

A Model for Home Dialysis

Australia - 2012



Acknowledgements

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Information contained in this report has been obtained from many sources, published, written and anecdotal. References to providers of dialysis are not endorsements of their products. KHA do not accept any responsibility for the outcomes of development of home dialysis programmes related to this document. The document is intended to promote discussion and evaluation of home dialysis programmes throughout Australia, leading to development of and improved options for the patient. Every programme must carefully consider the best option for development based on information available at the time.

Contents

- Executive Summary 4
- Pathway to Home Dialysis (Diagram 1) 6
- Introduction..... 7
- Dialysis Modality Definition 10
- Benefits and Barriers for Home Dialysis..... 11
- Defining a Home Dialysis Model 15
- Funding for Home Dialysis..... 16
- Government/State/Organisation Philosophy and Targets 18
- Clinical Governance, Quality and Leadership..... 21
- Pre-Dialysis Education 23
- Preparing for Home Dialysis..... 27
- Infrastructure for Home Training Units and Home..... 29
- Environmental Factor and Carbon Footprint 32
- Home Training Process..... 33
- Transition to Home..... 35
- Support at Home 37
- Retention on the Programme – Minimising Risk Factors 40
- Withdrawal from Home 43
- Summary 45
- Recommendations Kidney Health Australia: 45
- Barriers and Actions defined by grouping and including responsibilities..... 46
- Glossary 50
- Appendices 51
- References:..... 62

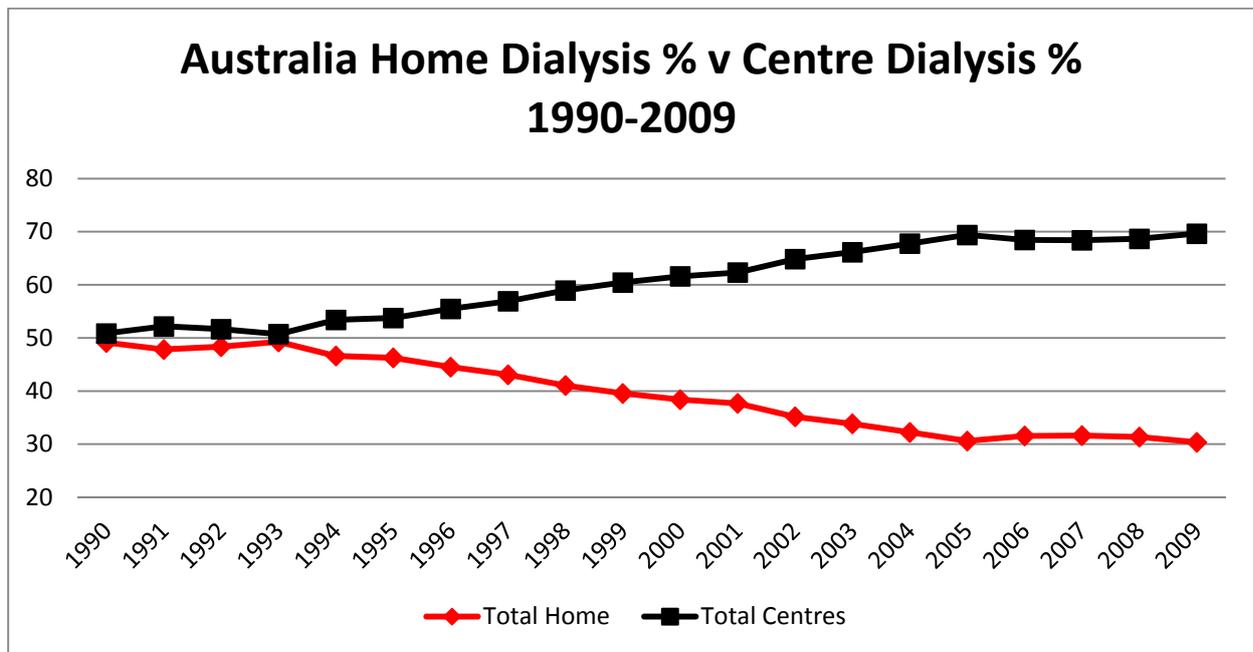
- Appendix 1 State Percentages of Dialysis modalities – Source – ANZDATA 2000-2010 Reports..... 51
- Appendix 2 Distribution of Home Dialysis Units across Australia 54
- Appendix 3 Patient Testimonies..... 56
- Appendix 4 Summary of Australian Funding Mechanism for Renal Replacement Therapy..... 57
- Appendix 5 Victoria Funding Model - General Information 58
- Appendix 6 CARI Guidelines 60
- Appendix 7 Nxstage and Impact on Home Dialysis in the US..... 61

Executive Summary

Kidney Health Australia, (KHA) formerly known as the Australian Kidney Foundation, is a national not for profit organisation focused on saving lives and reducing the need for dialysis. Our work focuses on awareness, detection, prevention and management of kidney disease in Australia and surrounding regions.

Chronic Kidney Disease (CKD) refers to all conditions of the kidney, lasting three months or more, where a person has had evidence of kidney damage and/or reduced kidney function, regardless of the specific diagnosis of the disease or condition causing the disease.¹ Dialysis or a kidney transplant is needed when the kidneys have stopped working, stage 5 CKD.² KHA support the provision of high quality home dialysis as a treatment option for all of those with CKD who would prefer this treatment option.

In December 2009 there were 10,341 individuals on dialysis in Australia with 1293 (12.5%) on Automated Peritoneal Dialysis (APD); 894 (8.6%) on Continuous Ambulatory Peritoneal Dialysis (CAPD); and 963 (9.4%) on Home Haemodialysis (HHD).³ Prevalent growth averages 6% per annum.³ The utilisation of home dialysis is highly variable by State and by jurisdiction within those States. New Zealand operating on a home first policy has the highest rate of home dialysis in the world. Home dialysis as a percentage in Australia is decreasing.



Data courtesy of ANZDATA (3)

The incident rate for treated end stage kidney disease, considering diabetes and an aging population is projected to increase from 11 per 100,000 population in 2009 to 19 per 100,000 in 2020.² This equates to an 80% increase. To manage this increased growth all renal replacement therapy programmes including home dialysis programmes will expand. Effective expansion of these services will require detailed planning, considering all relevant factors.

Consumers with kidney failure enter a system that offers the treatment options of home dialysis, transplant, centre-based dialysis or conservative treatment. Currently there are many factors determining which options may be available or encouraged. Consumer preferences are pivotal to a system if adherence to treatment regimes and maximised quality of life is to be achieved. The KHA consumer survey determined that education about, and the option to choose, certain modalities is not equal across Australia.⁶ Perceptions of life-style advantages and quality of life remain the primary factors that influence the choices of the consumer. How health professionals provide education and information influences these choices.

Concurrent with life-style considerations known health outcomes influence the recommendations for health care treatment options. Clear and consistent benefits of more intensive haemodialysis have been demonstrated in 100 abstracts and peer-reviewed journal articles.⁵ Observational data, retrospective analysis and qualitative research underpin most home dialysis studies. Whilst some benefits of home dialysis occur regardless of the hours on dialysis, or the modality, the best medical advantages of enhancing haemodialysis hours and dialysing at home are becoming widely accepted.

Budgets and funding also influence the provision of health care options, including dialysis. Consistently during cost analysis of dialysis the cost of HHD is the lowest for all the dialysis modalities. CAPD is a similar price to HHD and APD or satellite is about 25% more expensive depending on the providers' contracts. Hospital HD is the most expensive. HHD starts at \$49,137, compared to \$79,072 for hospital dialysis.⁴ KHA estimates 'that increasing the use of home dialysis over the next 10 years would lead to an estimated net savings of between \$378 and \$430 million for the health system'.⁴

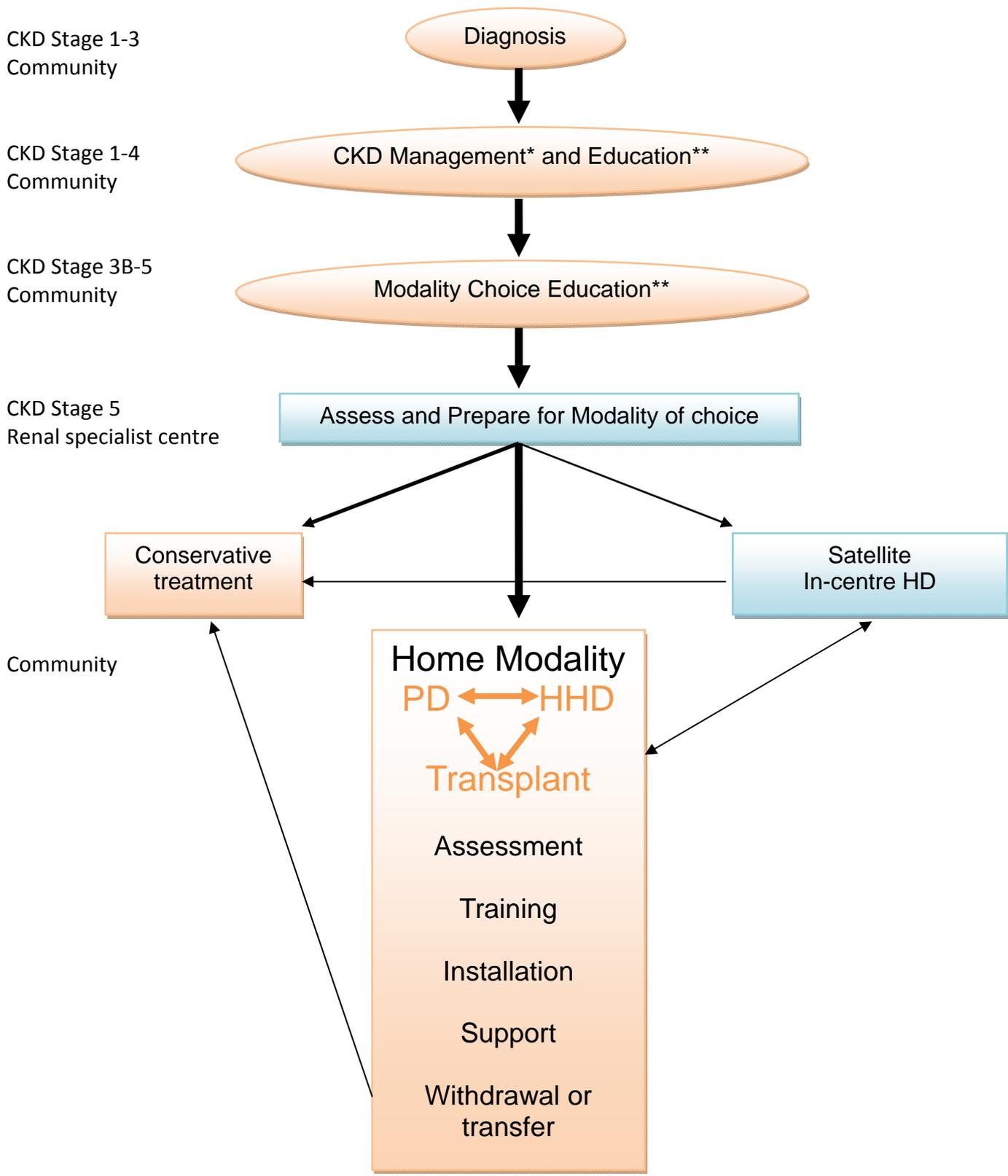
It is clear that the most economically viable options with positive health outcomes are home dialysis and transplant. In a fiscally responsible system, that recommends treatments with best outcomes these would be prioritised for all of those with end stage CKD. The reality is that only 30% of consumers are at home and there are barriers that prevent maximum uptake.

Potential, perceived and actual barriers to home dialysis all contribute. Barriers range from system level barriers to those at an individual unit level and those directly linked to the consumer. Identification of barriers followed by implementation of solutions by all stakeholders is the identified pathway forward. Stakeholders include all of those who are advantaged by an increase in access to and uptake of home dialysis; Government, State renal executive groups, health systems, nephrologists, nurses and all direct health care professionals, industry providers of dialysis equipment and importantly the consumers supported by Kidney Health Australia. Strong leadership from health care leaders is critical.

To identify all barriers a complete model of dialysis has been developed and explored. It includes the overarching areas of funding, government and unit philosophy and targets, clinical governance, quality and leadership, home dialysis models, infrastructure of home dialysis units and the environment. For the consumer focusing on a patient centred approach it involves multiple facets and considerations of the journey from diagnosis through planning, training, installation at home and ongoing support until withdrawal of home dialysis occurs. Home dialysis throughout relies on education that maximises self-management skills, promoting autonomy and control. The majority of the care and pathway occur in the community.^{Diagram 1}

A successful home dialysis programme has many facets and involves system factors as well as local factors. Many barriers exist that have reduced the uptake of home dialysis over the last decade. All barriers have a solution that will allow them to be tackled and removed or at minimum reduced. To overcome the barriers will require a comprehensive approach with commitment from the entire population who contribute both to policy and to the renal health workforce. When this is achieved the consumer will have equity in choice and the option to choose the dialysis modality that will best enhance their quality of life.

Pathway to Home Dialysis (Diagram 1)



Transition between home modalities is anticipated
 Home Dialysis units can be hospital, satellite or community based
 Home Dialysis is the primary treatment modality
 *CKD management should be GP based with renal specialist (Dr or NP) support
 **Primary education should be provided by a skilled renal practitioner

Introduction

Home dialysis is currently a widely debated topic in renal around the globe. A common theme is that it is the way of the future to meet the growing demand for renal services.¹ The USA, UK, Finland, Asia and Australia as examples all have active groups, committees and reports expressing and working to increase this intended growth area.^{8,9,10,11,12,13,14,15}

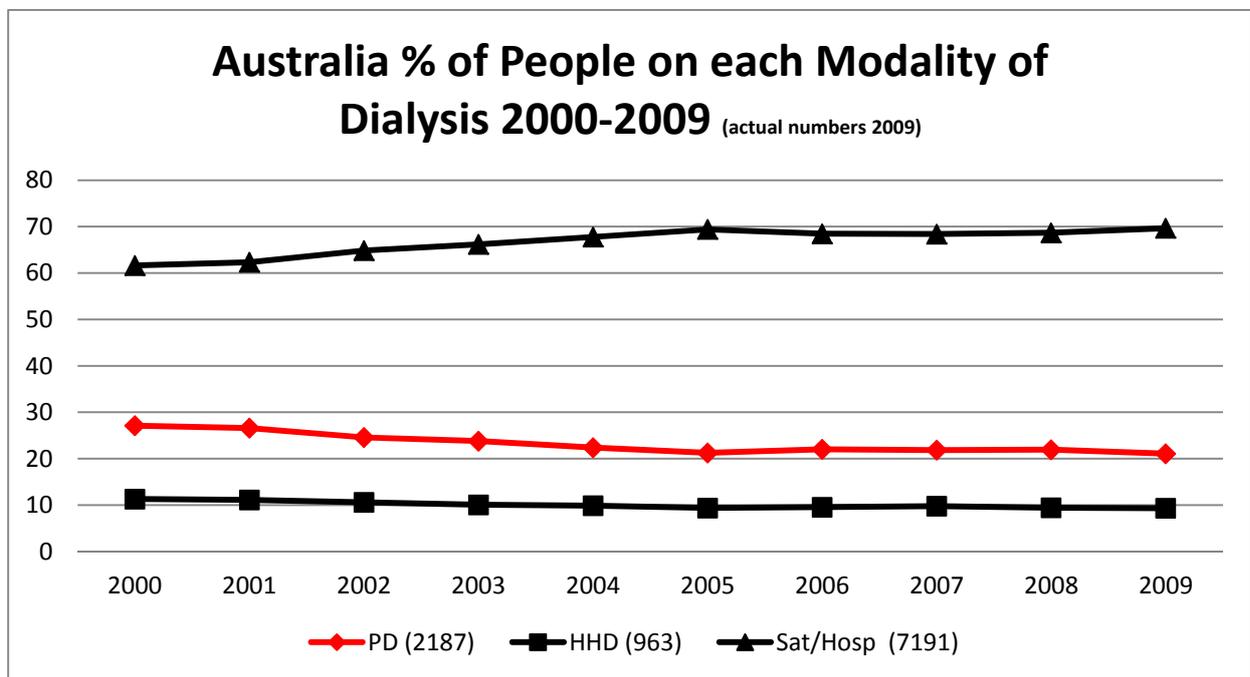
History of home dialysis

HHD accounted for nearly 50% of Australian patients in the 1970s.¹⁵ The advent of PD in the 1980s and development of satellites contributed to a transition away from HHD.¹⁶ Concurrently Government policies and funding models were not promoting home dialysis. From the year 2000 the growth in satellite facilities removed the drive to prioritise any modality of home dialysis as the first option. PD rates stabilised by 2005, down to 21%, and HHD at 10% with a wide variance between States.^{15, appendix 1} Senior renal staff developed dialysis programmes concurrent with regional variances, personal experience or preferences and available resources for modalities. In many jurisdictions this did not favour home dialysis, but despite this in some home dialysis programmes flourished. The overall result was a system with an overwhelming demand for in-centre or satellite dialysis, the most resource and cost intensive modality. Consequently there was reduced equity in choice for the consumer.⁶

