

**Centre for Primary Health Care and Equity**

# **A Report to inform an Equity focused Health Impact Assessment of the Introduction of an Optimal Care Pathway for Renal Services**

Prepared for Renal Services, Sydney LHD

Assoc. Prof. Marilyn Wise

Ms Marcia Grand Ortega

Dr Michiko Hoshiko

Centre for Primary Health Care and Equity, University of New South Wales

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1. The equity focused health impact assessment

An Equity Focused Health Impact Assessment is a structured method to assist in planning and delivering health services to improve health equity. EFHIA uses scientific data, professional expertise, and stakeholder input to identify the likely public health consequences of proposals and recommends actions that would minimise adverse health impacts and optimise beneficial ones.

Through a set of structured steps, an EFHIA helps to identify the impact of a proposal (policy, project, plan) on the health of a defined population and of particular groups within that population, to determine whether the impacts are likely to reduce, reinforce, or increase inequity (unfair, unjust differences in the outcomes of care and in health) - and to recommend actions that can be taken to strengthen positive impacts and reduce or ameliorate negative impacts.

The Equity Focused HIA has six steps. The first two of these, screening and scoping, were conducted at RPAH in September 2012. The screening step recommended that the EFHIA proceed (on the grounds that it would contribute positively to the Model of Care pathway being proposed for CKD 3, 4, and 5 patients). The scoping step identified the following indicators of the impact of the Model of Care proposal.

This EFHIA is being conducted on the proposed introduction of the Sydney LHD Renal Service’s revised Optimal Care Pathway to dialysis, including its specific focus on early detection of chronic kidney disease and integration of patients into an ambulatory care system. The EFHIA will identify potential impacts on the access of all patients with CKD 3, 4, or 5 to RRT, potential differential impacts on patients from pre-determined high-risk groups, and recommend ways to strengthen positive impacts and to reduce or ameliorate negative impacts.

# 2. the identification stage of the equity focused health impact assessment (EFHIA)

The identification stage of an Equity Focused HIA includes a profile of the communities or populations likely to be affected by the proposal and collects information to help in identifying the potential health impacts of a proposal – with a particular focus on identifying differential impacts that are unfair and avoidable.

This paper includes:

* a summary of data on the prevalence of CKD and on current treatment of ESKD in the Australian population;
* a brief review of literature identifying differentials in the incidence of CKD in different population groups, and in the incidence of RRT in different population groups;
* a brief review of the literature identifying determinants of the differentials among different population groups;
* a summary demographic/socioeconomic profile of the population of the Sydney LHD;
* an overview of renal services provided by the Sydney LHD Renal Service, the range of services and the locations in which they are provided;
* a brief overview of population projections and projected levels of demand for renal services by the population of the Sydney LHD in the next decade.

The purpose of the information in this paper is to develop a transparent overview of:

* the background to the proposal – the incidence and prevalence of kidney disease, the prevalence of renal replacement therapy options, and the problems for renal services arising currently to meet demands, and that are projected to arise in the future;
* the proposal (in this case, the Optimal Care Pathway) and its intended goals/outcomes;
* the size, age, socioeconomic characteristics, and LGA of residence of the communities/populations whose health will be affected by the implementation of the Optimal Care Pathway;
* information about the determinants of differentials in incidence of kidney disease, in access to diagnosis and RRT, in modality of RRT selected, and in outcomes;
* information available about actual or potentially unfair, avoidable risks of unequal access to preventive measures, and to any of the measures in the proposed Optimal Care Pathway.

# 3. The prevalence of and the incidence of treatment for CKD in the Australian population

##### 3.1 Prevalence of CKD

The AusDiab study (1999-2000) estimated that 16% of adult Australians had at least one indicator of kidney damage. The study also estimated that more than one in seven (13.4%) of Australians aged 25 years or over had some degree of CKD - more than half of which was at stages 3 -5. Thirty per cent of people aged over 65 years had CKD stages 3 -5.[[1]](#endnote-1)

The rising incidence and prevalence of diabetes, and of overweight and obesity in the Australian population, combined with a growth in the proportion of the population aged 55 years or more mean that demand for screening, diagnosis, treatment, and palliative care to reduce the incidence of CKD, to reduce the prevalence and rate of progression of CKD (along the continuum to stages 3, 4 and 5), and to reduce the rate of onset and severity of complications of CKD is projected to continue to rise in NSW (and in Sydney LHD) over the next decade.

##### 3.2 Incidence of Renal Replacement Therapy

In 2007 around 9,600 Australians were receiving kidney dialysis, of whom 78% were receiving haemodialysis and 22% were receiving peritoneal dialysis. Just over 7,100 people were living with a functioning kidney transplant. In 2007, as well, just over 2,300 people in Australia began treatment for ESKD. The average age of patients beginning treatment has steadily and markedly increased over time from 44.5 years in 1978 to 60.2 years in 2007.[[2]](#endnote-2) Older people – aged 65 years or more – represented the greatest proportion of people receiving treatment. Between 2000-1 and 2007-08 the number of hospitalisations for regular dialysis increased by about 70%.[[3]](#endnote-3)

In 2011 a review of the implementation of the NSW Renal Dialysis Service Plan to 2011 found that there had been a 5% increase in patient numbers for renal dialysis in metropolitan locations between 2009 and 2010 and an increase of 2.6% in non-metropolitan areas during the same period – an average growth of 4.3% for the state as a whole. The report also projected an expected average increase of 150 patients (for dialysis) per annum rising to 5,466 patients in NSW by 2012. There will be marked differences in increases in prevalence across the state based on differences in population increases and population age structures.

Although the best treatment for patients with renal failure is a successful renal transplant, the supply of suitable kidneys means that transplantation is an option for approximately 10% of people with ESRF. In 2007, 14% of patients receiving dialysis were on the kidney transplant waiting list. Average waiting time for a deceased donor is 3 – 4 years. There is a growing number of live donor transplants being carried out.[[4]](#endnote-4) However, for the large majority of patients, dialysis is a way to prolong life. There is a growing demand for dialysis – a growth rate of approximately 5% per annum.[[5]](#endnote-5)

In 2007 57% of patients receiving haemodialysis did so at specialised dialysis units – satellite centres - while 30% received it at a hospital and the remaining 13% performed haemodialysis at home. Between 2000 and 2007 the number of people having haemodialysis increased from 4,670 to 7,536. The number of people using peritoneal dialysis also increased but the increase in proportion using haemodialysis was greater.[[6]](#endnote-6)

NSW is leading the country with 46% of CKD patients undergoing home based and 54% undergoing facility-based dialysis. However, the distribution of home haemodialysis and peritoneal dialysis is far from consistent across different catchments in NSW. SLAs with lower socio-economic status, with higher proportions of Indigenous residents, and rural areas were shown to have higher incidence and prevalence of dialysis – accounting for 24% of difference in geographic variations.[[7]](#endnote-7)

A recent Australian study found that one in seven patients with ESRD managed in renal units planned to forego dialysis therapy. In addition to describing the demographic, socio-economic and health characteristics of the patients who chose conservative care, the study highlighted the need for attention to be given to treatment decision-making and to the further development of model care pathways for conservative care clinical programs.[[8]](#endnote-8)

The NSW health sector responded to the projected growth in demand with a Renal Dialysis Service Plan to 2011 identifying strategies to meet the demand renal dialysis and to improve outcomes. The plan recognised the need to address factors influencing the accessibility and quality of renal services (including dialysis) for all potential and current patient groups[[9]](#endnote-9).

