and staffing resources available, some dialysis units may run three sessions a day (e.g. an evening shift from 7–11pm or providing nocturnal dialysis treatment). Nocturnal dialysis is a slower, longer HD treatment (for six to eight hours) that takes place at

night while patients sleep³⁵. It can offer benefits and improved outcomes for patients (e.g. it is a gentler treatment, has less dietary impacts and leaves patients with more time during the day). To increase the number of treatments per chair, some units open seven days a week.

Hospitals and healthcare centres cannot operate at 100% occupancy, as spare bed/chair capacity is needed to accommodate variations in demand and ensure that patients can flow through the system. Protocols for management of multi-resistant organisms must also be taken into consideration. However, low occupancy rates may be a sign of underutilisation and leave scope for improving efficiency. Given the more predictable pattern of dialysis delivery for ESKD patients, an occupancy rate of 90% is generally assumed in calculating chairs required. However, local circumstances should be considered, particularly in smaller rural facilities, if there are not additional machines available to replace machines when they are undergoing maintenance.

Please refer to Table 3 (p18) for more information on calculating the annual number of chairbased facility dialysis treatments. Note: this does not include chairs dedicated solely for home HD and PD training, discussed later under 'Home haemodialysis and peritoneal dialysis' (pp24-25) and 'Patient education and training' (p26).

Figure 9: Formula to determine number of dialysis chairs required (with worked example)



To maximise capacity, hospitals, satellite or self-care centres can:

- Increase home-based dialysis rates where appropriate
- Ensure maximum use of existing District or Network infrastructure through effective scheduling
- Configure chairs so that more chairs operate on fewer days per week (requiring fewer nurses overall), particularly in centres with smaller volumes e.g. in Figure 10 (overleaf), Example A would require 4 nurses each working 3 days/week whereas example B would need 2 nurses each working 3 days/week (as a minimum of 2 nurses are required per session).

³⁵ National Kidney Foundation. Nocturnal Haemodialysis. New York: National Kidney Foundation; 2023. Available from: <u>https://www.kidney.org/atoz/content/nocturnal-</u> <u>dialysis#:~:text=Nocturnal%20dialysis%20is%20a%20slower,times%20or%20more%20a%20week</u>

Staff profile and resourcing levels in a Dialysis Unit (including nursing and allied health) will vary depending on the service model including whether home training services are provided, the level of patient acuity and dependency, and the proposed staffing model. The staffing profile and requirements will need to be determined early in the planning process³⁶. In smaller rural settings, sometimes operational costs can be reduced if more chairs deliver fewer sessions per chair per week. Although more chairs are a greater capital expense, it may be more efficient in the long-term to buy more chairs and reduce operating costs (see Figure 10). The impact on ability to attract and retain workforce should also be considered.

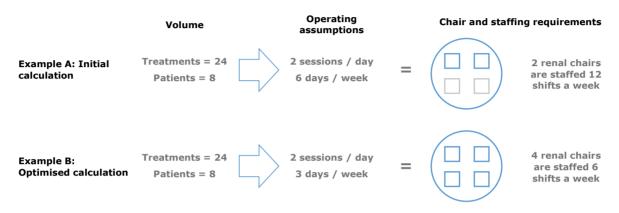


Figure 10: Dialysis chair calculation optimised for staffing requirements

Several rural districts have been innovative in their approach to establishing satellite-like dialysis services to ensure access for patients in lower catchment areas (examples in APPENDIX D).

Finally, identify and profile private renal services your service plan including a description of their role in delivering dialysis services. There may be opportunities for private providers to enter into formal agreements with a district/network to deliver services to public patients. However, the best value for the patients and health system should be considered (e.g. through cost benefit analysis), as permanent private services may cost more.

Home haemodialysis and peritoneal dialysis

Home dialysis service is a crucial aspect of managing Australians with ESKD as it provides them the flexibility to receive treatment in the comfort of their own homes. There are two main types of home dialysis – HD and PD.

Patients and carers are generally trained in outpatient clinics but may also be trained in the patients' home. Consider the need for additional dedicated dialysis machines and trained nurses to ensure patients and their carers receive comprehensive education and training on how to perform home dialysis safely and effectively, how to monitor blood pressure and fluid levels and how to respond to emergencies. Technicians to service home machines are also required. PD can be undertaken in hospital if patients are admitted. Nursing staff in selected wards and emergency departments require comprehensive training to provide PD and PD

³⁶ Australasian Health Infrastructure Alliance. Australasian Health Facility Guidelines, Part B – Health Facility Briefing and Planning, 0620 Renal Dialysis Unit, Revision 7.0. p6. 2021 Available at: <u>https://aushfg-prod-com-au.s3.amazonaws.com/HPU_B.0620_7%206.pdf</u>

care for patients in the acute hospital setting. PD machine and supplies must be available in the wards. For more information on patient education and training, see page 26.