Current Statistics

In December 2009, 10,341 individuals were on dialysis in Australia with 1293 (12.5%) on APD, 894 (8.6%) on CAPD and 963 (9.4%) on HHD.³ Prevalent growth averages 6% per annum.³

Diagram 2: Australia % of People on each modality of Dialysis



Data source ANZDATA registry (3)

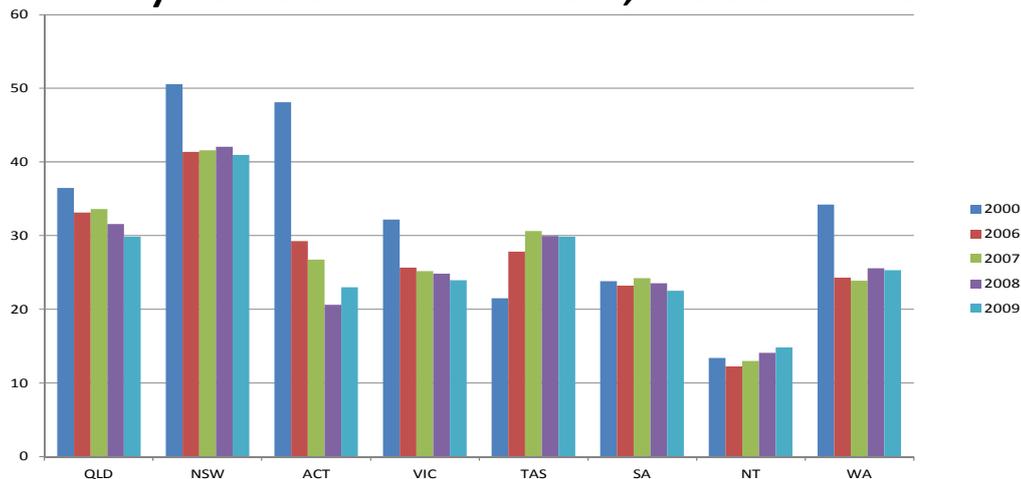
In Australia 43 home training units provide the training and support for those at home.^{appendix 2}

Recent Australian Trends

Between 2000-2006 home dialysis decreased from 38% of the dialysis population to 31% caused principally by a 6% decrease in PD.^{diagram 3} HHD has remained reasonably static. Since 2005 the prevalence of home dialysis in Australia as a percentage has remained constant with 30% overall at home. PD numbers are now static around 21% in Australia with APD increasing from 45% to 60% of PD between 2005 and 2009. State variance and trends continue though within each modality.^{append 1, diagram 3}

Diagram 3: HHD and PD as % of all Australian Dialysis By Jurisdiction, 2000, 2006-2009

HHD and PD as % of all Australian Dialysis By Jurisdiction 2000, 2006-2009



Source Information ANZDATA registry

International statistics and trends

Internationally HHD rates vary from 0.1 to 77 per million population in comparative demographic populations across the world fluctuating up and down widely over the decades. Current percentages of renal replacement therapy RRT on HHD vary from 0 - 15.6% (New Zealand).¹⁶ PD rates show similar variance. Identified factors that influence rates of home dialysis include government policy and funding, available technology and individual passion from nephrologists or nurses to promote the therapy.^{14,17} Individual choice and ability is not demonstrated to be the main influence.¹⁷

In New Zealand the percentage at home between 2000-2004 fell from 65% but since 2005 has remained around 50%. Of note is that the satellite HD is around 48% in Australia and only 19% in New Zealand.³ Home peritoneal dialysis however is currently decreasing world-wide despite discussion that it should increase. The UK now has only 17% on PD.¹⁸ Opposing the world-trend is Hong Kong with a PD first policy which is achieving high rates of 80% with 2 year patient survival of 84%.¹⁹ Factors considered to influence PD choice are perceived negative health outcomes by health care workers, availability of satellites and physician preference.^{12,17}

Future of home dialysis

The Australian goal of growth for home dialysis is aligned with many countries, and is based on the identified limited physical, human and finite funding resources, that will be required to meet the annual 6-7% increases in demand for dialysis.¹⁵ Consumer rights are also identified.

Growth of a successful home dialysis programme requires supportive health policy, a formal infrastructure, committed individuals, home dialysis expertise, and a supportive approach from all health care workers who connect with the patient providing a patient centred approach as they travel on their renal journey.

Kidney Health Australia (KHA) support growth of the home programme to improve access for individuals and adopt cost-efficient dialysis provision.²⁰

The KHA national CKD strategy recommended:

- Recommendation 16:
To provide all people with advanced CKD with appropriate access to all modalities of RRT and opportunities for active involvement in the identification of preferred treatment options
- Recommendation 22:
All State/territory governments undertake ongoing reviews of dialysis service delivery to ensure health systems plan for and resource adequately the number of people dependent on dialysis.
- Recommendation 26:
To maximise opportunities for home dialysis by identifying and addressing current impediments to this form of treatment.
- Recommendation 45:
To develop, implement and monitor for effectiveness initiatives to minimise the health and social disruption associated with relocation to access treatment for Aboriginal and Torres Strait Islanders with renal disease.⁸

The Home Dialysis model

This model for home dialysis provides information to support that the option of home dialysis should be widely available and be expanded.

It outlines a framework to identify all factors to be considered for an 'effective and complete home dialysis programme'. Barriers and potential actions to reduce these are provided. The resources required to facilitate existing services or plan new programmes are identified. Where available references are made to existing literature but there is limited information regarding complete home dialysis models.

Dialysis Modality Definition

The two dialysis treatment modalities considered are haemodialysis (HD) and peritoneal dialysis (PD):

- HD uses a dialysis machine to circulate blood from the patient’s body through an artificial kidney (dialyser) for purification and then returns it to the patient. An alternative version of HD is Haemodiafiltration (HDF) that aims to increase the range of molecules that are removed during the purification process. HDF is traditionally an in-centre or satellite therapy.
- PD involves filling the peritoneal cavity with dialysis solution through a catheter. Waste and extra fluid are exchanged across the membrane and then transferred to the dialysis solution. After a pre-determined period, the solution is then drained out of the body and replaced with a fresh solution. Each repetition of this cycle is called an exchange.

These therapies can be delivered by different locations:

- In-centre or hospital HD and HDF
- Satellite, or stand-alone unit HD (SHD and SHDF)
- Self-care units or community centre HD (independent but not at own home)
- Home HD (HHD)
- Home Continuous Ambulatory PD (CAPD)
- Home Automated PD (APD)

These therapies can be delivered by different regimes:

Haemodialysis:

- Standard HD: HD is performed 3 times per week for 4-5 hours. This is the usual regime for hospital and satellite units and some individuals at home
- Enhanced HD: Additional sessions i.e. alternate daily or 4-5 times per week. This includes nocturnal and short daily with all regimes improving efficiency.²²
- Short Daily HD: HD is performed 6 times a week for an average of 2-3hours (also known as enhanced HD)
- Nocturnal Haemodialysis: HD is performed overnight for an average of 8hrs. This is done up to 6 times per week.

Diagram 4: Currently in Australia 45% of patients still receive below 13.5hrs of HD per week¹⁴

Australia – Hemodialysis 2010 Total Weekly Hours and Location



Peritoneal Dialysis

- CAPD, a simple manual bag exchange is usually performed four times a day taking about 30 minutes to complete each 2-3 Litre exchange.
- APD involves the use of an automated cycler to perform the fluid exchanges. The dialysis is completed by a machine overnight that performs six to eight exchanges whilst the individual is asleep. During the day, dialysis solution can be left in the peritoneal cavity to optimise dialysis.

Benefits and Barriers for Home Dialysis

The opportunity to conduct large, prospective, randomised controlled trials in home dialysis has been limited. However over 100 abstracts and peer-reviewed journal articles demonstrate clear and consistent benefits of more intensive haemodialysis.⁵ Whilst some benefits of home dialysis occur regardless of the hours on dialysis, or the modality, the best medical advantages of enhancing haemodialysis hours is the signal in the literature. It is acknowledged that randomised controlled clinical trials are needed for further evidence.

Individual Benefits:

Control of health and treatment regimes

All home dialysis provides patients with autonomy and flexibility. The option for when to dialyse is determined by the individual within the parameters that are required for good dialysis outcomes. Attending a family function can be a life situation that does not require permission, with agreement for appointment changes, from a dialysis unit.

Quality of Life

Home dialysis patients have proven improvement in quality of life and have more family engagement.^{22,23} Patient testimonies support this fact.^{appendix3} Improvement in patient mood, interactivity and cognition is noted by carers.²² Sexual drive, an often over-looked but important aspect of life for many, is also increased.²²

Dialysis does not require relocation

Patients residing in rural and remote locations are able to stay in their own homes. For the indigenous this ability to be at home is vital pertaining to their strong connection to culture and the land. This has socio-economic benefits for the individual allowing them to remain an integral part of their family and community at a time when support is critical.

Travel and Holidays

PD allows travel to any region that can provide the necessary supplies. HHD with new technology may allow travel similar to PD.²³ A HHD patient may also find agreement to dialyse as a holiday patient in a satellite unit is easier gained if they can care for themselves.

Reduced travel to have treatment (saved time and cost)

Many patients have to travel many kilometres to a dialysis unit. Just a 30 minute 10km journey one way is 156 hours and 3120km per annum. Parking difficulties, fees and the inability to drive oneself to or home from dialysis add to this burden and then involve other family members or community resources. Home dialysis, once training is complete eradicates this need.

Improved diet and fluid allowances with reduced medications

HHD with increased hours offers reduced dietary restrictions and reduced medications.^{5,21} For those on nocturnal dialysis for 5-6 nights dietary restrictions can be removed. If completing 4-5 nocturnal sessions a week phosphate binders are not required and BP medications are removed for most patients.^{5,21} The Freedom study found a reduction from 79% of patients to 53% over 12 months on short daily dialysis.²⁵ Short or frequent daily dialysis also demonstrates reduction in phosphate levels.^{5,26,27,28} Erythropoetin use (EPO) a very costly medication is also reported in some cases to be reduced in enhanced dialysis therapy.⁵

PD allows a liberal diet with gentle continuous electrolyte removal. Most commonly patients are encouraged to increase their potassium input, a commonly restricted element of the diet for those on standard HD. Protein is encouraged and fluid can usually be consumed at 1-2 litres per day.

Ability to work

Patients receiving HHD or PD are more likely to work.²⁸ The flexibility of regimes and improved sense of well-being promotes this.

Extended Hours/sessions of HHD

81% of nephrologists agree HHD patients can perform more frequent or extended-hours of haemodialysis which may have improved medical outcomes.²⁴

Improved morbidity and mortality

Those using HHD have lower mortality rates, experience less hospitalization, and have less dialysis-related complications than satellite or hospital based HD patients.^{5,28} Mortality and cardiac related hospital admissions increase during the long (two day) inter-dialytic interval inherent with standard dialysis regimes.²⁹ Relative patient mortality risk adjusted for demographics and co-morbidities in 26,016 Australian patients were:

Table 1²⁶

	HHD (Conventional)	Facility HD (extended)	HHD (extended)	Peritoneal Dialysis	Facility HD (conventional)
Risk of death	0.51	1.16	0.53	1.10	1.0

For those on a programme over 4 years increased survival was demonstrated for extended hour therapies. Reduced infections risks and treatment adherence were the only determined plausible explanations for the variance in survival rates and better outcomes for home.²⁶ Reductions in left ventricular mass, improved blood pressure and lower circulating catecholamines are all factors which have been identified that may contribute to lower mortality caused by cardiovascular disease and these outcomes have all been found in various studies on enhanced dialysis hours patients.^{5,27,29,30}

Haemodialysis versus Peritoneal Dialysis morbidity and mortality

The Cochrane library concluded that PD versus HD has not been adequately researched and there is no demonstrated difference in survival between HD and PD.³¹ Another study found the risk for death in patients with ESRD undergoing dialysis depends on dialysis type after the first year and that further studies are needed to evaluate a possible survival benefit of a timely change from PD to haemodialysis.³² HD and PD mortality outcomes are reported annually in ANZDATA. To date HHD patients are included as part of the HD report.^{appendix 4, 3}

Reduced depression, improved sleep and decreased restless leg syndrome

The Freedom study found that depression decreased significantly using short daily dialysis over 12 months in 239 participants. The Beck depression inventory score (BDI) of >10 decreased from 41% to 27% (P=0.03).³³ Post-dialysis recovery time decreased from an average of 476 minutes to only 63 minutes. The symptom of restless leg syndrome decreased from 35% to 26% of participants, with similar associated improvements in sleep disturbances.³³ Sleep is also reported to be improved for those on nocturnal dialysis.²¹

Reduced non-dialysis related infection rate

Attendance at a community or hospital facility increases exposure to pathogens and potentially diseases.²⁶

Individual Barriers

Negative considerations that impact the individual are rarely documented and negative health outcomes have not been found in the literature reviewed. However there are known barriers that may prevent an individual commencing home or decrease the time they can remain at home.

Fear of cannulation and coping at home with dialysis

Fear of cannulation and worries regarding how to cope with problems at home are often discussed as a barrier. It is a challenge for the pre-dialysis educator and home dialysis team to support the individual to overcome the majority of these fears. Home visits, on-call systems, extensive training and support materials have meant that those who appear unsuitable for home dialysis: frail, non-English speaking, and illiterate individuals, can succeed. Personal drive is often a critical factor. Fears should be determined early allowing them to be addressed and home training to be attempted. Possibly early self-care at a satellite facility will allow time to overcome initial fears.

Social Isolation

The barrier that can be difficult for home dialysis patients and support systems to overcome is de-socialisation and a feeling of abandonment. Despite this it is rare that a home dialysis patient seeks to return to in-centre care.⁷ Support groups and volunteers, and regular respite dialysis are potential solutions to this concern.