##### 3.3 patterns of inequality in the incidence and prevalence of chronic kidney disease and in access to renal replacement therapy

The incidence of kidney disease is higher than the population average among older people, socioeconomically disadvantaged people, people who live in outer urban, rural and remote areas, Aboriginal and Torres Strait Islander peoples, some refugee/immigrant groups, and people with complex conditions and co-morbidities. These groups experience higher levels of morbidity and premature mortality associated with CKD than the population average and chronic kidney disease also progresses faster in people who live in socioeconomically disadvantaged areas. [[10]](#endnote-10)

Cass et al[[11]](#endnote-11) used an eco-psychosocial model to identify causes or determinants of significantly higher rates of ESRD experienced by Aboriginal and Torres Strait Islander populations compared with the rest of the Australian population. The model was based on understanding that the determinants of differences are a combination of decisions made by Aboriginal and Torres Strait Islander patients themselves, the social and economic environments within which their decisions are made, and decisions made by the health-care system about the design and delivery of services.

The study showed that Aboriginal and Torres Strait Islander people with CKD are less likely to attend antenatal care early in and throughout pregnancy and to have less access than non-Indigenous Australians to:

* comprehensive primary health care facilities;
* secondary prevention programs (to diagnose, treat, manage and reduce risk of renal disease progression);
* screening at community level and access to tertiary ESRD treatment services;
* renal transplantation (not explained by differences in age, sex, co-morbidities, or cause of renal disease).[[12]](#endnote-12)

Even when Indigenous patients received medical care there were differences in the number undergoing biopsy, and in the interpretation of histological findings depending on nephrologists’ knowledge of patients’ race. Almost 40% of Indigenous ESRD patients needed to commence dialysis within three months of referral to a nephrologist. The analysis suggested that there may be systematic differences in the treatment of Indigenous patients[[13]](#endnote-13) - the *provision* of services being at the core of the limited access that was described in the study.

There are also clear links between socioeconomic status and the incidence of renal replacement therapy (RRT) among non-Indigenous Australians. Patients from the lowest socioeconomic decile started RRT with lower levels of kidney function, and were, on average, 5.4 years younger than patients from the most advantaged decile. The incidence rates for RRT were always higher for males than females.[[14]](#endnote-14) And people living in rural areas were likely to have worse outcomes on dialysis than Australians living in urban areas.

##### 3.4 Determinants of inequalities in the incidence and prevalence of kidney disease and in the incidence of renal replacement therapy

Socioeconomic disadvantage is associated with higher incidence of RRT in Australia. Access to appropriate health care appears to be one of the pathways by which socioeconomic disadvantage affects the need for and access to RRT. [[15]](#endnote-15)

The higher incidence of RRT among people living in more disadvantaged areas is likely to reflect higher prevalence of precursor diseases including milder forms of chronic kidney disease, differing rates of progress of kidney disease, and higher prevalence of behavioural risk factors. These are, in turn, influenced by people’s health literacy, by their childhood health, and by the extent to which they are exposed to risks to health in the economic and social environments within which they live and work.

Two studies of access to renal replacement therapy in rural and urban Australia[[16]](#endnote-16) [[17]](#endnote-17) proposed several explanations for their findings that Australians living in rural areas, compared with cities, are more likely to have poor access to RRT and worse outcomes on dialysis. People who live in rural or remote areas may relocate to cities prior to starting RRT. Patients in rural areas may choose palliation rather than dialysis more frequently – to reduce the burden of travel to dialysis or specialist care, non-referral to specialist care, and poor education about RRT options. For older people in particular, distance, availability of transport and cost are significant barriers to medical care. Although home dialysis may be a preferred option to reduce travel, water quantity and quality may be problematic. Having to be away from home to undertake training to conduct haemodialysis at home may mean patients choose a palliative pathway. In addition to distance, not being able to drive, difficulties living away from home, financial concerns, and feelings of being a burden on others and being away from family and friends were all factors influencing the likelihood of patients receiving (or taking up) optimal care.

Access to a nephrologist has been shown to influence the outcomes of patients with chronic kidney disease (in Canada), and patient compliance may be different between city and country patients – with medications and/or dialysis hours. And the limited availability of a skilled qualified workforce is widely recognised in Australia – not only in relation to CKD but also to all medical care. [[18]](#endnote-18)

It is also the case that CKD5 patients referred to nephrologists may plan not to dialyse. In the US the fastest growing cohort of patients accepted onto dialysis therapy (in 2008) was people aged 75 years or more. The provision of information on the range of treatment options (and on the consequences of selecting any one of them) is a critical component of optimal patient care for this group in particular.

##### 3.5 Determinants of differentials in rates of home-based and facility based dialysis

Reasons for differences in the distribution of home-based and facility-based dialysis include supply-side decisions made by the health sector and clinicians; and demand-side decisions made by patients.

*3.5.1 Supply-side reasons*

* historical investment in large healthcare facilities making it harder to shift to home-based options
* clinician preferences and/or variations in patient education regarding full range of treatment options
* lack of local facilities for provision of vascular access – long waiting times, timeliness of referral and access to specialist nephrologists –, and the availability of technical support and nursing outreach services.
* affordability of care (and associated costs such as transport, pharmaceutical and other products, opportunity costs)
* accessibility – time, location, transport, physical design, range of professionals available. This includes access to patient and carer training – sometimes necessitates considerable travel, putting it out of the reach of some. For example, even in urban areas, lack of transport for older people (in particular) to renal services, including dialysis, is a barrier to access
* appropriateness – range of services being provided, quality (evidence-based care,[[19]](#endnote-19) continuity, match of services and information/communication/support to need (e.g. literacy, language, communication[[20]](#endnote-20); best practice clinical care[[21]](#endnote-21) [[22]](#endnote-22) [[23]](#endnote-23); fit between treatment and environment within which patients live, work, play)[[24]](#endnote-24)
* acceptability – cultural safety,[[25]](#endnote-25) [[26]](#endnote-26)language – literacy level in English and/or literacy in languages other than English, physical design of health service facilities, location of health services, provider characteristics and cultural competence, organisational culture, communication
* reach – extent to which services reach (or are provided to) intended patient/client/population groups[[27]](#endnote-27)

*3.5.2 Demand-side reasons*

* patient-related factors: age, belief systems, suitability of home environment, and capacity to meet out of pocket expenses[[28]](#endnote-28)
* differences in socioeconomic status[[29]](#endnote-29) – differences in living/working/recreational environments; differences in literacy and health literacy; differences in income and housing quality[[30]](#endnote-30); differences in access to transport, to primary and specialist health services; differences in lifestyle and underlying diseases, and in capacity to respond to management/treatment/care regimens; and differences in attitude/beliefs/values in relation to life expectancy and quality of life
* differences in age and geographic location of residence[[31]](#endnote-31) [[32]](#endnote-32) [[33]](#endnote-33)
* differences in culture, language, location, education, and history[[34]](#endnote-34) [[35]](#endnote-35) [[36]](#endnote-36)

The literature illustrates that multiple factors affect the likelihood of all eligible patients benefitting equally (or equitably) from the introduction of the proposed Optimal Care Pathway. Many of the factors are the responsibility of the health sector – decisions made by policy makers, managers, and clinicians. Some are a national responsibility; others more local. Gray et al[[37]](#endnote-37) identified, for example, significant differences in the numbers of full-time equivalent medical staff per head of population in metropolitan areas, compared with inner regional, outer regional, remote and very remote areas. They made a series of proposals to address the gaps:

* developing satellite haemodialysis units in rural areas has been shown to increase access for elderly patients and reduce travel times and distance;
* ongoing efforts to increase the medical workforce and FTE numbers across the nation, but particularly in outer regional, remote, and very remote areas;
* providing training for peritoneal dialysis and home haemodialysis in rural areas;
* using tele-health to improve access to specialist care; and
* improving preventive intervention by clinicians around smoking and other lifestyle issues. [[38]](#endnote-38)

Cass et al identified a life-course approach to the prevention of ESRD and recommended a series of actions to improve the quality of health care services and their delivery, and to improve the social and physical environments in which people (in this case, Aboriginal and Torres Strait Islander people) live and work. They recommended, as well, clinical guidelines and the provision of culturally appropriate interventions to assist people to improve their lives and reduce risks to health (including risk of kidney disease). [[39]](#endnote-39)

In summary, the evidence shows that some population groups are at greater risk of contracting kidney disease, of faster progression of the disease, and of not receiving optimal diagnosis, treatment, and ongoing care. The tables, below, summarise the literature, illustrating the ‘at risk’ population groups, and determinants of unequal diagnosis, treatment, care and outcomes that have been identified to date.