Districts may also consider the assisted home dialysis model of care, where patients meeting certain criteria receive support from trained nurses to perform dialysis at either the patients' home or in an assisted living facility. Assisted home dialysis can be an optimal modality (and less expensive than hospital dialysis) despite the required increase in dialysis nursing staff. Access to assisted home dialysis is supported by a limited number of private health funds (which increased in 2023, though only assisted home HD, not PD, was covered at this time). It is important to contract private providers to deliver the same level of care to meet individual patient needs as public providers.

Advances in dialysis machines have made it possible to remotely monitor patients and detect issues before they become severe. Remote management and monitoring can play a significant role in home dialysis service. Trained nurses can remotely monitor the patient's health status and provide necessary support and guidance to improve the quality of care provided to patients and increase patient safety at home.

Sorbent HD can be undertaken when there is limited access to water but concerns remain that clearance may be inadequate for some patients.

Renal supportive care

RSC (see APPENDIX B for detailed description) is largely delivered in clinics in outpatient departments, through virtual care and home visits. The requirements for clinic space will depend on demand and will likely increase over time as the program expands.

Larger sites may offer RSC for smaller sites within their District so this should be considered when calculating demand.

The number of RSC patients in the 2022-23 District and Network SLAs is calculated at a minimum of 20% of ESKD (stage 5) patients but also includes a significant number of stage 4 and some stage 3b patients. Renal patients eligible for RSC are described as stage 4-5 with symptoms and/or suffering on any treatment pathway.

Staffing includes the RSC nurse, dietitian and social worker and in larger sites or where available, an RSC physician (palliative care and/or renal), nurse practitioner and other allied health professionals.

5. OTHER CONSIDERATIONS

Patient education and training

When stage 3 CKD is diagnosed (usually in primary care), patients should be referred to a nephrologist. The multidisciplinary team should begin education and early discussions about treatment options with patients and families when patients reach Stage 4 of CKD, particularly for patients considering home dialysis. This education and discussion should take place before patients decide to commence dialysis, and options should also include the conservative kidney management pathway and RSC. The <u>Home First Dialysis Model of Care</u> evaluates each individual patient's needs and educates patients and their families about their home dialysis options. This requires clinic spaces for providing one to one education in a multi-disciplinary team environment as well as bookable large rooms for providing group education to many patients and their families.

Patients opting for home dialysis will need to be trained at the facility to manage their own PD or home HD. A separate area with training machines and staff will be required. Training for Home HD takes an average of six to eight weeks, of three to four sessions a week³⁷. Training times depending on the type of dialysis machine used and how quickly the patient feels comfortable and confident in cannulating their fistula or graft, operating the machine and mastering trouble shooting. PD training will on average take about one to two weeks of daily training at a clinic for several hours each day³⁸. Allow a few extra days if the patient is learning both the CAPD exchanges and APD machines at the same time.

By becoming educated and modifying their lifestyle, patients may be able to prevent or slow the disease progression and reduce the need for renal services.

Patients with AKI also require education that they are at increased risk of developing CKD.

Vascular access for patients starting dialysis

The type of vascular access will depend on whether the patient is receiving HD or PD. PD requires a catheter inserted into the abdomen to access the peritoneal cavity, while HD requires vascular access through a fistula, graft, or central venous catheter.

A surgeon generally completes and maintains vascular access, however, nephrologists are starting to do these procedures in some units. The District or Network's service plan must specify what resources are available for new dialysis patients. At a local level, challenges could include availability of vascular surgeons, interventional radiologists, access nurses and ultrasound services for surveillance as well as surgery waiting lists.

 ³⁷ Kidney Health Australia. An Introduction to Home Haemodialysis. Melbourne. 2013. Available from: <u>https://kidney.org.au/uploads/resources/KHA-Booklet-An-introduction-to-home-dialysis.pdf</u>
 ³⁸ Ibid.

Dialysis equipment and purchasing arrangements

Equipment for facility dialysis can be purchased in line with HealthShare processes for tender. Home HD and PD equipment can be obtained through existing procurement processes. Quality water sources and systems are a mandated requirement for dialysis and are expensive, particularly for facility dialysis. These need replacing approximately every 10 years. The <u>ACI's Water for Dialysis</u> guide has important information about water quality infrastructure.