Out of Pocket Costs

Currently there are costs to many home patients, dependable on State energy and water costs or concessions and also related to additional costs that are determined by State or hospital contracts. This should not remain a disadvantage as the solution is for the health system to ensure that all out of pocket costs are identified and reimbursed. Victoria has established a solution regarding this issue for home dialysis.^{appendix 5}

Access Infections

Button-hole cannulation is used more widely at home. There are concerns regarding an increased infection rate, especially in those who cannulate more frequently. Appropriate staff training and strict attention to hygiene can reduce this problem and regular reassessment of cannulation technique should be an integral part of ongoing programmes.¹⁰⁷

Carer burn-out

This barrier is a real concern. Respite programmes that either provide direct dialysis support or even other supports at home can reduce the overall burden. Ensuring that the individual manages as much of their own dialysis as possible also will reduce this risk. It is acknowledged that the elderly at home will require a greater support from carers and the home dialysis team should remain mindful of the workload they are taking on, ensuring that it is appropriate and not going to cause major stress very early on. Social work interventions that ensure that carers are made aware of how to access and how to use all relevant resources, is a critical part of any home dialysis programme.

Commencing at satellite and reluctance to transfer to home

Good pre-dialysis pathways, dialysis training units with adequate capacity and therefore short waiting lists, and a unit culture that does not allow the patient destined for home to be allowed to settle into a 'being cared for' role are strategies to prevent this barrier.

System Benefits and Considerations

Predicted Population and Prevalence of dialysis Growth

Based on current growth trends in the Australian population anticipated growth is:

Table 2:

	Population over 65	Incident (new) dialysis pts annual	Prevalent Home Dx (based on current 30%)	Prevalent Home Dx (based on target 40% in 2020)
2010	2.52 million	1100	963 HHD 2177 PD	NA
2020	3.94 million	2000	1750 HHD 3958 PD	2333 HHD

If HHD and PD percentages remain constant HHD could increase from 963 to 1750 patients by 2020. PD numbers will increase from 2,177 to 3,958.³⁵ An estimated 13,318 will be on HD at satellite or in-centre. Many models have attempted to predict this growth and whilst rates may vary the trend is consistently upwards. Whilst many factors may affect the predictions the increase in diabetes with its close link to renal disease, an ageing population, an increasing population and no current cure for CKD indicates that growth will occur.

Infrastructure and Workforce

Satellite and hospital dialysis units operate with a ratio of nurses to patients of 1:3 or 4. Home dialysis operates with ratios of 1:15 HHD or 1:25 PD. Each satellite dialysis chair accommodates 4 patients per week for three treatments each. For infrastructure predicted population and incidence growth could equate to 460 new dialysis units and 24,000 new dialysis machines.³⁵ Calculating workforce using current models up to 18,000 new renal nurses may be required.³⁵

The advantage to home dialysis is that whilst for every 1% Australia-wide increase in home dialysis an additional 217 patients will need to be accommodated the resources to support this growth for both workforce and infrastructure are far less than growth of the satellite model.

Environmental Issues

The carbon footprint of dialysis increases with each treatment.³⁶ If completing three treatments on HHD the carbon footprint remains lower than treatment away from home, enhanced by the reduced travel. However increased treatment numbers increase the carbon footprint.

This can be overcome with:

- New technology that use about 10% of the energy and has greatly reduced water requirements
- Use of the home environment rather than creation of new units
- Recycling and re-use of grey water and waste water from the reverse osmosis plant^{37,38}
- Renewable energy sources

Cost Benefits of increasing HHD for the health system

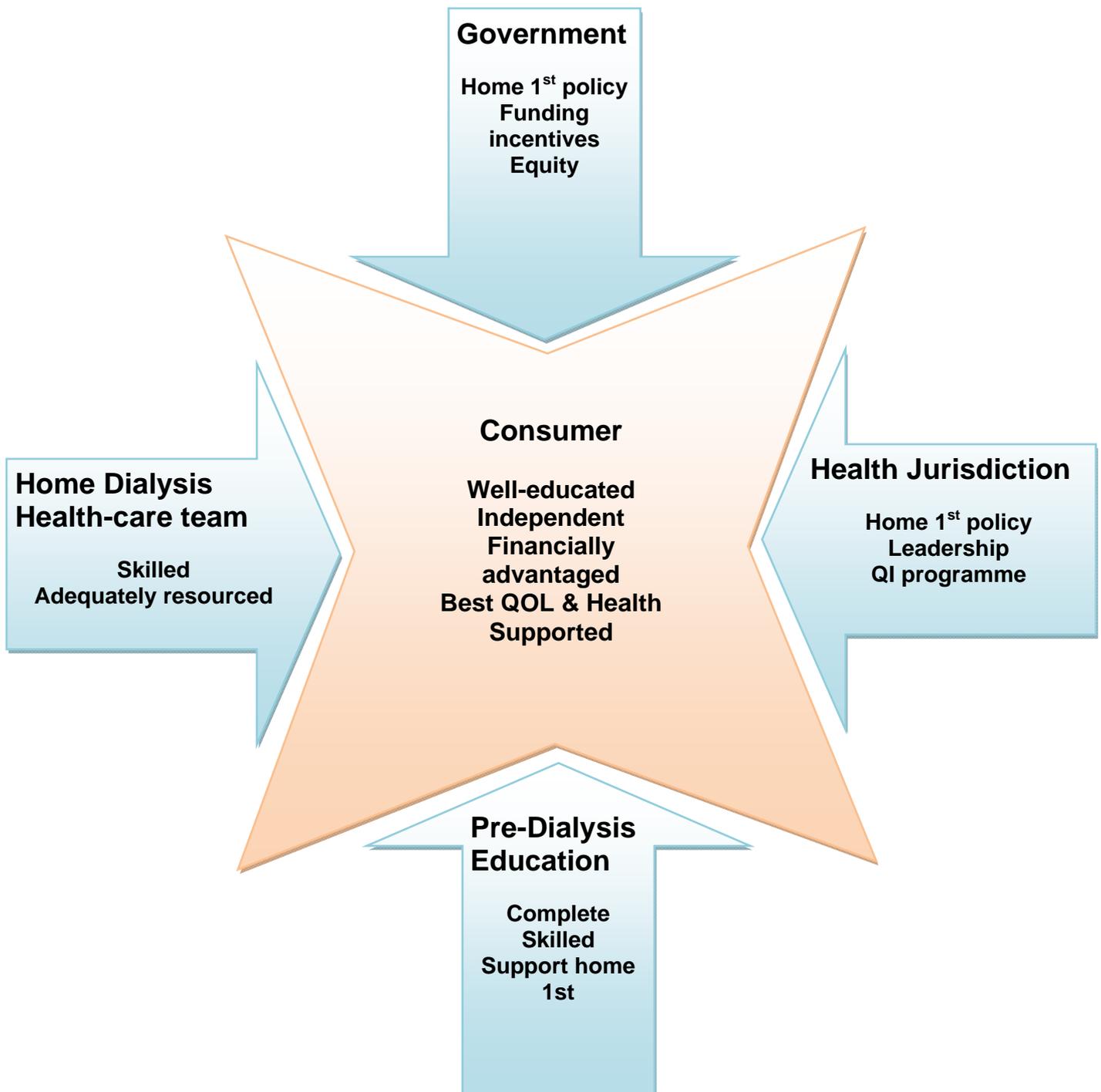
KHA estimates 'that increasing the use of home dialysis over the next 10 years would lead to an estimated net savings of between \$378 and \$430 million for our health system. Further discussion is provided in the funding aspect of this report.

Defining a Home Dialysis Model

A comprehensive home dialysis model considers multiple inputs who are all consumer focused.

Diagram 5: A Comprehensive Dialysis Model

Primary Functions of Stakeholders and Consumer Outcomes



Funding for Home Dialysis

Funding to support home

An active funding model that favours home dialysis may be controversial in a society that values right to choice but it can be effective. An example is the Hong Kong PD first model where reimbursement is only available for HD if PD is medically contraindicated.¹¹ The government in Ontario increased home care funding, assisted PD was introduced and thus increased PD rates.³⁹ In Australia funding models vary by State depending on current governments or health authorities and contract design. It is important that senior health professionals remain aware of funding opportunities and access these. As new funding avenues or structures are developed finance should be directed towards home dialysis instead of traditional dialysis chairs and institutional nursing staff.¹³

Current funding arrangements

Australian funding is derived from a mix of Commonwealth funds and grants, State funds, private health insurance companies, veteran's affairs and personal costs.^{appendix 4} Victoria has an example of a clear funding model developed to improve equity in funding.^{appendix 5} A positive federal government initiative to give home dialysis funding equity (2005) was the introduction of medicare rebate for medical support of home patients.⁴⁰ Limiting this initiative, reimbursement has not yet been extended to rural medical practitioners who also perform the role of a supporting nephrologist. Only limited funding reimbursement for Nurse Practitioners is currently available.⁴¹ There is no absolute perfect funding model but the key issue is equity and support for all aspects of home dialysis and no favour for hospital or satellite models.

Diagnostic related groups (DRG's) and activity based funding (ABF) is the current Commonwealth funding strategy.⁴² From 2012 ABF will be rolled across the whole of health and this has commenced in some States already.⁴³ In July 2012 the pricing umpire will fix costs within the Commonwealth and State pricing agreement. Capturing PD and HHD activity will be essential to obtain funding. This is an opportunity for renal to secure funding that favours home dialysis.

Cost advantages of Home Dialysis

There is clearly proven data regarding the cost effectiveness of home dialysis in Australia and overseas. KHA estimates 'that increasing the use of home dialysis over the next 10 years would lead to an estimated net savings of between \$378 and \$430 million for our health system'.⁵ 'In the US If the PD share of total dialysis was to decrease from the current 8% to 5%, Medicare spending for dialysis would increase by an additional \$401 million over a 5-year period. Alternatively, if the PD share of total dialysis were to increase to 15%, Medicare could realise potential savings of greater than \$1.1 billion over 5 years'.⁴⁴

Geelong hospital determined that nocturnal dialysis for 6 nights had a 10.75% saving on standard SHD.⁴⁶ International research supports this when reduced hospitalisations and medications are included in costing.^{47,48} It is recognised that initially training and installation costs are high and HHD is most cost-effective after one year indicating patient selection for HHD may be necessary.⁸ All analyses indicate positive cost benefits to home dialysis.

Consistently the cost of HHD is significantly less than satellite and hospital HD. CAPD is a similar price to HHD with APD positioning itself between CAPD and satellite HD depending on the providers' contracts.^{table 3} Costing usually includes the nursing component, infrastructure, equipment and consumables. Hospitalisation is more difficult to capture and not always included. Approximately for every ten persons on SHD sixteen could be financed for HHD or PD and only seven can have HD in-centre.

Table 3: Examples of weighted costings with the most common modality SHD as 1.0:

	HHD	CAPD	APD	SHD	HD (in-centre)
WA	0.46	0.57-0.62	0.83-0.99	1.0	1.7
NSW	0.55	0.55	0.55	1.0	1.23
UK	0.59	0.44	0.61	1.0	1.0
Canada	0.71	0.64		1.0	1.21
NT	0.64	0.77		1.0	1.19

WA – Draft Home Dialysis report, 12,14, 45,47

Future Funding

Assuming dialysis modality percentages remain constant, future funding must allow for the average 6% increase in prevalence, plus annual CPI, which is an estimated growth in renal expenditure of 10% per year. If this budget growth is not desirable then cost saving models such as increased home dialysis must be introduced.

Funding costs for actual programmes

Programmes include set-up costs, specifically infrastructure and maintenance costs, labour, overheads and consumables. Detailed funding analysis and considerations for HHD versus SHD have been completed in Geelong and America.^{46,47,48,49} The cost of starting a HHD programme in Canada gives clear guidelines for cost considerations.⁴⁸ The central Australia renal study details modality costs by equipment, consumables, staff and overheads.⁴⁵ There is a completed report for NSW regarding funding for dialysis.¹³ All indicate and detail cost savings for home.

Influence of Contracts

Funding models within actual dialysis contracts vary. All include capital and recurrent costs. Outright purchase of machines and consumables with care provided by health department nursing staff was the traditional model. A move towards price per treatment options that may include machines, consumables and or staffing are models that allow a pay as you go system. In WA a completely outsourced price per treatment model which includes all aspects of home dialysis was put in place in 2007. This overcame the barrier of funding for HHD and in 3 years the rate of HHD doubled.

Funding Barrier 1: Home dialysis has a cap or funding limitation preventing those who are choosing home dialysis from being placed onto the home programme.

Funding Barrier 2: The funding stream and costings are not clearly identified

Funding Activity 1: Determine if there are any limitations and if so are those capital, recurrent or policy/contract based.

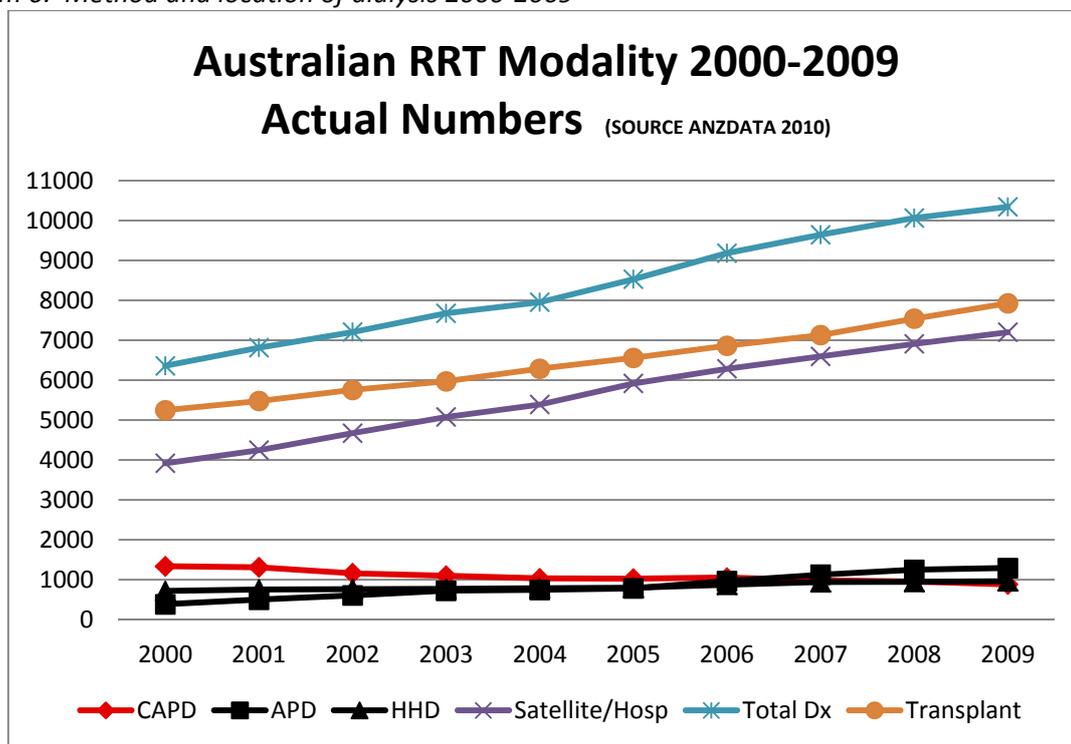
Funding Activity 2: Determine current model and potential appropriate models for the health districts concerned.

Funding activity 2: Develop a business case to lobby for a change in funding arrangements.

Government/State/Organisation Philosophy and Targets

Historically Australian State and worldwide models are clearly linked to the rates of home dialysis.¹³ Government policy, both Commonwealth and State impact on home dialysis programmes. Demonstrating this in 2009, PD ranged from 8% in the NT to 27% in NSW. HHD ranged from 2% in SA to 14% in NSW.³ In 2007, in NSW individual units varied between 12-41% for PD and 6-31% for HHD.¹³ Socio-economic factors that may influence this are local physician preferences and access to training facilities. Demographics do vary by hospital and State but do not account for the variance. Over supply of satellites does decrease rates of home dialysis although satellites that promote self-care can contribute to a positive HHD programme. If home dialysis programmes are to grow the individuals, who work in renal health care and support the patient on their journey, must understand why and believe in the principle that home dialysis is the best choice when appropriate. The ethical debate between patient choice and the ability of a State to use health dollars effectively must always be considered.