Table 1: Summary of domains of inequality, populations affected, and determinants of inequality

|  |  |  |
| --- | --- | --- |
| **What is unequal?** | **Who is affected unequally?** | **Why or how?** |
| Incidence of kidney disease | Older people | Prevalence of diabetes  Risk factors – blood pressure, vascular disease  Glomerular senescence  Reduced ability to access care (cost, mobility) |
|  | Aboriginal people and Torres Strait Islanders | Prevalence of diabetes  Risk factors  Exposure to risks in social and economic environments |
|  | Socioeconomically disadvantaged people | Kidney disease progresses faster  Weight  Diabetes  Ability to afford costs of care – transport, meds, fees |
|  | Some refugee/immigrant groups |  |
|  | People with complex conditions/comorbidities |  |
| Medical care provided | Aboriginal people and Torres Strait Islanders | Number undergoing biopsy  Nephrologists knowledge of patients’ race affecting interpretation of histological findings  Shorter time between referral to nephrologist and commencement of dialysis (indicator that disease has progressed further before seeing a nephrologist) |
|  | Residents of rural or remote areas | Distance to services  Limited specialist/medical workforce |
| Access to a nephrologist | Patients with CKD5 | May plan not to dialyse  Limited information on range of treatment options and consequences of selecting any one of them |
| Higher rates of ESRD | Aboriginal people and Torres Strait Islanders | Lower rates of early attendance at antenatal care and attendance throughout pregnancy  Limited access to:   * Comprehensive primary health care; * Secondary prevention programs; * Screening at community level; * Tertiary RRT; * Renal transplantation   (None of which are explained by differences in age, sex, co-morbidities or causes of renal disease)  Literacy and health literacy |
| Incidence of RRT | Non-Indigenous patients from low socioeconomic backgrounds | * Start RRT with lower levels of kidney function * More than 5 years younger when beginning RRT (than advantaged groups) * Higher prevalence of precursor diseases, risk factors and milder forms of CKD * Faster rates of progress of kidney disease * SES shown to have greater influence in major cities than in rural areas because: * Patients may move to cities * Patients may be less likely to obtain specialist care * Patients may be less likely to be offered RRT * Patients may choose palliative care over RRT * History and language |
|  | People from advantaged areas | Less likely to be referred late for RRT |
| Incidence and benefits of RRT | People living in rural/remote areas | * Worse outcomes on dialysis than urban counterparts * Choose palliation rather than dialysis more frequently – reduce burden of travel to dialysis or specialist care * Non-referral to specialist care * Poor education about RRT options - health literacy |
| Access to and uptake of home-based dialysis | Health service managers | Health sector investment in large facilities for dialysis care – harder to shift to home-based options |
|  | Clinicians | Clinicians – difference in preferences and in offering patient education about full range of options |
|  | Health service managers | Lack of local facilities for provision of vascular access |
|  | Patients with CKD | * Access to patient/carer training * Travel * Age, belief systems * Suitability of home environment – including water quality and/or water quantity * Costs * Long waiting times * Timeliness of referral * Availability of technical support * Availability of and access to nursing outreach services * Availability of transport * Having to be away from home to undertake training * Not being able to drive * Difficulties living away from home * Financial concerns * Feeling of being a burden on others * Being away from family and friends |

# 4. The proposal

##### 4.1 The revised optimal care pathway

In response to projected growing demand, to NSW statewide renal service policy initiatives, to evidence that it is possible to delay the progression of CKD in adults in the pre-dialysis phase of this condition[[40]](#endnote-40), and to evidence that better outcomes are achieved when adults are offered, early, the opportunity to select the mode of care they wish to undertake for CKD stages 3 – 5, the Sydney LHD Renal Services developed an Optimal Care Pathway to be implemented from 2013. The purpose is to maximise the extent to which the diagnosis and treatments offered on the pathway are available equally (for equal need) to all current and potential patients who require renal care; that all patients have opportunities to consider each of the options for renal care; that the uptake of each of the options is consistent with national/state benchmarks; and that the predicted benefits of selecting each the Optimal Care options are distributed equitably.

##### 4.2 the Optimal Care Pathway?

The table in Appendix One maps the Optimal Model Care Pathway for patients with CKD 3 – CKD 5. The table summarises in columns from left to right:

1. the care options available to patients at each stage of CKD diagnosis and treatment;
2. the composition of the health professional workforce that the health system needs to provide to patients to ensure optimal care at each stage of CKD;
3. the resources, quality of care, and quality of communication to which patients need access in order to achieve optimal health outcomes.

##### 4.3 A proposed goal for the introduction of the Optimal Care Pathway

The goal of implementing the Optimal Care Pathway is to increase to 100% the proportion of people who reside in Sydney LHD (or who live in catchment areas for the Sydney LHD Renal Services) and who have CKD 3 – 5 who receive optimal renal care including a choice of home-based dialysis; or transplantation; or supportive/palliative/no treatment. What indicators should used to assess the impacts of the introduction of the proposed optimal care pathway on the health of patients with CKD 3, 4, or 5?

Proposed indicators of intermediate and health outcomes following the introduction of the optimal care pathway

* increase in the number/proportion of patients over all and in each of the high risk groups receiving evidence-based information[[41]](#footnote-1)  about treatment options and criteria to use in selecting each of the options at an early point in their experience of CKD
* increase in time from diagnosis of ESRD to dialysis treatment for high-risk groups to equal that of population average
* increase in the number/proportion of patients over all and in each of the high-risk groups receiving accredited education about the RRT available to them and about criteria for selection to meet personal need
* positive trends in the number/proportion of patients overall and from each of the high risk groups participating in optimal care (for them) – transplantation, home-based dialysis, ambulatory satellite dialysis, and palliative care
* increase in the number/proportion of patients overall and from each of the high risk groups receiving pre-emptive and subsequent kidney transplantation
* increase in the similarity in 3 – 5 year survival rates for all patient groups on haemodialysis or peritoneal dialysis
* Increase in quality of life measures in patients on the palliative care versus dialysis options.

# 5. The demographic and socioeconomic characteristics of the population of the Sydney LHD

Given the evidence of inequalities in the incidence and prevalence of CKD and of the incidence of RRT and of the population groups most likely to be affected, it is necessary to identify the demographic and socioeconomic characteristics (and the health) of the populations in the catchment area for Sydney LHD Renal Services.[[42]](#endnote-41)

Table 2: Population of the Sydney Local Health District by age group by LGA/SLA  
Source: ABS 2011[[43]](#endnote-42)

The Sydney LHD is responsible for providing care to almost 550,000 people. Canterbury LGA accounts for the largest population within the District, followed by Marrickville and Canada Bay. This is particularly interesting when considering that almost a quarter of the LHD’s population lives within the LGA with the highest level of social and economic disadvantage (see Table 2 above).