Contracts with equipment providers can be either a Managed Equipment Service with a single monthly payment or payment on a price-per-treatment treatment basis. For both types of contracts the dialysis machines, water filtration and reverse osmosis systems are installed and maintained by the provider. The cost also includes provision of supplies and consumables. HealthShare can provide advice on both contract options.

Environmental Impact

Dialysis facilities have a large environmental impact including the need for large quantities of water, high power demand and significant amounts of waste. There are options to reduce the environmental impact of dialysis units including re-cycling water to reduce wastage. More information on environmentally sustainable design for kidney care facilities is available in:

- <u>AusHFG Renal Dialysis Unit (0620)</u> Health Facility Briefing and Planning document (section 2.2.13 of Revision 7.0, February 2021)
- Australian and New Zealand Society of Nephrology (ANZSN), the Renal Society of Australasia and Kidney Health New Zealand <u>Position Statement on Environmental</u> <u>Sustainability & Kidney Care</u>
- ANZSN <u>Environmentally Sustainable Design (ESD) Guidelines for Kidney Care</u> <u>Facilities</u>.

Workforce

When planning your workforce, consider the planned service mix. The staff profile and skill mix to support facility dialysis may be slightly different from home dialysis. For example, with home visits, consultations by nursing staff, allied health and technicians may be required.

Transplant centres require a large multidisciplinary highly specialised team providing a 24/7 service.

The typical renal staffing model is a multi-disciplinary team consisting of renal physicians, nurses and allied health professionals (mainly dietitian and social worker but may also include clinical psychologist, physiotherapist, exercise physiologist, podiatrist, audiologist, pharmacist and occupational therapist), a nurse practitioner and a palliative care physician in larger centres. RSC services in particular are increasingly seeking dual trained palliative/renal physicians or nurse practitioners.

Some hospitals, particularly in rural areas, may not have access to all allied health, renal outreach specialist nursing and palliative services in particular. In the latter case, you will need to consider how your service can network with other services that provide palliative knowledge such as nurse practitioners and virtual care.

Funding

In your service plan, address changes in capital and operating expenditure. When building new capacity, capital expenditure may be needed for equipment such as chairs and dialysis machines. If the service mix, service use or staff and machine training needs to be changed, the operational expenditure may also change.

If building a new facility, consider potential future demand by installing dialysis access points even if not utilised initially. This may be cheaper than building a facility that is rapidly filled and new capital works are required.

APPENDIX A: ACUTE AND CHRONIC RENAL CARE

Acute kidney injury

AKI is a sudden episode of kidney failure or damage to the kidneys that occurs within a few hours or a few days. AKI is common in hospitalised intensive care patients, is a common cause of admission and mostly occurs in older adults.

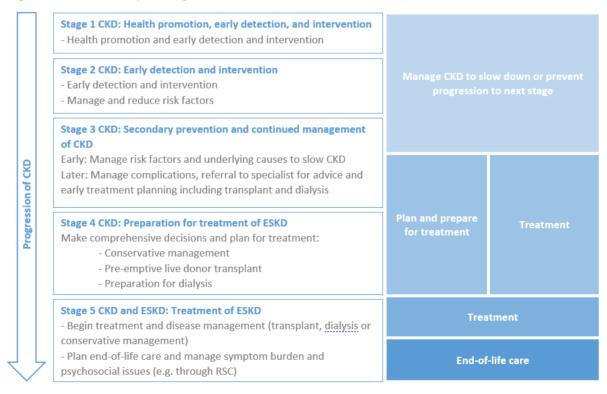
To avoid progression to kidney failure, early diagnosis and treatment is important. Treatment for AKI generally requires hospital admission. Some patients may have been admitted to hospital with another condition which could result in an AKI. For more complex conditions, short-term treatment with dialysis may be needed to help replace kidney function until the kidneys recover.

Patients who have had AKI are at increased future risk of developing CKD.

Chronic kidney disease

CKD is the occurrence of kidney damage and/or decreased kidney function for a period of three or more months. Clinically, CKD is classified into five stages from mild kidney damage with no loss of kidney function to severe loss of kidney function. Lower-stage CKD (stages 1 to 3) is less serious and patients often show no symptoms. Prevention, early detection and management, such as reducing risk factors, can prevent or delay the disease progressing to stages 4 and 5^{39.}

Figure 11: CKD care pathway



³⁹ Kidney Health Australia: Stages of Chronic Kidney Disease

Treatment in stages 1 to 3 typically focuses on making lifestyle changes (e.g. exercise and diet), reducing cardiovascular disease risk and potentially prescribing medications. If a patient progresses to late stage 3 CKD, the disease will usually progress to stage 4.