Diagram 6: Method and location of dialysis 2000-2009



Home Dialysis First

A recommended philosophy is home dialysis first; either PD or HD, with hospital or satellite only offered when home is contraindicated for any reason.^{13, 50} New Zealand (35% PD), and Hong Kong (80% PD) have developed high home ratios following this policy.^{3,17} PD first operates in 34% of surveyed Australian units with 87% encouraging home dialysis.²⁴ Prominent figures in the US now support a home first policy with the targeted education option of home or hospital not PD or HD.⁵⁰

Renal Health/Clinical Networks

All States except the NT, ACT and Tasmania have a renal health network. The role of the network is to provide strategic planning and overarching direction and leadership for the provision of renal services in each State. The networks include nephrologists, renal nurses and consumer representation. To achieve goals and benchmarks for renal care a combinations of meetings, workshops, commissioning of reports and working parties are used. Renal health networks are not the fund-holders but are advisory on health policy and pathways. Linkage with other health networks sharing common goals including chronic disease management, aboriginal affairs and palliative care is now occurring.

Documentation of philosophy

To achieve the appropriate State philosophy and targets the first step is for the home dialysis target to be written into endorsed models of care or health service plans.^{8,9,12,45} The current trend is for renal health networks to document philosophy and targets within State models of care.

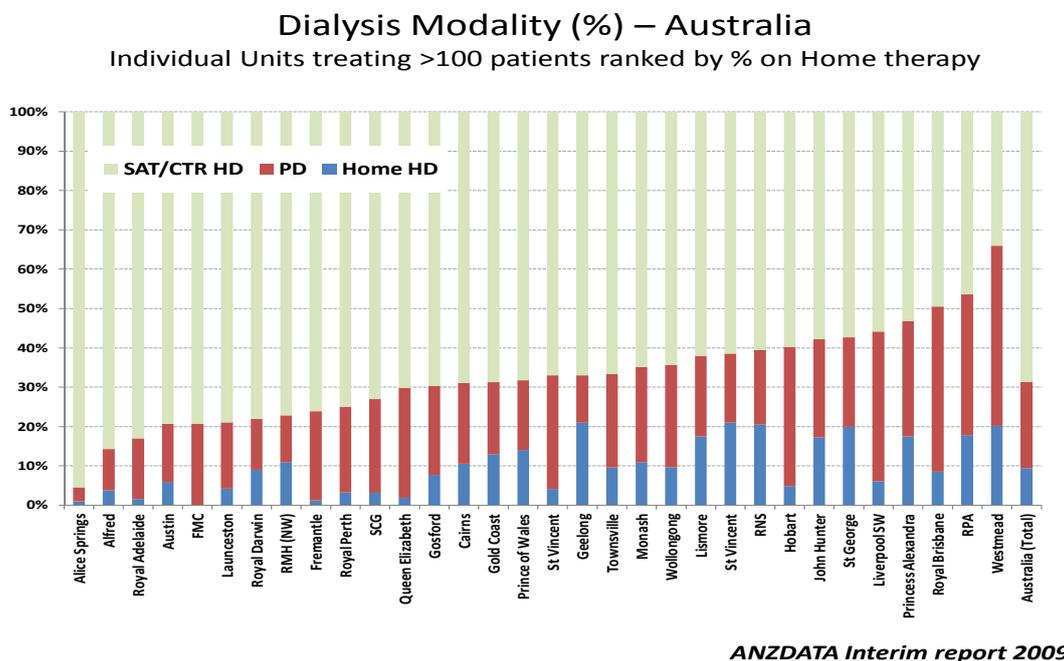
Once a philosophy is agreed upon all mission and values, educational materials, training programmes, and orientation programmes should reflect this. The QLD government have linked funding to home dialysis targets specified in the State model of care in a bid to drive a State home philosophy.⁹

Table 4: Documented State Targets (current achieved 2009)^{8,9,12,13}

	NSW	Vic	QLD	WA	NT	Tas	SA	ACT
By Year	2015	Draft	2017	2013	Not found	Not found	Not found	2022
PD	30 (27)	(16)	(20)	25 (22)	(8)	(25)	(20)	25 (11)
HHD	20 (14)	(8)	(10)	8 (4)	(7)	(5)	(2)	20 (12)
Combined	50 (41)	35 (24)	50 (30)	33 (26)	(15)	(30)	(22)	45 (23)

In reality home dialysis rates achieved by individual units show wide variance, often not meeting targets.³ Determining targets can be controversial and not accepted by all stakeholders. The ultimate target is for each hospital to achieve the national average or the New Zealand rate of 50%. Realistic targets may be less and for achievable targets a structured plan that aims for 1-2% per year, each year for a 5 year period is more attainable. Projected calculations when determining how to reach a target need to consider additional training to replace exits from programmes.

Diagram 7: Dialysis Modality (%) By Individual units. - Australia



Non-traditional home models

Whilst physical parameters may render a home unsuitable social issues may also preclude an individual from dialysis at home. Optional models for HHD still require the person to be independent in their care but the site for the dialysis is not their own home. Difficulties with water, power and cramped living conditions in housing have been overcome with community housing models as in Auckland, and WA, and self-care units as in QLD and Tasmania. Yorkshire in the UK has adopted a shared care strategy utilising a room elsewhere when HHD at home is not feasible.⁵² An alternative model could include use of satellite machines out of hours.

Auckland's shared houses allow several HHD patients attend a community house on a roster and complete their dialysis independently. The cost of the house is funded by local organisations with the cost of dialysis funded as per usual home patients by the renal programme. WA use community buildings, often aboriginal health care clinics and provide one dialysis machine for each individual that attends these premises. The cost of the infrastructure is provided by the owners of the building. QLD have self-care units. The individuals are all trained to be independent and do not require staff supervision but are housed together on a site that may be independent or attached to a satellite dialysis unit. Tasmania are also commencing this model within their training unit in Hobart.

Supported Care models

Home dialysis models utilising paid support require costing and consideration for future planning. Social restrictions can be addressed for PD or HHD with innovative care models. In an Australian consumer survey non-home dialysis respondents indicated that they were willing to consider dialysis at home if they received nursing support (47%) or professional carer support (35%) relating to the dialysis.⁶ Availability of home care was found to increase the potential PD pool from 65% to 80% of a Canadian population.³⁹ For HHD supported care may be for cannulation, one patient barrier to HHD.³⁹ Nursing homes are another option and several States have residents in nursing homes on PD.

Expertise

State philosophy and training must consider that lack of nephrologist expertise and nurse expertise can limit home dialysis programmes.¹⁴ Effective PD nurses develop over years.⁵³ Renal registrars may not readily encounter home dialysis of either modality during training instead focusing on in-centre, satellites and transplantation. Therefore once they are nephrologists it is harder to advocate for home modalities. Formal nephrologist training curriculums in Australia now include home dialysis, and it is important they see well home patients and not the hospitalised patients.⁵⁴

Marketing

Marketing regarding home dialysis may be underutilised. Recent marketing by NxStage in the USA to both dialysis professionals and patients demonstrates success in building home dialysis programmes.^{10,55} The strategies include a website that markets home dialysis to the consumer, and consumer networks.^{appendix 7} To support the philosophy that home dialysis is a good product all units should consider if they would benefit from marketing.⁵⁶ Supporting tools for marketing include electronic media and written materials. Web searches in Australia link first to home dialysis central from the USA, a deliberately designed one-stop website for home dialysis needs and information in the USA. Geelong however is prominent in searches for nocturnal haemodialysis.²¹

- Philosophy Barrier 1: Individuals or organisations may prevent a positive home dialysis philosophy.
- Philosophy Barrier 2: Realistic targets have not been determined and written into the State philosophy.
- Philosophy Barrier 3: Lack of flexibility in contracts or models to meet the individual needs of the local population.
- Philosophy Barrier 4: Local lack of expertise in home dialysis.
- Philosophy Barrier 5: No marketing strategy to support home dialysis.

- Philosophy Action 1: Determine who the barriers are. Consider and address these individually.
- Philosophy Action 2: Determine and agree upon the State/organisation home dialysis philosophy with benchmark targets.
- Philosophy Action 3: Incorporate the home dialysis philosophy with benchmark targets into all relevant written documentation.
- Philosophy Action 4: Determine local barriers and develop a model to address these.
- Philosophy Action 5: Education for nephrologist, registrars and nurses in home dialysis.
- Philosophy Action 6: Develop a marketing strategy based on fact for home dialysis.

Clinical Governance, Quality and Leadership

An effective programme requires clinical governance and leadership. For large programmes a dedicated nephrologist and senior nurse will be able to lead a programme with evidence based clinical outcomes and monitoring.^{13,52} Additionally a financial manager is an asset. In business a budget of multi-millions with potential savings of millions for alternative models would be underpinned with tight financial control. For smaller programmes individuals with passion and time specifically allocated could take the leadership roles. QLD advocate a hub and spoke model of service network and governance framework.⁸

The role of clinical leads is to;

- Support, advocate for and promote home dialysis education for all renal health care staff
- Provide financial management (with a financial manager) of the home programme
- Lead procurement processes incorporating machines and consumables
- Identify new technologies for PD and HHD and plan for timely inclusion of these^{55,57}
- Standardise policy and guideline development based on evidence based research. In 2010 only 33% of nurses agreed that their unit had a standard unit policy regarding home dialysis.⁵⁸
- Manage the quality programmes including clinical indicators (CI) and key performance indicators (KPI)
- Be a communication resource and link for metro, rural and remote
- Participate in future planning for appropriate home dialysis services
- Lead implementation and development of information technology/database systems
- Act in an advisory capacity to health department
- Develop strategies to identify those who are not yet on home programmes but could be (13% of HD patients were willing to transfer in a consumer survey)⁶
- Develop and support a patient centred philosophy

Basic data collection (for CI or KPI):

- Cost per treatment/programme
- Prevalence and Incidence with 5 year trends
- Dropout rate from programme
- Reasons for dropout
- Peritoneal dialysis – peritonitis rates
- Peritoneal Dialysis – access complications
- Haemodialysis – access complications
- Morbidity and mortality
- Time to training/Training time to home

Optional data collection:

- Did the patient have true choice
- Clinical parameters – haematology and biochemical
- Weight management
- Nutritional markers
- Adequacy
- Quality of Life indicators
- Access to conservative care or palliative care support

Standardised and appropriate national KPIs or CI's would allow for benchmarking Australia wide.

Quality Improvement

ANZDATA allows for easy national benchmarking and target determination although it is 1-2 years retrospective.³ Caring for Australians with Renal Impairment (CARI), Kidney Disease Improving Global Outcomes (KDIGO) and National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF-KDOQI) are examples of guidelines that may provide guidance to appropriate KPIs, monitoring and best practice in a wide range of topics related to CKD management and treatment.^{59,60,61} The International Society Peritoneal Dialysis (ISPD) have detailed guidelines regarding peritonitis and PD management.⁶³ Currently limited information is available specific to home haemodialysis.

Patient centred care

Home dialysis by nature has a greater focus of patient centred care than satellite or in-centre HD. For total patient centred care the focus must remain so that the patient works with the health care teams to determine the best RRT solution for themselves. At all stages commencing with diagnosis and education through to final withdrawal of dialysis the patients should sense they are being listened to and actively involved in their own care decision making and care administration. This improves patient satisfaction, reduces complaints and leads to improved recovery and emotional health.⁶³

Information Technology (IT) and databases

An effective IT system will support every role within leadership. It is also a desired and recognised tool to support effective clinical care, clinical monitoring and streamlined transition for the consumer on the renal journey.^{64, 65, 66} In most jurisdictions a comprehensive shared IT system is still on the wish list.

- Leadership Barrier 1: Inadequate funding
- Leadership Barrier 2: Lack of interest to hold this role by individuals
- Leadership Barrier 3: Politics weaken the power of the leadership team
- Leadership Barrier 4: No structure IT/database system
- Leadership Barrier 5: The model does not have a complete patient focus
- Leadership Barrier 6: No clear policy procedures and guidelines to ensure best practice

- Leadership Activity 1: Determine a business case: use the cost analysis of saving based on targets expected to cover funding
- Leadership Activity 2: Determine and recruit potential candidates for senior roles
- Leadership Activity 3: Assign the appointed leader the power to determine the future of the programme based on objective policy development
- Leadership Activity 4: Develop a business case for a database based on efficacy, effective clinical follow-up and capacity to produce KPIs leading to quality programmes
- Leadership Activity 5: Develop a patient centred focus and consult consumers for opinion
- Leadership Activity 6: Access relevant information to ensure programme is based on best practice and monitored appropriately for best outcomes

Pre-Dialysis Education

Pre-dialysis education is the most significant process in determining choice of dialysis modality. The role of pre-dialysis educators is clearly established in most programmes but time limitations may reduce the impact of this role. Only 54% of surveyed patients in 2010 chose their current modality.⁶ The recommended FTE for nurse pre-dialysis educators is not yet defined and actual rates vary widely. QLD have not determined a figure in their workforce recommendations. WA in the draft home dialysis report has determined that 1:50 new patients per year would be appropriate. Central Australia recommends 1:100 incident patients.⁴⁵

Nephrologist and Health Professional Influence

Patients are influenced by their nephrologists. This is demonstrated by the wide range in uptake of various modalities in different hospitals and even within the practising group at each site. Interestingly 7000 world-wide nephrologists felt that the most important driver for increasing home dialysis was patient motivation.²⁴ The variability in prevalence of home therapies suggests otherwise. Careful examination of programmes to determine whether co-morbidities, patient choice or personal bias influences the uptake of home is required for objective data. Personal biases and beliefs should be addressed.

A commonly held belief amongst health professionals is that age is a barrier to HHD. State HHD for over 65 year olds varies from 1.1% in W.A. to 5.6% in the ACT.³ A total of 52, over 85 year olds are at home across Australia.³ For future planning 50% of patients are in the over 65 demographic and as they are not suitable for transplantation they are an ideal static home population. With the predicted growth in this demographic they are an essential target for home.⁸

Health professional roles within education

Nephrologists have limited time for one-on-one education but importantly their role includes determining if a modality is not appropriate for medical reasons. A high proportion of pre-dialysis and also CKD education is now performed by specialist nurses. A small proportion are nurse practitioners.

A CKD or pre-dialysis educator requires:

- Good communication skills especially listening and non-verbal skills
- Intermediate knowledge of best-practice health care management (nurse practitioners holding those role have advanced knowledge)
- Advanced knowledge of the objective advantages and disadvantages of each modality
CARI guidelines details evidence re starting HD versus PD but not home dialysis ^{appendix 6}
- No subjective personal bias re a specific therapy
- Strong links and acceptance within the renal team
- Flexibility re style of teaching and willingness to use/access multiple resources
- Knowledge of relevant cultural issues and culturally specific communication skills
- Good database skills
- Membership of professional groups

Referral into Education

An official referral pathway is required to capture patients at a time deemed appropriate by the individual units. If the capacity for health education is present referral may occur at stage 2. Most units accept stage 4 or 5 with limited capacity to educate stage 3. CKD educators, specifically employed for promotion of positive health outcomes in earlier CKD are utilised in some States and these positions are increasing with many practising as nurse practitioners.