The adult population of the LHD includes a higher proportion of residents aged 20-44 and a lower proportion of residents over 45 than the NSW population as a whole.   
The highest proportions of younger people (0-14) are based in Canterbury, Canada Bay, Leichardt and Strathfield. The highest proportions of people aged 55 years or more are based in Ashfield, Burwood, Canada Bay and Canterbury.

Table 3: SLHD Population Projections by sex and LGAs/SLAs

Source: Dep. Of Planning 2009[[44]](#endnote-43)

Table 3 sets out the projected populations of each of the LGAs in Sydney LHD from 2011 to 2036. The total population is likely to grow by more than 150,000 people over that period.

By 2021, the population in SLHD is expected to reach 642,000 people. The highest growth is expected to be in the City of Sydney with 2.3% growth projected per annum.[[45]](#endnote-44) Significant planned urban developments include: the new Green Square Development in Zetland and Beaconsfield; urban consolidation along the Parramatta Road corridor; and new developments in Rhodes, Breakfast Point, the former Carlton Brewery site and Redfern/Waterloo.

In SLHD, the number of residents aged over 70 years is projected to increase by 29% over the next decade and by 44% to 2026.[[46]](#endnote-45)

Sydney LHD Renal Services also provide outreach services and service some patients from adjacent metropolitan areas.

Sydney LHD provides complete renal medical care through an outreach service to the population of Griffith, NSW.

Some patients from Northern Sydney referred by physicians working at the Mater and Adventist Hospitals are serviced by RPAH although this is not a large number or proportion of patients. Some patients from North Ryde are serviced by Concord Hospital.

Dubbo, Maruya, Wagga Wagga and Coffs Harbour are in transition as renal services are now available in these centres. The Sydney LHD Renal Service continues to provide support and transplantation. When patients from these centres, and from Griffith, require tertiary/quarternary care, they come to Sydney LHD.

Sydney LHD Renal Services go out to see pre-transplant patients in these country centres once a year. The Service does the transplantations and provides the three-months of post-transplant patient care to these patients. As well, Sydney LHD provides pre-transplantation, transplantation, and post-transplantation services to patients from Canberra, Liverpool and southwest Sydney.

We have assumed that the projected demand for services from locations outside Sydney LHD is unlikely to be much change in referral patterns in the next five years.

Table 4: Aboriginal and/or Torres Strait Islander residents of Sydney LHD by LGA/SLA by age group compared with the whole of the NSW population

Source: ABS 2011[[47]](#endnote-46)

Almost 5,000 residents of the Sydney LHD identified as Aboriginal in the 2011 census – comprising 0.89% of the population of the LHD. Almost half (2,248 people; 46%) of the Aboriginal population of the Sydney LHD lived in the Sydney South SLA and Marrickville, and a further 797 (16%) lived in the Canterbury LGA.

Greater proportions of the Aboriginal population than the NSW population were young. In each of the age groups from 0 – 44 years the proportion of Aboriginal people was higher than in the New South Wales population. But the proportion of Aboriginal people in every age group over 45 years was lower than the rest of the population.

Specifically 24.7% of the Aboriginal population of the Sydney LHD was aged 0 – 14 years compared with 19.3% of the NSW population; 18.9% of the Aboriginal population was aged 15-24 years compared with 12.9% of the NSW population; 15.8% of the Aboriginal population of the Sydney LHD was aged 25-34 years compared with13.6% of the NSW population; 14.5% of the Aboriginal population was aged 35 – 44 years compared with 14.0% of the NSW population; 12.9% of the Aboriginal population of the Sydney LHD was aged 45 – 54 years compared with 13.7% of the NSW population; 8.2% of the Aboriginal population was aged 55 – 64 years compared with 11.7% of the NSW population; and 5.1% of the Aboriginal population was aged 65 years or more compared with 14.7% of the NSW population.

Table 5: Projected Aboriginal and Torres Strait Islander population (SLHD) 2011-2021

 \*Population projections estimated based on growth rates for 2011, 2016 and 2021 from NSW Aboriginal Housing Office 2008. Source: ABS 2011[[48]](#endnote-47), NSW Aboriginal Housing Office 2008[[49]](#endnote-48)

##### 5.1 social characteristics of the population of Sydney LHD

Table 6: Residents of Sydney LHD born overseas by LGA/SLA  
 Source: ABS 2011[[50]](#endnote-49)

The 2010 census showed that more than 40% of the Sydney LHD population was born overseas. While Strathfield and Burwood had the highest proportions of residents (52.7% and 52.6% respectively) born overseas, Canterbury LGA had the largest number of residents born overseas – more than 66,000 people.

Table 7: Humanitarian Entrants resident in Sydney LHD by LGA of initial settlement 2005-11

Source: DIAC 2012 in SLHD 2012[[51]](#endnote-50)

Canterbury also hosted almost two thirds of the Sydney LHD’s humanitarian entrants when they first settled. The City of Sydney and Strathfield were the next most common settlement areas for humanitarian entrants.

Table 8: Language(s) spoken at home - by overseas-born residents by LGA/SLA of residence by Sydney LHD Source: \*ABS 2006 in SLHD 2012[[52]](#endnote-51), \*\*ABS 2011[[53]](#endnote-52)

Almost 80% of the residents of Sydney LHD who were born overseas reported that they speak English very well or well. Almost 74% of the overseas-born residents of Canterbury reported speaking English well or very well.

Thirty per cent (30%) of the overseas-born residents of Canterbury reported speaking English at home, and the proportions of overseas-born residents of Burwood and Strathfield who reported speaking English at home were similar (37% and 36%, respectively).

The languages other than English most commonly spoken at home in the LHD were Mandarin and Cantonese, Arabic, Greek, Korean, Italian and Vietnamese.

The Socio-Economic Indexes for Areas (SEIFA) is a product developed by ABS to provide summary measures derived from the Census to measure different aspects of socio-economic conditions by geographic area. The deciles reported in Table 7 are calculated for each LGA and compared with New South Wale as a whole.

Table 9, below, shows that Canterbury is the LGA with the highest level of relative socioeconomic disadvantage in the Sydney LHD – although it is in the 7th decile on the index of education and occupation, (perhaps reflecting a high proportion of overseas born residents who are well educated in their own countries of birth but who have not been able to find jobs in Australia that are economically commensurate with their qualifications and experience). The Sydney West SLA is in the fourth decile for economic resources, but in deciles 10, 9, and 8 for other measures of relative socioeconomic disadvantage. The Sydney South SLA is in the 6th decile on economic resources and in deciles 10, 8 and 9 for the other three measures.

The other LGAs are all in the 7th decile or better for each of the other measures of socioeconomic advantage/disadvantage illustrated in Table 9, below.

Table 9: SEIFA Index deciles of the LGAs/SLAs in the Sydney LHD (2006)

Source: ABS 2006b[[54]](#footnote-2)[[55]](#endnote-53)

# 6. Treatment and care for chronic kidney disease in Sydney LHD

##### 6.1 Sydney Local Health District – Renal Services

In 2006, the Sydney LHD Renal Service was the largest renal treatment program in NSW with outreach services in a number of non-metropolitan locations such as Brewarrinna, Bourke, Coffs Harbour, Dubbo, Wagga Wagga and Goulburn. [[56]](#endnote-54) The Service provided acute renal services (in centre) and ambulatory satellite dialysis services at Dame Eadith Walker Hospital. Royal Prince Alfred Hospital and Concord Repatriation and General Hospital provided level 6 renal services – both in and out of hours.

No services were provided at Canterbury Hospital. Dame Eadith Walker provided a 23-chair satellite unit.[[57]](#endnote-55)

##### 6.2 What renal services are being provided and where?

Wherever possible, data specific to the population of the Sydney LHD have been used in the section that follows. However, we have used Australian or NSW data in the absence of more local information.