Early treatment planning needs to begin at stage 4 CKD. At this stage a patient may have a pre-emptive live transplant if they have a suitable donor to prevent them from progressing to ESKD.

A description of each stage in the CKD care pathway is outlined below⁴⁰.

Stages 1 and 2: Health promotion, early detection and intervention

To ensure high quality and sustainable care for renal services across NSW, Districts and Networks need to make health promotion and education a priority. Community health literacy, awareness of CKD and associated risk factors need to be increased and enhanced.

Early detection and management of CKD and associated risk factors may delay disease progression and lower demand for resource intensive services.

Resources need to be allocated to promotion and prevention activities and Districts and Networks should regularly evaluate these strategies to determine their impact on progression of CKD and ESKD incidence and prevalence. Collaboration and integration with primary care services supports these activities given the key role of primary care in early detection and management of risk factors⁴¹.

Stage 3: Secondary prevention and continued management of CKD

The aim of this stage in the care pathway is to continue to reduce risk factors, slow the progression of kidney disease and prevent and manage complications of CKD as they arise.

Where possible, care for relatively stable patients should be mostly delivered by the primary health care sector with intervention aimed at improving and maintaining health, reducing risk factors, managing underlying causes, and delaying disease progression. Where access to primary care is limited, such as in some regional and rural areas, this can be undertaken via appropriate alternative models of care, such as CKD (pre-treatment) nurses. CKD nurses may link GPs, nephrologists and the renal service and educate patients in their disease.

Stage 4: Preparation for treatment of ESKD

Patients at this stage have severely reduced kidney function and require timely and appropriate access to specialist nephrology management and comprehensive planning. CKD (pre-treatment) nurses may discuss dialysis modality options and refer patients to appropriate allied health and vascular teams in preparations for commencing RSC and/or transfer to conservative or RRT pathway. This includes a pre-emptive transplant if a live donor is available. Patients considering transplantation should be referred to a specialist renal unit at least 12 months before the expected need for transplant.

⁴⁰ Renal Integrated Care Pathway: Guide for Victorian renal services. 2016.

⁴¹ Hull SA et al. Do virtual renal clinics improve access to kidney care? A preliminary impact evaluation of a virtual clinic in East London. BMC Nephrol 21, 10, 2020. Available at: <u>https://doi.org/10.1186/s12882-020-1682-6</u>

Patients who select dialysis must be referred to a vascular surgeon at least three months before dialysis begins to create their vascular access or insert the peritoneal dialysis catheter and provide psychosocial support.

Criteria for treatment pathway options should be consistent and take into account medical and patient circumstances. Shared decision-making between the patient and clinician should be practised (e.g. on the appropriate type of vascular access or optimum pathway).

Stage 5: Treatment of ESKD

ESKD is the most severe form of CKD and occurs when there is significant loss of kidney function. By stage 5, patients will need either a transplant, dialysis (HD or PD) or conservative kidney management. These pathways are interlinked, as demand for one pathway may reduce demand for another. They may also receive RSC as an adjunct to their usual renal care.

APPENDIX B: TREATMENT OPTIONS FOR ESKD

Conservative kidney management

Conservative kidney management is a comprehensive treatment option for patients medically unsuitable for or those who prefer not to have RRT (i.e. transplant or dialysis). Conservative kidney management focuses on symptom relief, preserving kidney function for as long as possible and avoiding treatments and hospital stays that may worsen quality of life.

It offers physical and psychological support using a combination of medications and diet to manage fluid and electrolytes as well as counselling. As for other treatment options it may rely on the additional support of the renal supportive care team to affect the patient's best quality of life.

Renal transplant

For many patients, transplantation represents the optimal treatment for ESKD. Although transplantation is not without risk, a successful transplantation means improved quality of life without the need for dialysis. As transplantation depends on the availability of organs, increases to the donation rate would reduce the number of patients requiring dialysis and conservative kidney management.

For the majority of hospitals which are not transplantation sites, consider how equity of access to transplantation can be achieved for local patients, such as a nurse coordinator and accommodation for regional and rural patients at metro sites.

Renal transplant can be performed from deceased or live donor organs. The additional resource requirements for the donor's post-surgical care should be considered when planning renal transplant services.