Timing of Education:

- Stage 2-3: Healthy lifestyle with renal failure
- Stage 3-4 Healthy lifestyle and introduce all options for treatment
- Stage 5 Confirmation regarding dialysis choice

Pre-education regarding modality choice should be given at stage 4-5, or 6-12 months prior to commencing treatment option.⁶⁷ In a recent survey covering 66 Australian renal units only 16% commenced dialysis with no education compared to previous statistics of 30%.⁶⁷ 92% of patients starting home dialysis had been referred over three months from their start date whereas 71% starting in-centre were late referrals. International guidelines support the notion that information is given 6-12 months prior to commencement.⁶⁷

Late Referral

Late referral is a key issue that prevents timely education. It may be late presentation by the patient, GP delay in detection and referral or a delay between the nephrologist review and pathway to the pre-dialysis educator. A pathway can solve referral delays within the hospital system. To reduce delayed referral by GPs it is important that they have access to information that can assist them to identify the appropriate referral time, WA has a referral tool.⁶⁸ Easy access to website information is important. Education of the community health professional contacts is also important. KHA administer extensive GP education programmes, operating under the umbrella of KCAT.⁶⁹

Time required for delivery of basic education:

- Minimum of two sessions of any type per individual
- Use of written, computer etc for individual to refer to after education sessions

Content of Education

Education must be delivered to promote patient choice.^{67,70} The educator needs to offer hope and find out about the patient's priorities and expectations.^{71,72} Patients and family caregivers highly value treatment that enhances survival and can be performed at home.⁶⁷ Understanding why RRT is required or the consequences of no treatment is an inevitable part of education. The practical aspects, advantages and disadvantages of each option then need discussion with positive marketing for the ideal modality to achieve best outcomes. Costs to the individual for each treatment type should be detailed. For satellite and in-centre this will be travel. For home it may be a chair and ongoing costs. Information regarding any incentives provided by the State should be available.

Education can be delivered:

- Solo with an individual and their significant others
- Group as lectures and interactive workshops
- Using media i.e. teleconferencing. webinar
- Utilising a combination of verbal, written and demonstration
- Personal experience - networking or visiting others who are experiencing home dialysis

Solo is the most prevalent method of education.⁵¹ Group can have advantages over written material but education should be one hour blocks.⁵¹ Networking and use of human resources are positive outcomes of group education. Patient narratives do influence treatment decision making.⁷² Attendance by a care partner increases home dialysis uptake.⁵¹ WA pre-dialysis educators group and KHA are currently offering co-joined 3 monthly workshops regarding modality choices which are well attended, cost effective and receive positive feedback.⁷³

Additional education sources (group and solo):

- Anaemia coordinators
- Bone coordinators
- Vascular access nurses
- Dieticians
- Social Workers
- Home training team

Recommended training materials/tools:

- Simple tool for decision making regarding suitable modality i.e. Match-D ⁷⁴
- Written information regarding normal kidney function and how peritoneal and haemodialysis replace these
- Written information regarding transplant and choosing no dialysis
- DVDs or computer links re the above
- Models/posters/demo models of dialysis machines/peritoneal dialysis equipment
- Written materials or computer links for materials that are culturally/linguistically specific
- Risk assessment tool for home dialysis

Cultural considerations:

Only 11 of 273 chronic disease programmes that were examined to determine cultural appropriateness met benchmarks.⁷⁵ Programme and education materials should be examined for and aligned with culturally appropriate resources and communication. The message to consider home must be based on the value and belief system of the individual. Many cultures say yes because they believe they should so understanding and true feelings must be checked for. Health trained interpreters must be used if the message cannot be sent and received in English.

Rural Considerations

Renal nurses in satellite units can perform the education role however they must be adequately educated in all modalities and have access to the training materials. Nurses in satellite units may have a biased interest towards increasing the dialysis numbers locally. Roving educators or teleconferencing can overcome the distance barrier. Nurse practitioners conducting remote CKD clinics would be a potential model for providing rural education and support.

Pathway via education to home dialysis

Either a paper record or electronic record is essential regarding all patients who are referred for education. This can be completed in the format of a pathway. A pathway would cover all the milestones of pre-dialysis education including social requirements, symptom management and dialysis access formation. This will allow the individuals are to receive a timely transition to home dialysis and not fall into the hospital/satellite system. MMEX and Audit 4 are IT systems that have pre-education pages or pathways.^{65,66} Of note is that education often occurs over a 2-3 year period and therefore it cannot be assumed that the individual who commences the education process will complete it.

Lost to follow-up

All efforts should be made to keep in touch with those referred into the programmes. Databases can pick up those lost to follow-up. Another group lost to home dialysis follow-up are those who commence in-centre and are transferred quickly to a satellite centre, public or private. Home Dialysis as an option should be reintroduced to this group at a later stage.

A Model for Home Dialysis – Australia 2012

Pre-education Barrier 1:	No pre-educator or inadequate hours available
Pre-education Barrier 2:	Biased educator/nephrologist not supporting home dialysis
Pre-education Barrier 3:	Late referrals
Pre-education Barrier 4:	Inadequate pathway and follow through
Pre-Education Barrier 5:	Lack of culturally specific education or educators
Pre-Education Barrier 6:	Limited computer or take home resources to consolidate teaching
Pre-Education Barrier 7:	Health care professionals inadequately informed regarding home dialysis
Pre-Education Action 1:	Educate appropriate community renal nurses at country sites. Partner with larger organisations for co-joined education
Pre-Education Action 2:	Identify biased educators and nephrologists. Promote State or district philosophy and provide objective education
Pre-Education Action 3:	Education and provision of tools to GP network to support timely referrals
Pre-Education Action 4:	Invest in a pathway either on paper or preferably electronic.
Pre-Education Action 5:	Identify the key cultures in the catchment and employ appropriate individuals or access appropriate tools
Pre-Education Action 6:	Establish an easily accessible list of training resources via sources including KHA websites, dialysis providers, overseas renal sites, pharmaceutical companies
Pre-Education Action 7:	Educate all health care professionals with accurate data

Preparing for Home Dialysis

Preparation for home dialysis will include access surgery, adaptations to home and pre-determining a suitable training time based on social needs.

Surgery - Access

It is critical for home dialysis that surgery is available in a timely fashion. Fistulae or graft that are appropriately created or placed and are able to be needled independently with good flows support a smooth and positive transition onto home dialysis. PD tubes are preferably placed 2 weeks prior to use, require effective flow and should be infection free at the time of commencement of dialysis.⁷⁶ The surgical technique by an experienced surgeon, use of antibacterial preparations, dressing techniques and timing of commencement should all follow best practice guidelines such as the CARL guidelines or ISPD guidelines.^{59,76} Nephrologists perform surgery in some countries. Focused dialysis access theatre lists that are co-ordinated by a nurse access coordinator promotes effective use of surgical time.⁶ Recommended FTE for an access coordinator in QLD is 1:200.⁷⁷

Long-term central venous catheters are an option for home dialysis and if it can be determined that the infection risks can be minimised do not have to be a deterrent. Options of using buried peritoneal dialysis tubes have had success in remote areas in WA and the NT with indigenous populations, allowing the tube to be used immediately symptoms indicate a need for dialysis. Pre-sternal PD tubes are used in limited centres, including WA, but do require the expertise of a local surgeon.

Adaptations to Home or location options:

- Space to accommodate consumables and for the HHD or APD machine
- For HHD adequate water supply and drainage that must be directed to the dialysis room.
- For HHD a reclining chair or bed
- Permission for HHD alterations if a home is rented privately or from the State
- A move may be required to more suitable accommodation
- Source alternative dialysis location i.e. Community centre, bus, out of hours satellite

To promote home therapies for the consumer it should be cost neutral. Basic plumbing and electrical costs are an integral part of many home dialysis installations and require consideration regarding who is responsible for the costs. Victoria currently have a funding incentive of \$503 per PD patient and \$1,327 per HHD patient per annum.⁷⁸

Role of Allied Health/support services

If rehousing is required the social work team are critical for support in this area. Individuals may also become eligible to access superannuation and new pensions and again social work can advise. One recommended FTE for social work is 1:125, with other supports being the dietician 1:150 and psychologist 1:200.^{45,77} Determined by the needs of the local populations an allocation of allied health time, referral pathways and use of community resources to support this must be determined within the education model. Community resources must not be forgotten and GP referrals can be made for psychologists allowing up to six visits for example. Multidisciplinary CKD clinics are an optional model that may link all services.

Pre-determining a training time

For HHD particularly, but also for PD, training may be preferred considering school holidays and time off work for either the patient or their care partner. A structured introduction via a self-care satellite unit with a planned time for intense HHD training may shorten training time and interruptions to work schedules. Many individuals have a window of opportunity to start dialysis and if flexibility can be offered to them within this window it can increase their acceptance.

Pre-training

For HHD if the satellite and hospital units operate in close collaboration with the home training unit (HTU) they can commence self-care. Any procedures taught prior to training should mimic those of the home dialysis training unit. The advantage of prior training is reduced training time at HTU and a diminished fear of having the capability to learn. For the staff at the satellite sites training time is returned when the patient can perform certain functions for themselves saving staff time.

Rural Factor/Travel and Accommodation:

Rural patients rarely have a training unit close by due to lack of concentration of numbers. Family impact for a HHD train can be intense and this group can benefit the most from early training at local satellites. Patient assisted transport schemes can provide financial reimbursement for travel (15-19c per km) and accommodation (\$30-60 per night).⁷⁹ The system varies by State and details are available via the KHA website (patients/financial assistance).⁸⁰ A novel solution in W.A. is the faith house leased by KHA and furnished by Lotteries West which can be used by home training patients when available.⁸⁰ The cost to the patient is covered by the WA PATS system.⁷⁹

Transition to the Home Dialysis Unit

- Meet the home training staff and visit the HTU
- Pathway for transition including information regarding access and parking at the site
- Commence self-care at the current HHD facility if transitioning to HHD

Preparing Barrier 1:	Surgery waitlist and lack of access coordinator
Preparing Barrier 2:	Ineffective surgery
Preparing Barrier 3:	Cost of preparing home or relocating
Preparing Barrier 4:	Inadequate social work support
Preparing Barrier 5:	Lack of accommodation or travel assistance with anticipated cost to patient/carer during training i.e. travel, lost earnings
Preparing Barrier 6:	Waitlist for larger or appropriate rental housing/community centre
Preparing Barrier 7:	Poor planning and communication for transition
Preparing Action 1:	Collect data and lobby for increased surgical time, access coordinator based on cost savings if patients transitioned earlier
Preparing Action 2:	Collect and monitor data re access failure
Preparing Action 3:	Collect data and participate in lobbying for out of pocket expenses
Preparing Action 4:	Prepare business case to increase social work to appropriate levels
Preparing Action 5:	Obtain social work support to establish a local resource list and application forms for current financial, travel and accommodation support for training
Preparing Action 6:	Consider training models of care where patients commence training as per official curriculums at their current satellite/hospital dialysis unit with fine-tuning at HDU
Preparing Action 7:	Develop and implement a concise transition pathway

Infrastructure for Home Training Units and Home

Home Training Units Location Options:

- Co-located in-centre at hospitals
- Co-located with satellite in the community
- Stand alone in the community
- Train at home

These are the typical characteristics of many training units and State models of care across Australia. Distance from the parent hospital decreases the direct access to support resources but often improves the physical training space and access for the individual. For stand-alone units co-operative support partnerships with hospitals and satellites are required for best delivery of care. Australian nephrologists reported lack of physical infrastructure for training impeded their HHD (38%) and PD (26%) programmes.²⁴ Nurses reported higher rates for HHD (59%) and PD (40%), which may be influenced by them actually working in the environment.⁵⁸ Despite this Morton 2010 reported that only two PD and zero HD of 721 patients were not given information because there was no training facility, indicating that health care staff work around the inadequate facilities.⁶⁷ Improved outcomes have been reported in PD patients trained at home.⁵⁶ Training in the home can have risks and travel pressures for staff.

Table 5. Comparison of Location Options

Criteria/Access to	Hospital	Satellite	Specific stand alone	Home
Nephrologist on site	√√√	√√	√	
Training Nurses	√√√	√√√	√√√	√√
Allied Health on site	√√√	√	√	
Visibility of home training	√√√	√√		
Proximity to home (metro) & parking	√	√√	√√√	√√√
Proximity to home (rural) & parking	√	√√√	√√	√√√
Safety and security	√√√	√√	√√√	√√√
Specialist nurses i.e. anaemia	√√√	√	√√	
Appropriate train space	√	√√	√	√√√
Home like environment	√	√	√√	√√√
Options to commence training pre HTU	√√	√√√	√	√

√√√ - Constantly available

√√ Intermittently available

√ Occasionally available

Physical requirements:

- Training/clinic rooms – solo and group options are ideal
Note minimal room sizes may apply according to State legislation
- Storage space including for spare equipment/wheelchairs
- Office space for nurses, nephrologists
- Dirty utility room
- Rest room/kitchen/lounge areas for staff and patients
- Reception/admin areas and storage
- Computers
- Safety systems i.e. fire and safety, to meet OH&S requirements and State licensing
- Training resources – DVD players, TVs, Whiteboards, written materials

Dialysis Equipment and Consumables

Complexity of equipment is an identified barrier to home dialysis²⁴

Dialysis machinery for HHD and PD and water treatment equipment must be

- Proven to be safe and effective (Therapeutic Goods Administration governs this)⁸¹
- Cost effective – consider machine and consumables
- User friendly
- Be reliable and have ongoing efficient technical support for equipment failure
- For home preferably be portable

All equipment should be evaluated considering objective criteria. Alternative providers may excel in one area over another and therefore flexibility in choice of equipment will maximise outcomes. However contracts to one provider may be more financially competitive. Current Australian providers are Baxter (PD only), Gambro (HD only) and Fresenius (both HD and PD). NXstage is a new technology HHD machine developed to overcome traditional barriers⁵⁵ and following positive uptake in the USA is currently on trial in Australia. Sorbent technology is also currently under review for home haemodialysis.⁸² It is anticipated that many of the dialysis providers will be offering new technology for HHD in the near future and as it becomes available this will expand programme options and consumer choice. Of note NZ has high home dialysis rates using all standard single pass dialysis machines successfully and no access to the most recent innovations.⁷ In the UK a document has been written as a buyer's guide for home haemodialysis equipment.⁸³

Contracts vary considerably, for example in Victoria every unit is responsible for their own equipment and has the freedom to purchase as preferred, Sydney dialysis centre purchase equipment on a contract for multiple areas and WA operate with a seven year contract to one provider for the State. If these contracts are exclusive to one provider and operate for a number of years there are limitations to the use of new products as they are released on the market. The longer and more exclusive contracts however may allow for agreement on a more favourable cost. The cost to the consumer of any consumables or equipment within the contracts should be zero. However different State contracts and inclusions within these contracts mean that consumers may have to purchase health monitoring equipment, hand hygiene solutions, dressings and pay to have additional deliveries.

Regulations - Electricity

Mandatory legislation, AS/NZS 3003:2011, that mandates individualised electrical circuits for HD and APD machines is potentially a barrier for all but especially for those in older properties, rental properties or units.⁸⁴ The requirement is for a separate circuit for all haemodialysis equipment plus a 10mAmp circuit breaker that can be reset by the person on dialysis. The new legislation took effect mandatory effect from April 2011 and may add up to \$1,000 on the cost of installation for HHD and APD.⁸⁴ It does not apply to existing installations. The specifics regarding travel with a portable machine are not considered but common-sense suggests the use of a circuit breaker must be applied. Protocols and policies regarding home dialysis must consider this legislation. Training units must also apply this legislation.

Regulations – Water

There are no Australian national standards, with different States developing different policies based on the American, European or ISO guidelines and local expertise.^{85,86,87,88} The training unit must complete water testing in line with State considerations and consider on-install and maintenance microbiological testing, hard water analysis, daily chlorine tests, and possibly endotoxin testing. A test for heavy metals is standard when a property is inspected for potential for home dialysis. Annual water testing can be achieved with annual machine maintenance in most cases. Trained technicians or nurses may perform this role.