Table 10: Type of renal services offered to patients of the Sydney LHD Renal Service by hospital/institution/location (2013)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **RPAH** | **Canterbury** | **Concord RGH** |
| **Renal medicine** | **Inpatient** | Y |  |  |
| **Outpatient clinic** | Y |  | Y |
| **Renal dialysis** | **Incentre** | Y |  | Y |
| **SWRS Satellite**  **Dialysis** | Y |  | Y |
| **Home training** | Y |  |  |
| **CAPD training** |  |  |  |
| **Transplantation unit** | **Inpatient** | Y |  |  |
| **Clinics – pre and post** | Y |  | Y |

Source: SSW Area Health Service Renal Services Service Plan 2006-2016. v3. [[58]](#endnote-56) Updated information in 2013 – personal communication, Professor J. Eris.

In 2013, SLHD has 22 in-centre and 44 satellite chairs and 10 home training chairs.

In 2013 the Statewide Renal Services managed renal services across the Eastern Zone of Sydney South West Area Health Service, providing acute renal services at Royal Prince Alfred Hospital, Concord RGH, and ambulatory satellite dialysis services at RPAH and Concord RGH. Outreach services were provided at Brewarrinna, Bourke, Coffs Harbour, Dubbo, Wagga Wagga and Goulburn.

In 2006 and in 2013 no renal services were provided at Canterbury Hospital.

##### 6.3 Patients receiving treatment for renal disease and RRT in Sydney LHD (or SSWAHS)

In 2012/13, 220 patients were being treated in the Sydney Local Health District’s home dialysis program. The Renal Service data indicated there were 434 renal dialysis patients during 2012. (From: information prepared for the NSW Ministry of Health, April 2013).

The source of the information below is the Renal Services Clinical Services Plan 2006-2016 Version3 draft. Sydney South West Area Health Service.)

In 2003 there were 292 patients receiving dialysis treatment in the eastern zone (of the SWSAHS). Forty-seven per cent (137 patients) were receiving their care in the hospital; 53% were receiving home dialysis. Of the 125 rural patients receiving care from SWRS, 42% were receiving their care in the hospital setting and 58% received their care at home.

In 2004/5 there were 62 renal transplants carried out at RPAH or CRGH – and 450 long-term patients attend one or other of these hospitals for post transplantation care. In 2006 there were 325 people on the renal transplantation waiting list.

Ninety four percent point seven of the 4,102 separations for renal failure in SSWAHS were from public hospitals, 91.6% of the 7,397 separations for other renal medicine, 97.4% of the 8,701 separations for kidney and urinary tract infections, and 96.6% of the 41,666 separations for renal dialysis were from public hospitals. Eighty three percent of the public hospital separations were of residents of the SSWAHS area; 13.1% of the separations from public hospitals were of residents from the SE/Illawarra area.

In the Eastern Zone of SSWAHS 94% of all renal disease separations were from public hospitals, and 67.2% of these separations were of residents of the Eastern Zone.

No demographic or socioeconomic data were included about these patients in the Renal Services Clinical Services Plan 2006-2016 (Version 3 draft).

Currently, although Sydney LHD Renal Services have the highest rate of home based dialysis of any Renal Service in Australiathere has not been a complete transition to the application of the new Optimal Care Pathway to guide routine treatment and care for CKD patients requiring dialysis.

The NSW Health State Renal Services Plan 2006 - 2016 proposed the following guidelines for the optimal proportions of patients undertaking each of the modes of dialysis - 30% peritoneal dialysis, 20% hospital dialysis and 30% satellite dialysis.

In 2003/4 16% of patients in the Eastern Zone (of Sydney South West Area Health Service) were receiving dialysis in hospitals; 29% were receiving dialysis in satellite centres, 29% were on haemodialysis at home; and 26% were on peritoneal dialysis at home. Of 125 rural patients under the care of Sydney South West AHS Renal Services in 2003, 42% received their care in the hospital setting and 58% received their care at home.[[59]](#endnote-57)

Table 11: Prevalence of treated End Stage Kidney Disease (ESKD) by Indigenous and non-Indigenous status and sex, 2008, Australia and ESKD patient per 100,000 population  
  
\*Directly age-standardised to the 2001 Australian population.  
Source: AIHW projections based on ANZDATA 2011.[[60]](#endnote-58)

In 2008, the rate of treated ESKD per 100,000 population was significantly different for Indigenous and non-Indigenous people – the rate per 100,000 Indigenous males was 16 times greater than that for non-Indigenous males and the rate per 100,000 Indigenous females was 8 times greater than that for non-Indigenous females. In all, 1,306 Indigenous people were treated for ESKD in 2008 in Australia.

More than 16,000 non-Indigenous people were treated for ESKD in Australia in 2008 – 9,951 of whom were male, and 6,346 of whom were female.

Table 12: Prevalent Kidney Replacement Therapy (KRT)-treated ESKD patients with selected co-morbidities as at 31 December 2008, by Indigenous and non-Indigenous status, Australia  
Source: AIHW projections based on ANZDATA 2011.[[61]](#endnote-59)

Table 12 illustrates the significance of co-morbidities in the prevalence of ESKD. More than 80% of Aboriginal and Torres Strait Islander patients receiving Kidney Replacement Therapy in 2008 had at least one co-morbidity at first treatment – diabetes being the most common of these. Slightly more than half the non-Indigenous patients receiving Kidney Replacement Therapy had at least one co-morbidity at first treatment – cardiovascular disease being the most common.

There are useful data on the locations and types of treatment being provided to patients in the Sydney LHD (or previous equivalent areas), and/or in Australia. There are data on the differentials in the prevalence of Indigenous and non-Indigenous Australians receiving Kidney Replacement Therapy. But otherwise there are few data describing the socioeconomic characteristics of patient groups or describing access to services.

Table 13: Projected incidence of treated ESKD NSW/ACT per 100,000 population by sex, 2015 and 2020  
  
Source: AIHW projections based on ANZDATA 2011[[62]](#endnote-60)

Table 13 illustrates the projected increases in incidence of treated ESKD in New South Wales for males and females in 2015 and 2020 – with the gap between incidence in males and females projected to continue and widen.

Table 14: Projected incidence of treated ESKD NSW/ACT by sex and age group, 2015 and 2020  
  
Source: AIHW projections based on ANZDATA 2011[[63]](#endnote-61)

Table 14 illustrates that much of the projected increase in incidence of treated ESKD will occur among older people – aged 60 years or more. Again, the gap between male and female incidence is projected to continue, and the gap is projected to widen.

The aging of the ESKD treatment population poses questions about the most appropriate modality and location of RRT - whether home-based or hospital/satellite centre based.

Table 15: Projected incidence rates of treated ESKD for Indigenous Australians per 100,000 population by sex 2016 and 2021  
  
Source: AIHW projections based on ANZDATA 2011[[64]](#endnote-62)

Table 15 illustrates the projected incidence rates of treated ESKD for Indigenous Australians, highlighting, again, the very significant differential in rates between this population and the rest of the Australian population. There is a difference in projected incidence between male and female Aboriginal and Torres Strait Islander patients, but it is the huge differentials in projected incidence between this population and the Australian population that highlights the need for urgent action.

##### 6.4 The prevalence of behavioural risk factors by SLHD

Table 16: Current smoking Sydney LHD residents 2010-2011   
Source: Centre for Epidemiology and Evidence 2011[[65]](#endnote-63)  
An estimated 15% of adult residents of Sydney LHD aged 15 years or more were current smokers in 2010-2011.

Table 17: High Body Mass/Overweight Sydney LHD residents 2010-2011

****Source: Centre for Epidemiology and Evidence 2011[[66]](#endnote-64)

An estimated 15% residents of Sydney LHD aged 15 years or more were obese and 47% were overweight in 2010-2011.