Post-transplant, patients typically remain in the care of the hospital that completed the transplant. Patients return for blood tests and checks with nursing staff, and also meet with transplant doctors to review progress. The frequency of visits will decline over time as kidney function stabilises. After a period of approximately three months, patients return to their usual kidney doctor, although in some networks patients return to the care of their usual nephrologist much earlier.

Dialysis

There are two primary forms of dialysis which are performed in different locations and for different patient cohorts. These are described in Table 5 (overleaf).

Deciding on a dialysis treatment option depends on clinical factors such as age, presence of co-morbidities, frailty and other factors such as the patient's independence and the availability of a care partner to assist with home dialysis or transport to a facility. Considerations such as education and training, equipment and infrastructure requirements (e.g. water quality, electricity costs) will differ for patients in rural areas. A patient may need to travel and stay for several months to receive the intensive training required for home HD.

Dialysis type	Modality	Description	Patient characteristics
Haemodialysis (HD)	Hospital	Performed in hospital dialysis unit or ICU (if patients are too sick or need dialysis after- hours, or where there is no hospital dialysis unit or is closed or at capacity).	 Acutely ill patients who require highly specialised care Patients with acute exacerbation of chronic renal disease Patients with a temporary increase in dependence due to illness Patients who are too frail or unstable to attend a satellite unit or undertake home dialysis
	Satellite (stand- alone)	Provides care in lower- level settings, including community settings, supported by a tertiary hospital.	Medically stable, self-care, or relatively independent patients.
	Self-care unit or community centre	Provides facility-based dialysis in a centre close to home.	Patients who are able to dialyse by themselves but are unable to do so at home as their home environment is not suitable or preferable (e.g. due to water quality issues or lack of space).
	Home	HD machines are provided to people to dialyse at home after training and with some support provided through home visits by clinical and technical staff.	Independent, medically stable and motivated patients with adequate social and home support.
Peritoneal dialysis (PD) – see below for a more detailed description	Continuous ambulatory peritoneal dialysis (CAPD)	Uses manual bags with peritoneal fluid to cleanse blood. Manual bag exchanges of fluid are usually performed four times a day.	Very young children, people with limited kidney function and no serious other conditions. Equipment (e.g. bags, tubing and stand) is portable which may suit some patients. Patient preference or most suited therapy for the patient following a
			peritoneal equilibration test (PET) test result which shows peritoneal transport status.
p d	peritoneal r dialysis f	Similar to CAPD, but a machine controls the flow of fluid. Usually performed overnight.	Very young children, people with limited kidney function and no serious other conditions. People who wish to dialyse overnight.
			Personal preference or those suited following a PET test showing this is the most suitable PD modality.

Peritoneal dialysis

To perform PD, a catheter (tube) is inserted into the peritoneal cavity through a small incision in the abdomen. The catheter requires surgical or percutaneous insertion either by a surgeon (a vascular surgeon or other surgeon with specific training to insert PD catheters), an interventional radiologist or an interventional nephrologist.

After a period of healing the patient or carer attaches a bag of dialysis fluid to the catheter which is infused into the peritoneal cavity and left in the cavity for a period of time before the fluid now containing waste products is drained out and discarded. This process is repeated several times a day for CAPD or performed overnight using a machine for APD.

Both types of PD are usually done at home, either independently by the patient or with the help of a carer. For dependent patients without carers, 'assisted PD' by trained nurses either at home or assisted living facilities is another viable option for care.

The catheter must be properly cared for to prevent infection and the patient must undergo regular monitoring to ensure PD is working effectively. Complications can occur with PD catheters, such as blockage or infection which may require treatment in either the inpatient or outpatient setting or even catheter removal.

Renal supportive care - additional support for all treatment options

RSC is an interdisciplinary approach integrating the skills of renal medicine and palliative care. The aim is to help patients with stage 4 and 5 CKD live as well as possible with advanced disease by better managing their symptoms and/or suffering and supporting them and their families and care partners.

RSC encompasses advance care planning and end-of-life care⁴² and is closely linked with renal services and palliative care services.

The criteria for RSC are patients with stage 4 or 5 CKD with biopsychosocial issues regardless of what treatment pathway has been chosen.

The decision to be supported through RSC is made by the patient. Clinicians are guided by the <u>NSW Renal Supportive Care Service Model</u> when determining if a patient may be suitable for RSC.