Management requirements:

All home training units will require a structured management process to ensure there are systems and policies to promote best patient outcomes. It will include:

- Policy and procedures – dialysis, infection control, human resources, OH&S
- IT systems i.e. patient databases, risk management systems, clinical care system

Training Hours

Many units operate a business hours training unit. This is prohibitive to workers and those whose carers work. Patient centred units are innovative in how they offer training schedules. Small training units with a small training team will reduce the ability of a unit to be flexible and in many units unfortunately this is the norm. Co-location with a satellite unit may allow increased flexibility. Returning to satellite for one treatment a week also increases flexibility and has been done successfully.

HDU Barrier 1:	Lack of proximity and easy access for the patient
HDU Barrier 2:	Inadequate space and resources for effective and private training
HDU Barrier 3:	No direct access to nephrologists, allied health and specialist nurses
HDU Barrier 4:	Limited hours training available
HDU Barrier 5:	Lack of relevant policies and procedures to meet legislation and maximise patient safety
HDU Action 1:	Review location of home training and considering above required factors determine if a move is feasible and advantageous
HDU Action 2:	Establish referral pathways, outpatient systems and possible multidisciplinary clinics for HDUs, either at the hospital or on-site.
HDU Action 3:	Consider the use of telemedicine, GP networks, home visiting teams to manage ongoing care.
HDU Action 4:	Think outside the square re hours for training with flexible rosters and staggered staff. Develop partnerships with satellite units for some treatments if required.
HDU Action 5:	Develop policy and protocols that incorporate current legislation

Environmental Factor and Carbon Footprint

The design of a home training unit or the style of a home installation can alter the carbon footprint that is created and be more environmentally friendly.

Geelong dialysis unit in Victoria have led the way with a green model for dialysis.³⁸ Green models may not increase programme uptake but it is a positive for the environment. Recycling of waste, water and buildings that minimise power costs or use reusable energy sources are all areas for consideration.³⁷

Carbon footprint

HHD using standard energy sources creates a carbon footprint with emissions (37%), energy use (27%) and travel (20%).³⁶ In the UK it was determined that one in-centre HD patient has a carbon footprint of 3.8tonCO₂Eq per year. At home on standard dialysis equipment the carbon footprint increased determined by the hours on dialysis up to 7.2ton for a 6 nightly nocturnal regime. The lack of need for travel saves approximately 1 ton. The new technology of NxStage reduces the carbon footprint.⁵⁵ The electricity consumption is 0.1kWh compared to 1.29 kWh for a standard machine and water treatment equipment. For 6 nightly nocturnal it was estimated to require 2.1ton. This may be a future consideration when choosing dialysis equipment.³⁶

Water

Water recycling is an important consideration and with minor modifications can be achieved. A typical dialysis patient uses 80 000l of water per year.⁸⁹ Recycling of reject reverse osmosis water alone can reduce water consumption by approximately 60%.⁸⁹ Alternative use of grey water for gardens is also a consideration although this may be inhibited by council regulations that assume dialysis water is contaminated. For individuals reliant on the use tank water, recycling is essential.

Energy

The use of solar or wind power to provide electricity is also the future. This is positive for the environment and the energy bills. Some councils and energy schemes provide rebates for use of solar power. This is a consideration for future home training dialysis units. Geelong in Victoria are using solar power and claiming government subsidies.³⁸

Recycling

Recycling of plastic and paper waste should be accessed when possible. Local councils will advise on local regulations. Fresenius use biofine, a plastic free from DEHP in their PD consumables.⁹⁰

Environment Barrier 1:	Lack of knowledge regarding environmental impact and how to minimise this
Environment Barrier 2:	Equipment that creates a high carbon footprint
Environment Barrier 3:	Recycling not available
Environmental Action 1:	Consult an expert and develop environmentally friendly installations
Environmental Action 2:	Consider the environmental impact of the equipment during tender processes
Environmental Action 3:	Approach councils or private companies re the option of recycling

Home Training Process

Ratios of nursing staff need to be adequate to allow one-on-one training where required. Commonly accepted ratios for HHD are 1:15 and for PD are 1:25 including:

- Training
- Ongoing support at home

It is recognised that indigenous and remote are factors that increase the need for lower patient ratios. QLD renal clinical network in 2010 determined a ratio of 1:10 for HHD and 1:15 for PD as desirable and for review in 2011.⁷⁷

Staff characteristics

A home dialysis training nurse benefits from:

- Good communication skills particularly listening and non-verbal skills⁵³
- Advanced knowledge of the modality of dialysis including trouble shooting
- Patience, empathy and approachability
- Knowledge of principals of adult learning and ability to use these⁵³
- Knowledge of the different learning styles with reference to generational types
- Flexibility regarding style of teaching and willingness to use multiple resources
- Knowledge of relevant cultural issues and culturally specific communication skills
- A structured orientation, initial training and ongoing education⁵⁵

Lack of nursing expertise is a barrier to home dialysis for 30% of units according to nurses.⁵⁸ Skills of a PD trainer are augmented over a period of years.⁵³

Patient Training Components

- Demonstration and practice
- Visual pictures detailing how to perform the practical skills required
- Written/multimedia information re all aspects
- Theory to support rationale
- A check learning and competence component
- Trouble shooting
- Revision component

Training Curriculum

A structured training curriculum to encompass all of the above is the foundation of a good training programme.⁵³ A 2010 survey by the Australian HOME network revealed many gaps in resources and gaps by nurses in knowledge of existing education resources.⁹¹ Industry are acknowledged as providing specific product training information and handouts. Training tools need to be intellectually, language and culturally appropriate.^{53,75} Strategies are required to identify and support patients who are not literate. Documentation of progress is essential as multiple trainers are involved in many trains. It also provides back-up to demonstrate achievement of a skill if issues occur later. Training can be considered completed when competence is achieved.

Training Location

Options for training locations should be considered to maximise the learning opportunities for the individual.⁵³ The training unit may be appropriate for many and with clinic rooms, demonstration equipment and support for the trainer suit many training partnerships. However for the frail, aged, and those with transport difficulties or social dependents there may be occasions when a home train is more effective. The disadvantage for a home train is the travelling for the trainer and some environments that are not ideal for training. However the HTU should endeavour to have flexibility when it is thought the individual will benefit without detriment to the training team.

Possible Training fears:

- Fear of blood and blood spills
- Fear of needles
- Fear of giving themselves peritonitis
- Fear of machines
- Fear of being at home alone during emergencies

Any fear has the potential to be a barrier to achieving success at training. Early identification, acknowledgement and then strategies to overcome these fears will limit the negative impact. Sharing information such that it is rare to find a patient who can self-cannulate then allowing a nurse to insert the cannulae may foster confidence. Integration of peers, trusting relationships, gentle persuasion, hypnosis and assertive encouragement all supported with accurate information and a degree of autonomy are techniques that may overcome fears. Provision or recommendation of specialised equipment such as a blood monitors to detect needle dislodgement are practical solutions.

Care partners or support partners

Support is essential but dependence on another often has negative consequences. Support partner burn-out, and support partners becoming unavailable is a high risk. Loss of earnings can be significant. Nurses identified this as a primary issue for home patients.⁵⁸ To minimise dropout the patient should be made as independent as possible and in reality most can go solo with either HHD or PD.⁷ Care partners can learn the trouble-shooting and how to support whilst their most important role may be socialisation. Care partners require referral to social workers to ensure they gain all relevant available financial support. Home dialysis patients often do not meet current centre-link requirements meaning their carers are ineligible for the carers' pension.⁹⁸

Documentation and Consent

Electronic documentation is gold standard.⁶⁴ Generated data can also be used for reports and KPIs. Systems on the market include MMEX and Audit 4.^{65,66} IT systems should be networked and secure with the ability to link all members of the multidisciplinary team. Ideally it will be the same database as for pre-dialysis and then training data can be uploaded and ongoing care continue. Options for laptops and remote access increase the potential for streamlined care.⁶⁴ Documented consent to treatment serves two purposes. A correctly executed consent ensures the individual is adequately informed and confirms that they have agreed to undertake dialysis at home with its risks. Whilst there have been no court cases related to home dialysis to date this may occur in the future.

Training Barrier 1:	Inadequately skilled staff
Training Barrier 2:	Cultural/language inappropriate staff
Training Barrier 3:	Ad hoc training curriculum
Training Barrier 4:	Difficult to use equipment or consumables
Training Barrier 5:	Fears that block learning
Training Barrier 6:	Inadequate documentation capacity or access to pre-training information
Training Barrier 7:	No consent process
Training Action 1:	Up-skill staff with formal orientation and ongoing training programmes
Training Action 2:	Recruit staff with appropriate skills
Training Action 3:	Establish a formal training curriculum and pathway
Training Action 4:	Collect data on equipment failures or difficult to use consumables. Report these to the providers. Use objective equipment analysis criteria
Training Action 5:	Identify any training fears and determine individual solutions
Training Action 6:	Determine and implement a suitable IT solution
Training Action 7:	Establish a consent form and policy with a strategy for renewal as deemed appropriate.

Transition to Home

Quality of care at home

Dialysis at home must be as safe as dialysis in a hospital. Attention to emergency procedures on dialysis, application of industry guidelines, ongoing monitoring and disaster planning should all be included. Canada have published guidelines for safe installation and operation of haemodialysis and peritoneal dialysis in a home setting in November 2010.⁹² These guidelines cover all aspects of safety regarding dialysis at home including electrical, plumbing, quality management, waste management and disaster preparedness.

Deliveries and set up of supplies

Delivery of machines and consumables can be overwhelming and support to arrange stock will enhance a smooth transition. Purchase of items including scales, tables, chairs, and intravenous poles may be required depending on the contract each unit has. Many units provide these items for hardship cases at minimum even if it is via fundraising sources. Cost-neutrality for the patient is the goal in a programme encouraging home dialysis.

HHD Technical Installation

Prior to commencement of HHD an experienced technician will perform a home assessment. Availability of reliable power, water that reaches the required pressure and the ability to connect the machine to the sewage system are evaluated. Plumbers and electricians support the installation process which includes modifications to the water supply to deliver it to the required room, installation of a separate and protected electrical circuit and connection to a drainage outlet. Bore water, tank water, septic tanks, and old electricity circuits are all hurdles that can be overcome with time and money. The costs of installation are usually paid for by the health system but if costs exceed usual averages the individual may have to contribute to the cost. Given the savings gained by HHD it is recommended that this be made cost neutral.

Technique assessment

For peritoneal dialysis witnessing a minimum of one bag exchange in a home environment is mandatory. This allows for evaluation of peritonitis risk factors and has immeasurable benefits to understanding the family dynamics. Social issues will account for 42% of technique failure withdrawal. Peritonitis will account for 22%.³ For haemodialysis a minimum of two treatments is usually recommended or until the patient can complete the dialysis without physical support from the home training nurse. For haemodialysis a carefully timed plan involving the technical installation and consumable delivery and the nurse supervision must be coordinated. Effective and extensive communication with a discharge to home pathway can smooth this transition.

Medications and Administration of specialist drugs

A supply system that avoids a return to the hospital is preferable. The cost of medications, especially the anticoagulants, to the patient should equate to costs for in-centre patients. IV iron and erythropoietin can be safely given on HHD. Alternatively local clinics or community nursing services may administer these solutions. The aim is to develop a policy and provide training to reduce the need for a return to an in-centre for routine drug administration.

Waste removal and sharps disposal

Council regulations govern this area and do vary so it is important to check local regulations at present. In some States dialysis waste can be placed in domestic waste for both PD and HD. WA have a detailed policy.⁹³ Council misunderstandings regarding the risks of PD waste can result in expensive disposal methods that are unnecessary. Remote clinics in WA and NT have developed incinerators or link into existing medical services for waste removal. Sharps can usually be disposed of via chemists or the HTU.

Each HTU clinic should have written and up-to-date information for its own regions. If a cost will be incurred this should be reimbursed.

Community Education

Education of local supports i.e. GPs, community nurses and local hospital emergency departments will extend the capacity of the support at home especially for remote and rural patients. The USA has a higher dropout rate attributed to variable support.¹⁷ Indigenous are identified to have better outcomes with close and regular support networks.⁷⁵ The home dialysis nurse does not usually have resources for face to face checks with all home patients so clever use of alternative resources needs to be harnessed.

Transition barrier 1: Poor planning and coordination
Transition barrier 2: Inability to provide installation support
Transition Barrier 3: Costs to the individual

Transition action 1: Develop a clearly defined discharge to home pathway
Transition action 2: Incorporate home install visiting into nursing FTE and develop business case if needed to obtain funding
Transition Action 3: Reimburse all costs of dialysis

Support at Home

Best practice incorporates home visiting weighted towards those most at risk and the first year at home. Ongoing monitoring by qualified professionals who understand home dialysis is required. A formal guide to recommended ongoing surveillance can be found in the Hunter health care management booklet.⁹⁴ Options for daily assistance and support at home dialysis are also being considered by many programmes and lack of this has been identified as a major hurdle that may restrict home dialysis.⁶⁰

Follow-up Options:

- Casual phone-calls to HTU as required
- Email or electronic support techniques
- HTU clinic visits to assess clinical criteria and bloods
- HTU clinic technique assessment
- Home visits for clinical criteria and bloods
- Home technique assessment
- Phone check-ups
- Teleconference
- Tele-monitoring (a debateable and expensive monitoring tool)
- Nephrologist visits
- Allied Health visits

On-call

Technical and nursing supports are equally important. Dialysis equipment providers usually have 24 hour 1800 help-lines for technical issues. For clinical issues a 24 hour nursing support is also required.

Options are:

- Home dialysis nursing team (wards involve payment of an on-call allowance)
- Ward nurses specialised in renal
- In-centre dialysis unit nurses with skills in PD and HHD
- Centralised call service by a private provider
- Provider customer service for consumable requirements
- Attendance at emergency departments for urgent health issues

Gold standard is to have an individual on-call who knows the patient and has access to their medical records to personalise management of the call. Language barriers, fear of talking on the phone and lack of phone in remote areas or for economically disadvantaged groups are all barriers to on-call use.

Allied Health

Social workers, dieticians and psychologists should be a regular part of the programme. FTE ratios set by QLD include a 1:70 social worker; 1:100 dietician; 1:200 psychologist.⁷⁷ Aboriginal health care workers are invaluable for programmes with high ratios of indigenous clients allowing culturally supportive education and support.⁷⁵ Unfortunately allied health resources are often not built into home dialysis programmes and the role has to be filled by nurses. Multidisciplinary clinics that incorporate allied health would maximise good access to social support, dietetic support and strategies to cope with long-term maintenance dialysis as well as support those looking to end their time on dialysis. Occupational therapists are utilised by some programmes to overcome personal physical barriers to home dialysis.

Indigenous Factor

Lack of secure accommodation, insufficient services, lack of respite and lack of interpreters are all issues that may prevent transition to or reduce time at home.⁴⁵ It is therefore essential that nursing links with social work and aboriginal support services to address these needs and offer support.

Symptom Management

Any symptom which is impacting on life should be assessed utilising expertise and specific tools. Priority should be given to identification and implementation of a solution.⁹⁴ Pain, itching, restless legs and insomnia are symptoms that may be improved. Nephrologists, nurse practitioners and referral to a specialist symptom management team (palliative care) can support patients in this area.⁹⁵

Healthy lifestyle

Promotion of healthy eating and moderate exercise are often overlooked, but with the co-morbidities of this group may have health benefits. Exercise will reduce the risk of falls. Annual dental check-ups and podiatry support for diabetics are simple factors that promote health, and that can be encouraged with attendance monitored by the home dialysis team.