Table 18: Physical Activity/Nutrition Sydney LHD residents 2010-2011  
Source: Centre for Epidemiology and Evidence 2011[[67]](#endnote-65)

Just over half of the residents of Sydney LHD aged 15 years or more undertake an adequate level of physical activity. While half of the residents’ usual consumption of fruits was adequate, only 7% consumed the recommended amount of vegetables.

Table 19: Hospitalisations for cardiovascular disease Sydney LHD residents 2010-2011  
Source: Centre for Epidemiology and Evidence 2011[[68]](#endnote-66)

Cardiovascular disease includes coronary heart disease, heart failure, stroke, peripheral vascular disease, and other forms of CVD. The rate per 100,000 males is greater than that for females.

Table 20: Diabetes hospitalisations Sydney LHD residents 2010-2011  
Source: Centre for Epidemiology and Evidence 2011[[69]](#endnote-67)

For diabetes, however, the hospitalisation rates for males and females were much closer.

Table 21: Coronary heart disease/Stroke hospitalisations by LGA, 2009-10 to 2010-11  
Source: Centre for Epidemiology and Evidence 2011[[70]](#endnote-68)

Table 21 shows hospitalisations for coronary heart disease and stroke by LGAs within the Sydney LHD between 2009-10 and 2010-11. The hospitalisation rate per 100,000 population from coronary heart disease was highest in Canterbury LGA (579.13) followed by Strathfield (458.7) and Burwood (449.7). In comparison, the rate of hospitalisation for coronary heart disease from Leichardt was the lowest (359.9).

Canterbury LGA (230.8) also had the highest stroke hospitalisations rate per 100,000, followed by Ashfield (222.8) and Sydney LGA (219.5). In comparison, Strathfield had the lowest (190.9) rate of hospitalisation for stroke.

Table 22: Diabetes hospitalisations by LGA, 2009-10 to 2010-11  
Source: Centre for Epidemiology and Evidence 2011[[71]](#endnote-69)

Table 22 shows the number and rate for diabetes hospitalisations by LGA within the Sydney LHD between 2009-10 and 2010-11. The rate per 100,000 population was highest in Canterbury LGA (294.3) followed by Ashfield (275.1), Burwood (257.9) and Strathfield (256.4). In comparison the rate of hospitalisation for diabetes from the Sydney LGA was 147.1 per 100,000 population.

It was not possible to identify data on the prevalence of co-morbidity in the Sydney LHD population in particular. National data has been used estimating the prevalence of complex chronic illness among General Practice patients. A sub-study of the BEACH program[[72]](#footnote-3) found that 29% of people who attended general practice at least once in a year and 25% Australians overall, had multi-morbidities. Vascular problems were the most prevalent morbidity domain (on the Cumulative Illness Rating Scale). In all, 31.5% of GP encounters were with patients who had at least one vascular condition.

# 7. Summary of the review of implementation of the NSW Renal Dialysis Services Plan to 2011

The NSW Health Renal Dialysis Services Plan to 2011 was focused on meeting the demand for services capable of achieving secondary prevention of CKD for patients at stages 3, 4, and 5 – by slowing the rate of progression along the severity continuum, reducing the incidence and severity of complications, and reducing avoidable mortality associated with CKD.

The review of implementation of the NSW Renal Dialysis Services Plan to 2011 recommended the following actions to improve the availability and quality of care available to dialysis patients.

##### 7.1 Build the capacity of the renal service system

* Statewide perspective (highlight differentials too) to support local and regional level planning and service delivery
* Accommodate variations in service development at catchment level to address population demand
* Consider impact of population ageing on future uptake of dialysis modalities – and identify actions to overcome barriers to home treatment options
* Identify and re-allocate excess capacity – to increase the efficiency and coverage of the system
* Clarify the role of facility-based dialysis within the overall system (in relation to other forms and levels of assisted dialysis). Perhaps call the Facility-based Dialysis Self-care HD so that its link to increased patient independence is clear
* Link principles, benchmarks and indicators for Renal Dialysis to those developed for all services across the state
* statewide guidelines for procurement of machines and consumables – differentials can arise in availability and quality of equipment (maintenance of the equipment)
* nursing care – differentials can arise in availability and quality of clinical support.[[73]](#footnote-4)

##### 7.2 Expand and regulate the quality of Patient and Carer Training

* Standardise curriculum for the State – but will need to be linked with health literacy and cultural specificity
* Use performance indicators to assess variations in local access to training and waiting times for training – as a way of giving weight to the importance of training as a precursor to home dialysis and to quality of life outcomes for patients
* Standardise training curriculum to enable a wider range of training agencies to conduct the training, including, for example, Aboriginal trainers, or trainers using languages other than English etc. etc. The issue for the state is to register the training agencies and assess quality/integrity of program delivery[[74]](#footnote-5)
* Principles – values, including equity of access to all aspects of the service/care, including diagnosis, home care, education, and support; and self-reported quality of life; evidence-based care[[75]](#footnote-6)

The Review also highlighted the need for closer alignment with the New South Wales Aboriginal Health program, particularly; the Chronic Care for Aboriginal People program that included the articulation of a Model of Care for Aboriginal people with chronic disease. Although the Model of Care did not meet all the best practice criteria for managing people with Chronic Renal Disease it did provide a strong platform upon which to build. The Review also pointed to the particular needs of rural patients, and the need to address barriers to implementation of home-base modalities in rural areas, including treatment and patient training close to home.

# Sydney LHD assessment of future need 2013

In line with NSW Health’s key strategic priority of keeping people healthy and out of hospital, SLHD remains firmly supportive of future early intervention initiatives focusing on patients with renal disease.

The District’s previous proposals have been intended to address the rapidly increasing demand in renal dialysis. This has included enhanced Renal Preventative Clinics and enhancing support for training and extension of home dialysis services. Additional strategies include initiatives to harness the 20% of patients estimated to be suitable for pre-emptive transplant, and developing an Ambulatory Day Stay model of care to prevent Emergency Department attendances.

The SLHD is involved with the University of Sydney in developing a collaborative research centre as a core component of the Charles Perkins Centre. This research facility is uniquely placed to develop, evaluate and research clinical innovations and initiatives in the area of renal disease prevention and early intervention as detailed above. It provides an appropriate place for the development of new evidence and approaches in this important area of health care. This is a new venture which could yield, if supported, exciting opportunities to evaluate system approaches to contain the rapid growth of chronic renal disease and ESRF treatments. (From: SLHD submission to the NSW Ministry of Health, April 2013).

###### PROJECTED RENAL DIALYSIS NEED 2012, 2016, 2021 BASED ON MEDIUM GROWTH RATE

The following table summarises the District’s projected renal dialysis patient numbers and facility requirements to 2016 and 2021 using the medium annual growth rate of 5.8%. However, it is considered that a growth rate of 7-9% could easily be realised, especially if no action or strategies were in place to intervene early or to substantially increase the transplantation capacity. Should such strategies be vigorously pursued the growth in dialysis patients, over time, could be contained at the medium estimated level of 5.8% as per the following table.