Different cultural values and sensitivities regarding death are two important considerations for RSC. For example, Aboriginal and/or Torres Strait Islander people have unique cultural beliefs and practices with respect to death, and it may be a sensitive issue to discuss⁴³. Only 3% of current RSC patients are Aboriginal and/or Torres Strait Islander people⁴⁴.

The NSW RSC model is primarily nurse led. In addition to the nurse, patients and family are often supported by a palliative care physician (or other medical or nursing practitioner who can assist with the medical aspects of managing the high symptom burden of the target population), a dietitian and social worker as well as other allied health professionals where available. A nephrologist provides local leadership for the RSC service. Patients with CKD

⁴² NSW Renal Supportive Care Service: Service Model. 2017.

⁴³ Queensland Health. Sad news, sorry business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying. 2015.

⁴⁴ Above n 42.

and ESKD will continue to receive care from their nephrologist and the renal unit. The model can vary between Districts and Networks, often depending on workforce availability.

RSC is most needed at times of high patient and carer stress. Based on the principle of nonabandonment, in NSW RSC is a networked model that is embedded within existing renal services.

APPENDIX C: ACKNOWLEDGEMENTS

We would like the thank the consultancies and advisory groups, including expert advisors, clinicians, managers, reviewers, and staff who contributed to the development of this guideline and the *ESKD Patient Dialysis Projections*.

Table 6 shows key stakeholders involved in the 2023 update to the guideline (version 4.0). Consultation was also undertaken with renal service and service planning representatives from every District and Network, and the ACI Renal Network membership provided the opportunity to comment on the guideline.

Name	Role	Organisation
Lisa Brady	Principal Policy Officer, Strategic Reform & Planning Branch (SRPB)	NSW Ministry of Health
Tessa Gastrell	Senior Economic Analyst, SRPB	NSW Ministry of Health
Gerard Duck	Director, Strategic Analysis & Investment Unit, SRPB	NSW Ministry of Health
Gurkirt Singh	Planning and Policy Analyst, SRPB	NSW Ministry of Health
Annie Hutton	Manager, Renal Network	Agency for Clinical Innovation (ACI)
Maureen Lonergan	Nephrologist retired, Co-Chair ACI Renal Executive Committee	ACI
Elizabeth Josland	Renal supportive care CNC, Co- Chair ACI RSC Executive Committee, member ACI Renal Executive Committee	ACI (and St George Hospital)
Kelly Lambert	Associate Professor, Advanced Accredited Practising Dietitian, member ACI Renal Executive Committee	ACI (and University of Wollongong)
Maria Chan	PhD AdvAPD, Lead Renal Dietitian, member ACI Renal Executive Committee	ACI (and St George Hospital)
Linda McCorriston	District Renal Nurse Manager, Co- Chair ACI Renal Executive Committee	ACI (and Southern NSW Local Health District)
Chief Executive (CE) nominated representatives	Health service planners	Across Districts and Networks
CE nominated representatives	Renal service clinicians	Every District and Network
Executive nominated representatives	ACI Renal Network	ACI

Table 6: key stakeholders involved in the 2023 update to the guideline

APPENDIX D: MODELS FOR SATELLITE DIALYSIS IN NSW

To provide patients access to HD in smaller catchment areas, some rural districts have developed different models for satellite services.

Examples include:

- Mid North Coast Local Health District: A six-chair satellite service co-located with a
 primary care practice which operates a double shift on Monday, Wednesday, Friday and
 a single shift on Tuesday, Thursday and Saturday. The service can cater for 18 patients
 and could flex to 24 by including an additional evening shift on Tuesday, Thursday and
 Saturday.
- **Murrumbidgee Local Health District**: A nine-chair satellite service operating from a regional hospital with specialist medical and nursing support provided by the Royal Melbourne Hospital under a price-per-treatment contract arrangement. In addition, a chair-based service (4 renal and 2 infusion chairs) has commenced in a regional facility.
- Western NSW Local Health District: In addition to satellite dialysis services at procedural hospitals, chair-based dialysis services are co-located with some Multi-Purpose Services. The centre operates a hybrid model in response to local needs where patients are no longer independent with dialysis and/or are unable to dialyse at home (e.g. due to water quality). The service was originally set up as a self-care dialysis service but is now supported by trained nursing staff.
- South Eastern Sydney Local Health District: The district has commissioned a satellite renal service near St George Hospital through a private provider. The agreement includes all equipment, staffing and facility requirements. The clinical governance for public patients remains with the District.

For further information, connect with service planners in relevant Districts and Networks. If you require contact details, email the Ministry's SRPB: <u>MOH-CaSPA@health.nsw.gov.au</u>