Ongoing Delivery of consumables

Monthly is standard. A system must be developed with the provider that is user friendly, effective and accurate. Few components of dialysis are non-essential and backorders lead to stress and inability to dialyse. For remote patients delivery networks must be assessed as the consumables may have to transition via multiple haulage companies. Systems where excess consumables are delivered or additional deliveries required are costly for the providers and hospitals.

Financial Reimbursements and concessions

Ongoing carer payments, disability pensions, electricity and water rebates, medications costs, and dialysis consumables that must be paid for are all areas of concern that require attention.¹¹ KHA has detailed the current energy and water reimbursements by State.⁹⁷ If in-centre incurs none or minimal cost to the individual then home must provide a comparable structure. Health monitoring equipment, dressings, heparin, and EPO are amongst the items that may be of cost in some States. Carer pensions and payments are administered by centrelink.⁹⁸ Currently dialysis is not a criteria for eligibility but assistance with daily living is.⁹⁸

Holiday Dialysis

PD affords an individual the freedom to dialyse at alternative accommodation. For HHD holiday dialysis can be more difficult. Patients must be educated about how to organise travel. Whilst all costs are covered within Australia additional costs may need to be paid by the individual for overseas. For HHD access to a satellite is usually the only option. KHA provide holiday dialysis information.⁸⁰ Dialysis equipment providers have lists of the destination options available for holidays, including international possibilities and restrictions, accessed via dialysis units and customer service. Dialysis escape line run two cruises per year for both HD and PD patients.⁹⁶ If portable technology HHD machines becomes available in Australia travel opportunities for HHD will change. Difficulty in obtaining insurance is an ongoing issue.⁸⁰

Creative holiday models for home dialysis include dialysis machines in caravans and boats, use of a dialysis bus, dialysis houses that are State managed and funded by various sources.

Respite

Lack of respite was identified by nurses as a primary barrier to home dialysis.⁵⁸ Nursing homes can rarely provide this service and if available it does incur a daily cost equivalent to the aged pension. The potential resident must have an aged care assessment completed.

Few programmes offer nurses or a paid carer that could visit the home even on a temporary basis. With the growth of home care, silver chain services, funding for community programmes and DVA programmes there may be untapped resources in this area that should be investigated locally. Additional fee for service systems may also be an option that a number of patients would consider. Some new clinics are being built with the option for HHD respite in specially allocated chairs or by the use of training spots if available. It is still not a priority but requires increased consideration.

The function of respite may need to be widened and for families providing assistance with general living may allow them the time to focus on the dialysis with less stress. General home assistance would be easier to administer. Savings gained by the use of home dialysis can contribute to home dialysis respite.

Support groups

KHA offer a network of support groups that is growing.⁹⁹ The UK have similar groups.¹⁰⁰ These offer the individual friendship and support from others who are experiencing similar life challenges. It is important that home training teams acknowledge this need given the number of patients who stay in-centre for the company. Increasingly facebook groups and chat rooms are appearing with a dialysis focus.

Natural disasters

Home dialysis individuals must be considered in business continuity plans related to dialysis. Canada have Stated that each unit must have a disaster plan.⁹² NxStage have released a downloadable booklet for consumers.¹⁰¹ WA developed a complete collaborative business continuity plan for dialysis involving home dialysis.¹⁰²

Support barrier 1:	Inadequate FTE for nurses, allied health
Support barrier 2:	No structured follow-up programme or on-call service
Support barrier 3:	No system to manage debilitating symptoms
Support barrier 4:	No respite/holiday plan or availability
Support barrier 5:	Perceived and actual financial disadvantage
Support barrier 6:	Lack of local support groups
Support barrier 8:	Home dialysis model does not allow for supported care at home
Support barrier 9:	No plan for natural disasters

Support action 1:	Develop business cases and lobby for appropriate FTE
Support action 2:	Develop and implement a structured follow-up pathway
Support action 3:	Establish a model of care and referral pathway for symptom management
Support action 4:	Lobby for respite, consider nursing homes, care in the home
Support action 5:	Determine and document actual financial burden and lobby for reimbursement
Support action 6:	Liaise with KHA re setting up support groups or motivate a local individual
Support action 8:	Consider home dialysis models that allow supported care in the home
Support action 9:	Develop a business continuity plan and brochures for individuals

Retention on the Programme – Minimising Risk Factors

Stock and flow and the influence on Home Dialysis Numbers

Of a total 10,135 patients in the programme in 2009, 2534 were new patients who entered the programme. 1671 died and 813 were transplanted. Dropout averages 25% for HHD and 40% for PD.³ For PD this indicates that at minimum for every 2.5 patients in any programme one new patient will require training each year for numbers to remain static. For HD it is 1:4.

Table 6:

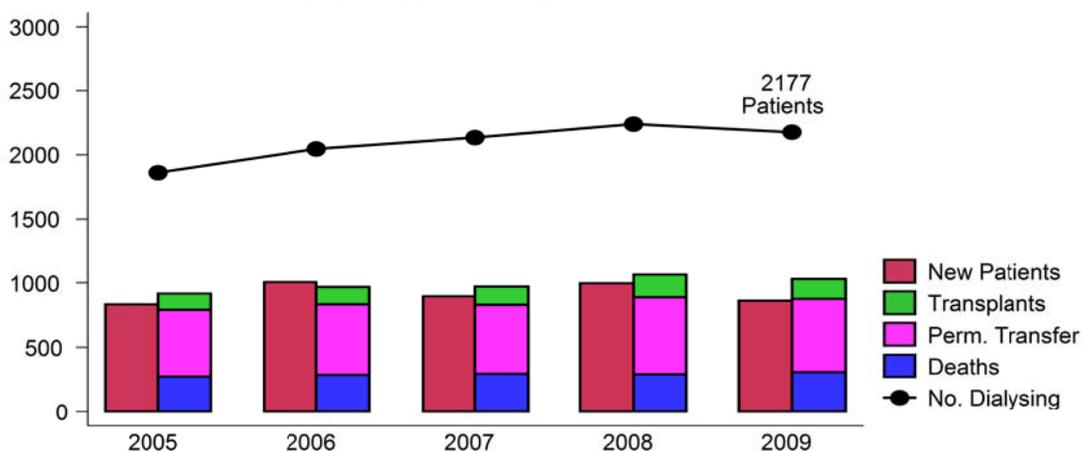
Figure 1.9							
National and State Stock and Flow 1-Jan-2009 to 31-Dec-2009							
() 31-Dec-2008 Figures							
State	New Patients	Transplant Operations *	Deaths		Dialysis Dependent	Functioning Transplants # *	Total
			Dialysis	Transplant			
Queensland	486 (531)	136 (140)	310 (337)	27 (47)	1944 (1881)	1567 (1485)	3511 (3366)
New South Wales	717 (805)	222 (223)	489 (472)	53 (49)	3374 (3346)	2232 (2127)	5606 (5473)
Aust. Capital Territory	41 (61)	14 (14)	27 (35)	4 (3)	239 (235)	199 (197)	438 (432)
Victoria	541 (537)	211 (219)	346 (311)	18 (28)	2513 (2476)	2028 (1887)	4541 (4363)
Tasmania	53 (54)	20 (26)	27 (28)	1 (3)	194 (179)	190 (177)	384 (356)
South Australia	195 (185)	82 (106)	107 (102)	17 (21)	670 (629)	861 (829)	1531 (1458)
Northern Territory	72 (89)	5 (4)	43 (57)	4 (3)	418 (397)	68 (74)	486 (471)
Western Australia	232 (272)	82 (81)	176 (149)	51 (52)	989 (992)	781 (745)	1770 (1737)
Australia	2337 (2534)	772 (813)	1525 (1493)	141 (178)	10,341 (10,135)	7926 (7521)	18,267 (17,656)
New Zealand	567 (497)	121 (122)	331 (360)	34 (28)	2260 (2102)	1379 (1325)	3639 (3427)

Patients lost to follow-up are not included * Resident State

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Diagram 8: Stock and Flow of Peritoneal Dialysis Patients

Stock and Flow of Peritoneal Dialysis Patients Australia 2005-2009



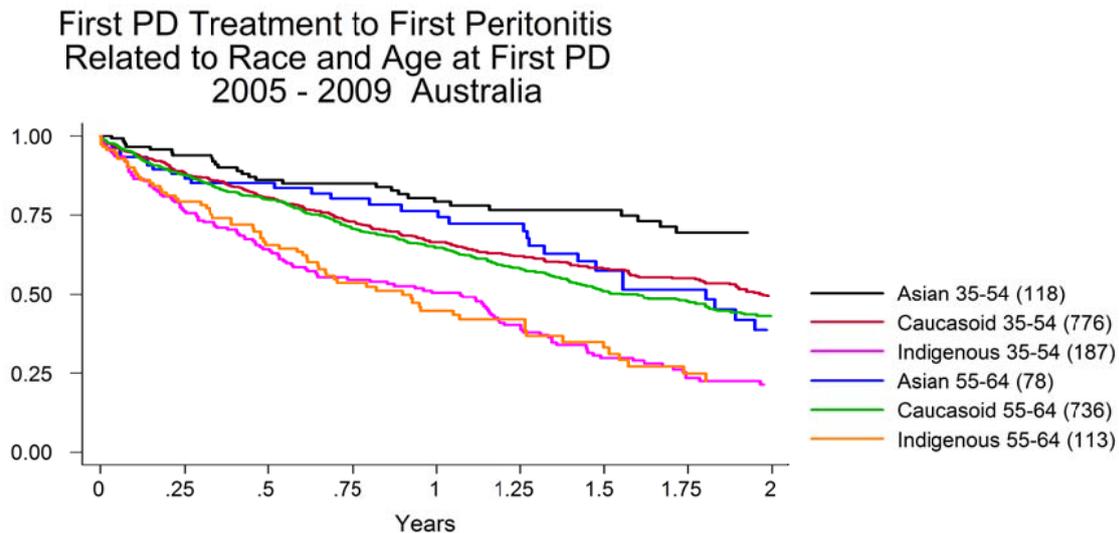
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Technique failure including peritonitis and social reasons accounts for 55% of PD dropouts. Currently more patients leave each programme than are trained per year. This churn is approximately 40% of the numbers on the programme. The primary reason for leaving HD programmes is death at 50% and transplant at 25%.³ HHD withdrawal has a weighting towards transplantation.

Monitoring of risk factors

In peritoneal dialysis programmes turnover is 40% per annum. Only 4% remain on PD after 5 years.³ Withdrawal causes (excluding death) are infectious complications (27%) and social or technique failure with 5% unable to self-care and 37% by choice – reason unspecified. 14% fail to clear adequate amounts of fluid and/or electrolytes.³ HHD dropout at 25% includes cardiac related death.³

Diagram 9: First PD treatment – Time to Peritonitis



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At minimum a unit must monitor its dropout rates with reasons and benchmark to comparative populations. Indigenous and remote are risk factors for failure in PD. Peritonitis rates for example vary between 1:36 to 1:6 pt months and some of this is accounted for by race prevalence.³ Quality projects should target areas where benchmarks are not met. All aspects of care and training should meet evidence based recommendations.³⁵

Table 7:

Figure 6.39					
Peritoneal Dialysis at 90 Days					
Technique Survival - Diabetic / Non Diabetic					
Censored for Transplant Commenced 1998 - 2009					
% [95% Confidence Interval]					
	No. of Patients	Survival			
		6 months	1 year	3 years	5 years
Australia					
Non Diabetic	5445	85 [83, 85]	71 [70, 73]	35 [33, 36]	16 [14, 17]
Diabetic	2283	81 [79, 83]	68 [66, 70]	25 [23, 27]	9 [7, 11]
New Zealand					
Non Diabetic	1449	88 [86, 89]	76 [74, 78]	42 [39, 45]	19 [16, 21]
Diabetic	1102	89 [87, 90]	76 [73, 78]	34 [31, 37]	11 [9, 13]

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Reduction of risk factors

Reductions in modifiable risk factors include preservation of residual renal function by ACE inhibitors, avoiding nephrotoxins and possibly by use of biocompatible dialysis solutions.¹⁰³ Residual renal function (RRF) is reported to be preserved on PD, however further research is needed in this area.¹⁰³ Reducing infections can be achieved by close follow-up, adhering to national guidelines, regular retraining on technique and a system to address social concerns and respite needs.¹⁹ Models that support care in the home, respite care and good community support can reduce social failure.³⁹ To prevent technique failure a minimum annual check on technique and trouble shooting is recommended. Social isolation can be reduced by use of support groups, nursing or community visits and newsletters or websites.

Management of complications

Monitoring of complications with benchmarking is critical if effective policy and protocols are to be developed. For effective treatment of complications must be as per evidence based guidelines.^{19,39,59,60,61} Peritonitis management and timely tube removal for recurrent peritonitis to preserve the peritoneum are important factors. For HHD managing access complications and early detection of fistula problems can be a challenge. The simple rule of reporting and investigating once needles require repeat insertion and observing venous/arterial pressures can be managed in home environments and in 19 out of 21 patients was indicative of stenosis in fistulae.¹⁰⁴ For both modalities adequate fluid control minimising the rate of left ventricular failure is recommended. Recent introduction of bio-impedance technology allows improved accuracy in fluid status and nutritional assessment which can be used at home.¹⁰⁵

Symptom management

The renal patients' uncontrolled pain, itch, cramps and depression all contribute to burnout on a programme. Weight, haematological and biochemical factors are routinely and carefully monitored. The level of pain, presence of itch and other signs that make life less tolerable are often overlooked. A tool that measures these symptoms should be considered at every check-up. Additionally the use of palliative care services to assist in management of difficult symptoms can be very effective.