**Table 23: SLHD Current and Projected Renal Dialysis Need 2012, 2016, 2021 Based on Medium Growth Rate**

***Scenario: Medium annual growth rate of* 5.8% to 2021*+***

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **SLHD Renal Patient and Chair Projections 2012-2021** | | | | | | | | | | |
|  | | **Actual** | | | **Projected** | | | | | |
| **Modality** | **Facility** | **2012** | | | **2016** | | | **2021** | |  |
| **Patients** | **Chairs** | **Treatments** | **Patients** | **Chairs** | **Treatments** | **Patients** | **Chairs** | **Treatments** |
| Facility-based | Concord in-centre | 38 | 12 | 5938 | 48 | 13 | 7440 | 63 | 18 | 9863 |
| Concord satellite | 36 | 14\* | 5604 | 45 | 11 | 7022 | 60 | 15 | 9308 |
| RPAH in-centre | 25 | 10 | 3934 | 31 | 10 | 4929 | 42 | 12 | 6534 |
| RPAH satellite | 122 | 33 | 17892 | 153 | 36\*\* | 22418 | 202 | 48 | 29719 |
| **Sub-total Facility** | **214** | **69** |  | **268** | **70** |  | **356** | **93** |  |
| Home-based | Concord | 90 | - | Var | 113 | - | Var | 149 | - |  |
| RPAH | 130 | - | Var | 163 | - | Var | 216 | - |  |
| **Sub-total Home** | **220** | **-** | **Var** | **276** | **-** | **Var** | **365** | **-** |  |
| **Total SLHD Renal Dialysis** | | **441** | **69** |  | **553** | **70** |  | **732** | **93** |  |

*\**

*\*Concord satellite is currently operating at 75% capacity, with chairs not currently utilised during Tuesday, Thursday & Saturday PM shifts.*

*\*\* RPAH North West Precinct planning includes five extra satellite stations plumbed. Funding, staffing and resources for the commissioning of this expansion has not been secured.*

*+ The District’s current ratio of in-centre/satellite to home-based dialysis at 107:110 is in line with NSW Health’s recommendations, and therefore projections have assumed a continuation of this ratio into the future. Other projection assumptions include: SLHD renal dialysis unit distribution will remain as per current arrangements; chairs at SLHD facilities will continue to operate for 2 shifts each day, 6 days a week, 52 weeks a year; each haemodialysis patient requires an average of 156 treatments per annum (based on 3 treatments per week for 52 weeks); each In-Centre chair can provide 562 treatments p.a. (based on 2 shifts per day for 6 days per week at 90% occupancy); each satellite dialysis chair can provide 624 treatments p.a. (based on 2 shifts per day for 6 days per week at 100% occupancy) or dialyse 4 patients p.a..*

It is estimated that SLHD will be operating at 90% in-centre capacity by 2015-16 and 100% of satellite capacity by 2017-18. Consequently, further investment in facilities is required to ensure renal dialysis services are adequate for the demand. In addition, the Canterbury LGA currently lacks a dialysis facility and patients from this area, who are frequently of low socio-economic status and from a CALD background, have inadequate local access to dialysis services.

# 8. Implications for Sydney LHD Renal Services

##### 8.1 Increasing demand

There were more than 53,000 people aged 55 years or more living in the Sydney LHD in 2011, with greater numbers and proportions projected in the next decade. The incidence rates of treated ESKD are projected to rise to 15 per 100,000 in 2015 and to 18 per 100,000 in 2020.

More than 2,000 Aboriginal adults lived in the Sydney LHD in 2011, and again, it is projected that the population will increase in the next decade. There will be a growing, diverse immigrant population.

There are projected increases in the incidence of diabetes, and already high prevalence of overweight and obesity across the Australian population – and the rates are likely to be similar in the Sydney LHD population. There are differentials in the distribution of these risk factors for kidney disease – also likely to be reflected in the Sydney LHD population.

##### 8.2 Potential for inequity

The overview of the demographic and socioeconomic characteristics of the population of Sydney LHD demonstrates the presence of population sub-groups (older people, Aboriginal and Torres Strait Islander people, humanitarian immigrants, and people with co-morbidities) that are likely to be at higher than average risk of CKD (and faster progression of severity), that are likely to have more limited access to optimal health care, and that are likely to have limited socioeconomic capacity to take full advantage of optimal care (e.g. poorer quality housing making home-based dialysis difficult; or living in rural areas with inadequate transport).

The optimal care pathway, the literature, and anecdotal evidence identify multiple points at which opportunities for decisions that lead to inequitable treatment and inequitable outcomes arise, and multiple determinants of inequity. Some of the decision points occur on the ‘supply side’ – pointing to the need for services and health care providers to reflect on and revise what is being provided, where, when, and perhaps most importantly, how. The need for services to be welcoming, culturally and physically safe, as well as physically accessible is clear; the need for communication between doctors and patients to be clear and appropriate to patients’ levels of literacy and health literacy and the need for the complex information and education required by CKD patients to be clear and appropriate and theory-based are also clear. At each point on the Optimal Care Pathway there are points at which differential treatment can occur – differential treatment that is not based on the course of CKD, but that is, rather based on characteristics and circumstances of the patient, of the service, or of the provider. Each of these is remediable – but only when recognised and acted upon.

It is important to note, therefore, that Canterbury LGA has the largest population of the LGAs in Sydney LHD; has the most socioeconomically disadvantaged population; hosted most of Sydney LHD’s humanitarian new entrants, and has the greatest number of overseas-born residents (although two other LGAs have higher proportions of overseas-born residents in 2011).

However no Renal Services were provided by Canterbury Hospital in 2006. This may not be a problem given that the distances to travel to the full range of specialist renal services are not, by outer urban and regional/remote area standards, great. On the other hand, the level of socioeconomic disadvantage, the relatively high numbers of people whose English language literacy is limited, and the likelihood of higher rates of smoking, overweight/obesity, and diabetes mean that care is needed to ensure that the supply of renal services (including those provided through primary health care) is commensurate with need.

It will be useful to identify data on the availability of primary health care services in the Canterbury LGA and the extent to which they have the capacity to diagnose, treat, and care optimally, for patients with CKD at all stages on the continuum.

# 9. summary: Ensuring universal access to the Optimal Care Pathway for End-Stage Kidney Disease for all residents of SLHD, with particular emphasis on the population of Canterbury LGA

###### Project description

An Equity-Focused Health Impact Assessment of the introduction of an optimal care pathway for the provision of renal services in Sydney LHD identified a high (and growing) level of need for optimal CKD (including ESKD) services for the population of the Sydney LHD and, particularly, for residents of the Canterbury LGA, and for Aboriginal and Torres Strait Islander residents of the LHD.

###### Rising demand & distribution of services

The AusDiab Study (1999-2000) found that more than 13.4% of Australians aged 25 years or more had some degree of CKD – more than half of which was at stages of CKD 3 – 5. Thirty percent of people aged 65 years or more had CKD stages 3 – 5. Across the Sydney LHD the number of residents aged 70 years or more is projected to increase by 29% over the next decade.

It has been projected that the renal dialysis patient numbers in SLHD will rise, annually, by 5.8% (medium annual growth rate); it is considered that a growth rate of 7-9% could easily be realised. These growth rates are likely to occur as a consequence of the aging of the population, of increasing prevalence of diabetes associated with increasing prevalence of obesity, and the high proportion of the population of the Canterbury LGA, in particular, with low socioeconomic status.

In 2011 the population of the SLHD was 548,632, 11.8% of which was aged 65 years or more. The population of the Canterbury LGA was 137,454, 13.4% of which was aged 65 years or more. The population of the Canterbury LHD is the most socioeconomically disadvantaged in the SLHD and includes a high number and proportion of humanitarian entrants and overseas-born residents. The Canterbury LGA also has almost 1,000 Aboriginal residents – whose risk of CKD is significantly greater than that of any other group in the population. The demand for optimal CKD treatment services for the population of the Canterbury LGA is growing and no dialysis services are provided at Canterbury Hospital – making it the only district hospital in the south western area of Sydney that does not do so. This is of concern given that the demand for End Stage Renal Failure services in the SLHD is likely to be highest in the Canterbury LGA.

###### Improvements in standard diagnosis, treatment, and care

Over the last decade an optimal care pathway has been developed globally to care for patients with CKD 3-5. The pathway seeks to maximise utilisation of optimal active treatments (pre-emptive transplantation where available), or home dialysis wherever appropriate. The pathway also serves to allow patients to make informed decisions about active or conservative management options. It is widely accepted that the pathway’s inclusion of patient education, timely insertion of access and work-up for dialysis and transplantation leads to the best clinical and health economic outcomes.

###### Limited supply of renal services

In 2013 no comprehensive renal services were provided at Canterbury Hospital, unlike those provided at Royal Prince Alfred Hospital and Concord RGH. In 2013 SLHD had 22 in-centre and 44 satellite chairs and 10 home training chairs for haemodialysis (120 patients on home haemodialysis) and more than 100 patients on peritoneal dialysis. It has been estimated that SLHD will be operating at 90% in-centre capacity by 2015-16 and 100% of satellite capacity by 2017-18.[[76]](#footnote-7) Future demand can be met only by increasing home dialysis rates and by expanding dialysis services. The population of Canterbury is most vulnerable and currently, has the most limited access to both these options.

In addition, although SLHD Renal Services have the highest rate of home-based dialysis of any renal service in Australia, full utilisation of home dialysis may not have been reached due to the lack of consistent and timely application of the optimal CKD pathway.

The capacity of SLHD Renal Service to ensure routine, consistent access to the optimal care pathway for all eligible patients has been limited by:

* Lack of skilled staff for a multidisciplinary, ambulatory care service equitably across all language, cultural, and socioeconomic groups in the SLHD;
* Lack of suitable facilities across the SLHD;
* Lack of an on-site renal dialysis service at Canterbury hospital.

###### Evidence of differentials in access to CKD care and of quality of clinical care

There are no data to confirm that the CKD patients in the SLHD as a whole, or in particular disadvantaged locations or population groups, are receiving sub-optimal diagnosis, treatment, and care for CKD 3 -5. However, there is a considerable body of evidence that population groups who are socioeconomically disadvantaged and/or who have been socially excluded are at greatest risk of contracting kidney disease, of faster progression of the disease, and of not receiving optimal diagnosis, treatment and on-going care.

###### Service need and anticipated benefits

The anticipated benefits of enhancing the delivery of the optimal care pathway for CKD 3-5 so that all CKD 3 – 5 patients resident in SLHD, including high-risk population groups, have equal access to optimal diagnosis, treatment and care for CKD 3 – 5 are that there will be:

* + - increased effectiveness of preventive measures to treat vascular risk factors, and reduced progression of CKD at stages 3-4;
    - increased uptake of optimal treatment options, including home-based dialysis and transplantation;
    - increase in informed choices about treatment options, including active or conservative care;
    - improved self-management capacity and decision-making among patients with CKD 3 – 5;
    - reductions in complications of CKD 3 – 5; and
    - reductions in premature mortality.

###### Alignment with Strategic Planning in the SLHD

The project is consistent with the SLHD Healthcare Services Plan, the NSW Renal Dialysis Services Plan, and the NSW Government State Health Plan (in preparation) – in its focus on improving access to optimal care, on ensuring that all patients receive optimal care, and on ensuring that access to services and to optimal quality care is equitable. It is understood that planning for the number and distribution of dialysis chairs within the SLHD will commence shortly and it is recommended that priority consideration be given to the services that will meet the needs of the population of the Canterbury area.

An enhanced CKD service will expand access to the network of comprehensive services provided by the SLHD Renal Service, making services that meet optimal quality standards accessible to high-need population groups and to all CKD patients in the SLHD.

The Equity Focused Health Impact Assessment showed that there are no alternative options to meet the demand for equitable access to optimal CKD 3 – 5 diagnostic, treatment, and care for the population of the SLHD, and that there are opportunities to increase the accessibility and quality of care for Aboriginal and Torres Strait Islander CKD patients and patients with low levels of literacy. There are no dialysis services in Canterbury, and across the whole SLHD there is a lack of a consistent CKD 3-5 clinic providing optimal care. The current model of care is physician (rather than multidisciplinary) based care.

The service need has been identified from analysis of socio-demographic, epidemiological, and service utilisation data, from a review of the literature (including NSW and SLHD policies and plans), and from clinical experience. The preferred option is to provide, consistently and routinely, a comprehensive service that meets current optimal care standards to all CKD patients in the SLHD and particularly, to population groups known to be at greatest risk of both developing CKD and of receiving less than optimal care.

The recommendation is for enhancement funding to expand the capacity of the SLHD Statewide Renal Service to provide optimal care to all CKD 3-5 patients in SLHD – and particularly, to ensure that access is equal to need across all population groups. The SLHD Renal Service is a leader in the field and should, with the proposed enhancements, be well placed to provide optimal care to the population of SLHD. The establishment of a satellite haemodialysis unit at Canterbury will also ensure that the optimal care is available more equitably in the SLHD.

# 10. Recommendations

The purposes of the recommendations below are to enable the SLHD Renal Service to meet current global standards of best practice by providing consistent, routine access to the optimal care pathway to all patients, to meet current and growing need for expanded renal services (as CKD is high and rising) in the SLHD, and to ensure that the services are available equitably.

It is recommended that:

1. the SLHD enhance investment to enable the appointment of a CKD CNC in the SLHD and the establishment of a CKD clinic for education, early assessment and application of the optimal care pathway to all LHD patients, and to explore the feasibility/utility of establishing a renal clinic at Redfern AMS and Canterbury Area;
2. in addition to actions to improve services to all ESKD patients in the Sydney LHD, the Renal Services Plan (consistent with the SLHD Healthcare Services Plan), in order to accommodate increasing dialysis needs, should establish a dialysis satellite unit in Canterbury **by 2015**.
3. the expanded service includes building collaborative relationships with the Redfern AMS, and Medicare Locals; expanded measurement and reporting on differentials in the provision of services and in treatment outcomes; increased access to appropriate active and passive care, and improvements in the health literacy of the SLHD Renal Services, particularly in the quality of communication with patients;
4. the implementation of the optimal CKD pathway be trialled and evaluated after three years, and, if found to be successful, be adopted as part of the standard of care for progressive CKD .

###### **In order to implement the recommendations**

* Enhancement funding is requested for a FTE CKD CNC position. It is proposed that the necessary sessional medical and allied health and Aboriginal Health Worker inputs be remunerated from existing sources (including Medicare rebates).
* The allocation of physical facilities is requested – to enable the provision of ambulatory clinical care in multidisciplinary settings across the SLHD.
* Enhancement funding for a part time social worker to support CKD clinic activities

### 11. Project governance and consultation

Assoc. Prof. Josette Eris, Dr Pam Garrett, Assoc. Prof. Marilyn Wise, Dr Elizabeth Harris, Ms Lou-Anne Blunden and Dr Teresa Anderson comprised the Project’s Steering Committee. Ms Hannah Barrington was the Project Administrator. Dr Michiko Hoshiko and Ms Marcia Grand Ortega provided research assistance and the design of the final report.

The Assessment step of the Equity Focused Health Impact Assessment included consultation with:

Prof Phil Harris, Clinical Director, Cardiovascular Services

Prof Steve Chadban, Staff Specialist, Renal Medicine

Dr Paul Snelling, Staff Specialist, Renal Medicine

Dr John Saunders, Staff Specialist, Renal Medicine

Ms Lorraine Garry, Haemodialysis Co-ordinator

Ms Jacqui Moustakas, Chronic Kidney Disease Co-ordinator

Ms Angela Manson, Director, Multicultural Health

Mr George Long, Director of Aboriginal Health

Ms Jodi McLeod, Community Nurse

Ms Claudia Pollauszach, Community Nurse

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