Adequacy of dialysis and Quality of life

Quality of life (QOL) and measured blood targets determine adequacy. Under-dialysis and malnutrition are predictive of poor outcomes. HHD offers the option for longer HHD hours whether nocturnal, short daily or alternate day dialysis. This increases adequacy and a sense of well-being and literature is pointing to improved mortality and well-being outcomes^{17,21,22,26} For PD it is important the prescription is maximised in relation to the membrane type and that adjustments are made as RRF is lost. Ongoing monitoring of quality of life with the use of an endorsed tool such as KDQOL36 available on the KDQOL complete monitoring service will track individuals and groups electronically and provide an objective overview of QOL outcomes of the home programme.¹⁰⁶

Retention Barrier 1: Clinical policy and procedure does not adhere to best practice guidelines

Retention Barrier 2: Lack of monitoring and QI programmes

Retention Barrier 3: Limited symptom control programmes

Retention Barrier 4: Individuals are not meeting minimum targets and have poor QOL

Retention Action 1: Develop and implement clinical policy and procedure that does adhere to best practice guidelines

Retention Action 2: Establish monitoring databases with benchmarks and realistic targets using the results to develop a minimum of one QI project each year to address deficiencies

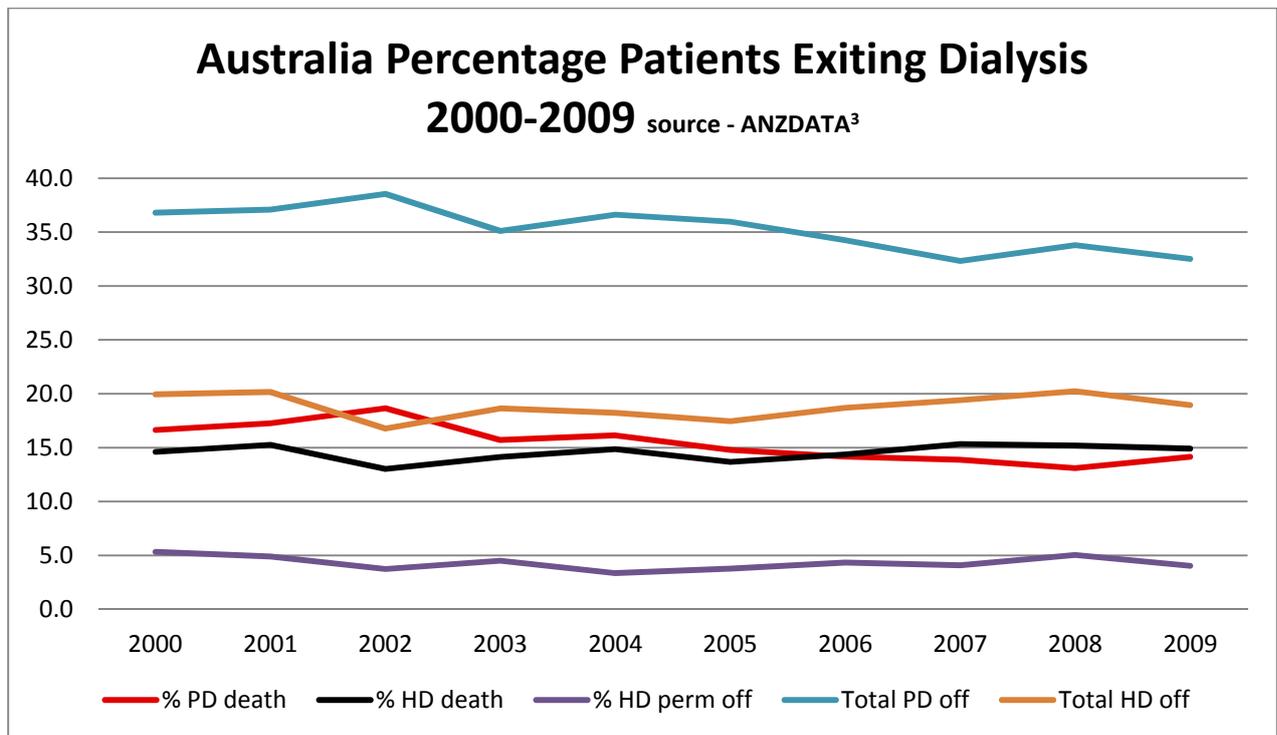
Retention Action 3: Establish a documented symptom assessment system and links with palliative care for difficult to manage symptoms

Retention Action 4: Include monitoring of individuals in ongoing assessment and be pro-active in maximising dialysis prescription in balance with QOL

Withdrawal from Home

Whether death, transplant or transfer to another modality of dialysis is the reason for withdrawal there will be a sense of life-change, possibly loss and possibly failure. For the family it may be relief. Those leaving the programme frequently share their dialysis experience with others later. Many patients and care partners appreciate some contact with the home training unit for closure. PD overall withdrawals and death rates per annum have decreased over the last 10 years.³

Diagram 10: Australian Percentage Exiting Dialysis 2000-2009



Withdrawal from PD and transfer to haemodialysis

A structured pathway should be in place to ensure that those suitable for HHD are captured. For planned transfer coordination of access creation and appointments will ease the transition. It is important if the withdrawal is temporary from PD that the individual does not get lost in the HD systems and never return to home dialysis. If the reason for leaving PD is temporary referral back to surgeons or the HTU to restart PD once the causal issue is rectified should be booked.

Withdrawal leading to death

A palliative care pathway should be followed for all dialysis patients on the programme and the early part of the pathway can be used for symptom management. This same network can be used for timely withdrawal and end of life support. St George in NSW are developing a detailed plan in this area which includes a renal palliative care clinic.⁹⁵ The two main objectives for end of life are for everyone to feel that withdrawal is timely and that the death was as symptom free as practicable. Palliative support and discussions can be conducted by trained nurses, trained nephrologists and specialist palliative care teams. Nurse referrals are often accepted by palliative care teams but nephrologist approval is politically appropriate.

Collection of equipment and consumables

If death is the cause of withdrawal this must be completed with empathy and support. Large amounts of equipment and consumables remain in the community if systems for retrieval are not tight. Therapeutic goods administration (TGA) regulations and provider regulations will limit redistribution of product for other consumers.⁸¹

Withdrawal Barrier 1: Ineffective pathways or support regarding withdrawal, palliation and transfer to alternative home modality

Withdrawal Barrier 2: Inadequately trained nurse or nephrologists

Withdrawal Barrier 3: Ineffective stock management systems

Withdrawal Action 1: Develop a pathway re withdrawal, palliation and transfer to alternative home modality at unit or State level

Withdrawal Action 2: Develop and provide training programmes accessing local resources

Withdrawal Action 3: Ensure stock management systems detail locations of equipment and pick-up

Summary

A successful home dialysis programme has many facets and involves system factors as well as local factors. Many barriers exist that have reduced the uptake of home dialysis over the last decade. All barriers have a solution that will allow them to be tackled and removed or at minimum reduced. To overcome the barriers will require a comprehensive approach with commitment from the entire population who contribute both to policy and to the renal health workforce. When this is achieved the consumer will have equity in choice and the option to choose the dialysis modality that will best enhance their quality of life.

Recommendations Kidney Health Australia:

The recommendations below relate to Kidney Health Australia and an intention to pursue barriers in consultation with or on behalf of the renal community and consumers:

Recommendation 1

Specific consumer barriers are identified and where appropriate government or the health service is objectively briefed regarding these issues.

Recommendation 2

KHA publishes a position Statement and distributes the KHA model of home dialysis.

Recommendation 3

KHA participates in State renal networks and provides assistance with Federal or State funding barriers with appropriate patient advocacy at local and Federal government level.

Recommendation 4

KHA reduces the education barriers with establishment of a neutral, central home dialysis website that provides education, tools and support for both consumers and health professionals. The role of KHA related to provision of education continues and home dialysis is incorporated into programmes.

Recommendation 5

KHA facilitates and supports the establishment of networks of pre-dialysis educators, home dialysis units and allied health and supports these groups in tackling individual and system barriers.

Recommendation 6

KHA supports the streamlining of renal health care across jurisdictions, which may include supporting development of senior home dialysis health professional positions, supporting senior working groups and participation in committees.

Recommendation 7

KHA repeat the consumer survey at 5 year intervals to determine if strategies are effective.

Recommendation 8

KHA advocate for and support ANZDATA to include detailed reports regarding home haemodialysis utilisation and outcomes.

Barriers and Actions Grouped by Type and Including Responsibilities for Actions

Philosophy Barrier	Action	Responsible
Individuals or organisations may prevent a positive home dialysis philosophy	Determine who the barriers are. Consider and address these individually.	Head of Department. Senior renal nurse
Realistic targets have not been determined and written into the State philosophy.	Determine and agree upon the State/organisation home dialysis philosophy with benchmark targets. Incorporate the home dialysis philosophy with benchmark targets into all relevant written documentation.	State Government. Renal Working groups Head of Department.
Lack of flexibility in contract or model to meet the individual needs of the local population	Determine local barriers and develop a model to address these	State Government Head of Department Senior renal nurse Contract managers
Local lack of expertise in home dialysis	Education for nephrologist, registrars and nurses in home dialysis	Educators Senior renal nurse Head of Department KHA
No marketing strategy to promote home dialysis to consumer and health professionals	Develop a marketing strategy based on fact for home dialysis	State Government Renal working groups
Lack of research, evidence based guidelines to support home dialysis	Support and encourage research and articles re home Use ANZDATA information Support CARI guideline re home dialysis	Renal working groups Head of Department Senior renal nurse KHA
Leadership Barrier	Action	Responsible
Inadequate funding to appoint leadership roles	Determine a business case: use the cost analysis of saving based on targets expected to cover funding.	Head of Department Senior renal nurse Renal working groups
Lack of interest by individuals to hold senior leadership roles	Determine and recruit potential candidates for senior roles	Head of Department Renal working groups
Politics weaken the ability of the leadership team to improve home dialysis access and outcomes	Assign the appointed leader the power to determine the future of the programme based on objective policy development	Renal working groups Head of Department
No structure or IT and database system	Develop a business case for a database based on efficacy, effective clinical follow-up and capacity to produce KPIs leading to quality programmes	Head of Department Renal Working groups Senior renal nurse
The home dialysis model does not have an appropriate patient focus	Develop a patient centred focus and consult consumers for opinion	Renal working groups Head of Department Consumer groups, KHA
No clear policy, procedures and guidelines to ensure best practice	Access relevant information to ensure programme is based on best practice and monitored appropriately for best outcomes	Renal working groups Head of Department
Funding Barrier	Action	Responsible
Home dialysis has a cap or funding limitation preventing those who are choosing home dialysis from being placed onto the programme	Determine if there are any limitations and if so are those capital, recurrent or policy/contract based Determine current model and potential appropriate models for the health districts concerned	Renal Working groups State Government Head of Department
The funding stream and costings are not clearly identified	Develop a business case to lobby for change in funding arrangements	Renal working groups Head of Department State Government

Key: Funding Health worker barrier Process or IT Model/Policy Education Consumer

Education Barrier	Action	Responsible
No pre-educator or inadequate hours available	Lobby for appropriate FTE Educate appropriate community renal nurses at country sites. Partner with larger organisations for co-joined education	Head of Department Senior renal nurse Pre-educator KHA
Biased educator /nephrologist not supporting home dialysis or programme delivered has inappropriate content	Identify biased educators and nephrologists. Promote State philosophy and provide objective education Develop curriculum that enhances positive aspects of home dialysis	Head of Department Nephrologist Senior renal nurse Pre-educator
Late referrals	Education and provision of tools to GP network to support timely referrals	Renal working groups KHA
Inadequate pathway and follow through	Invest in a pathway either on paper or electronic	Head of Department Senior renal nurse
Lack of culturally specific education or educators	Identify the key cultures in the catchment and employ appropriate individuals or access appropriate tools	Senior renal nurse Pre-educator KHA
Limited take-home resources to consolidate teaching	Establish an easily accessible list of training resources via sources including KHA, dialysis providers, overseas renal sites, pharmaceutical companies	Pre-educator Home Dialysis team KHA Industry
Health care professionals inadequately informed re home dialysis	Educate all health care professionals with accurate and objective data	Home Dialysis team Educators KHA
Preparing barrier	Action	
Surgery has a waitlist and lack of access coordinator	Collect data and lobby for increased surgical time, access coordinator based on cost savings if patients transitioned earlier	Head of Department Senior renal nurse
Ineffective surgery	Collect and monitor data re access failure	Head of Department
Cost of preparing home or relocating	Collect data and participate in lobbying for out of pocket expenses	Senior renal nurse Allied health Consumer groups KHA
Inadequate social work support leading to unresolved social issues	Establish a local resource list and application forms for current financial, travel and accommodation support for training. Develop business case for social work FTE	Head of Department Senior renal nurse Social work Department KHA
Lack of accommodation or travel assistance with anticipated cost to patient/carer during training i.e. travel, lost earnings	Consider training models where pts commence training as per official curriculums at their current satellite, hospital dialysis unit with fine-tuning at HTU Collect data and lobby for out of pocket expenses Access PATS systems	Home Dialysis team Senior renal nurse Consumer groups KHA
Waitlist for larger or appropriate rental housing/community centre	Notify Government. Lobby local ministers.	Renal working groups Consumer groups KHA
Poor planning and communication for transition	Develop and implement a concise transition pathway	Head of Department. Senior renal nurse Home Dialysis team

Key: Funding Health worker barrier Process or IT Model/Policy Education Consumer

Home Training Unit Barriers	Action	Responsible
Lack of proximity and easy access for the patient	Review location of home training and considering required factors determine if a move is feasible and advantageous	Head of Department State Government Senior renal nurse KHA
Inadequate space and resources for effective and private training	Review location of home training and considering required factors determine if a move is feasible and advantageous	Head of Department State Government Senior renal nurse KHA
No direct access to nephrologists, allied health and specialist nurses	Establish referral pathways, outpatient systems and possible multidisciplinary clinics with at the hospital or onsite at training. Consider telemedicine, GP networks, nurse practitioners in home dialysis	Senior renal nurse Home Dialysis team
Limited access to training hours	Think outside the square with flexible rostering, staggered staff shifts, partnerships with satellite units.	Senior renal nurse Home Dialysis team
Lack of relevant policies and procedures to meet legislation and maximise patient safety	Develop policy and protocols that incorporate current legislation	Senior renal nurse
Training Barrier	Action	Responsible
Inadequately skilled staff	Upskill staff with formal orientation and ongoing training programmes	Senior renal nurse Home Dialysis team
Cultural language inappropriate staff	Recruit staff with appropriate skills or train those employed	Senior renal nurse
Ad hoc training curriculum	Establish a formal training curriculum and pathway	Senior renal nurse Home Dialysis team
Difficult to use equipment or consumables	Collect data and report equipment failures or difficult to use consumables. Lobby industry for simpler machinery	Contract manager Industry Senior renal nurse
Fears that block learning	Identify and training fears and determine individual solutions	Home Dialysis team
Inadequate documentation capacity or access to pre-training information	Determine and implement a suitable IT solution	Head of Department Senior renal nurse
No consent process	Establish a consent form and policy with a strategy for renewal as deemed appropriate	Head of Department Senior renal nurse
Transition Barrier	Action	Responsible
Poor planning and coordination	Develop a clearly defined discharge to home pathway	Senior renal nurse
Inability to provide installation support related to staffing	Determine the benchmark FTE Incorporate home install visits into nursing FTE and develop business case if needed to obtain funding	Renal working Group Head of Department Senior renal nurse

Key: Funding Health worker barrier Process or IT Model/Policy Education Consumer

Support (ongoing care) Barrier	Action	Responsible
Inadequate FTE for nursing or allied health	Develop business case and lobby for appropriate FTE	Renal working Group Head of Department Senior renal nurse
No structured follow-up programme or on-call service	Develop and implement a structured follow-up pathway with funding	Head of Department Senior renal nurse
No system to manage debilitating symptoms	Establish a model of care and referral pathway for symptom management	Head of Department Senior renal nurse
No respite or holiday plan or availability	Lobby for respite, consider nursing homes, assisted care in the home	Renal working group Consumer group Senior renal nurse
Actual or perceived financial disadvantages	Determine and document actual financial burden and lobby for reimbursement	Renal working party Consumer group
Isolation and lack of local support groups	Newsletters, phone calls, online groups and home visits. Liaise with KHA re setting up support groups or motivate a local individual	KHA/consumer group Home dialysis team
Training curriculum or policy does not cover/allow administration of IV medications	Change policy re IV meds and develop a training component for this	Senior renal nurse
Home Dialysis Model does not allow for supported care at home	Consider home dialysis models that allow supported care in the home	Renal working group Senior renal nurse
No plan for natural disasters	Develop a business continuity plan and brochures for individuals	Senior renal nurse
Retention Barrier	Action	Responsible
Clinical policy and procedure does not adhere to best practice guidelines ie peritonitis prevention	Develop and implement clinical policy and procedure that does adhere to best practice guidelines	Head of Department Senior renal nurse
Lack of monitoring and QI programmes	Establish monitoring databases with benchmarks and develop a minimum of one QI project each year to address deficiencies. Set realistic targets	Head of Department Senior renal nurse
Individuals are not meeting minimum targets and have poor QOL	Include monitoring of individuals in a regular assessment and be proactive in coordinating dialysis prescription in balance with QOL	Home Dialysis team
Withdrawal Barrier	Action	Responsible
Ineffective pathways or support re withdrawal, palliation and transfer to alternative home modality	Develop a pathway re withdrawal, palliation or transfer to alternative home modality at unit or State level	Renal working groups Head of Department Senior renal nurse
Inadequately trained nurse or nephrologist re palliative care	Develop and provide training programmes accessing local resources	Educators Head of Department Senior renal nurse KHA
Ineffective stock management systems	Ensure stock management systems detail locations of equipment and pick-up	Industry

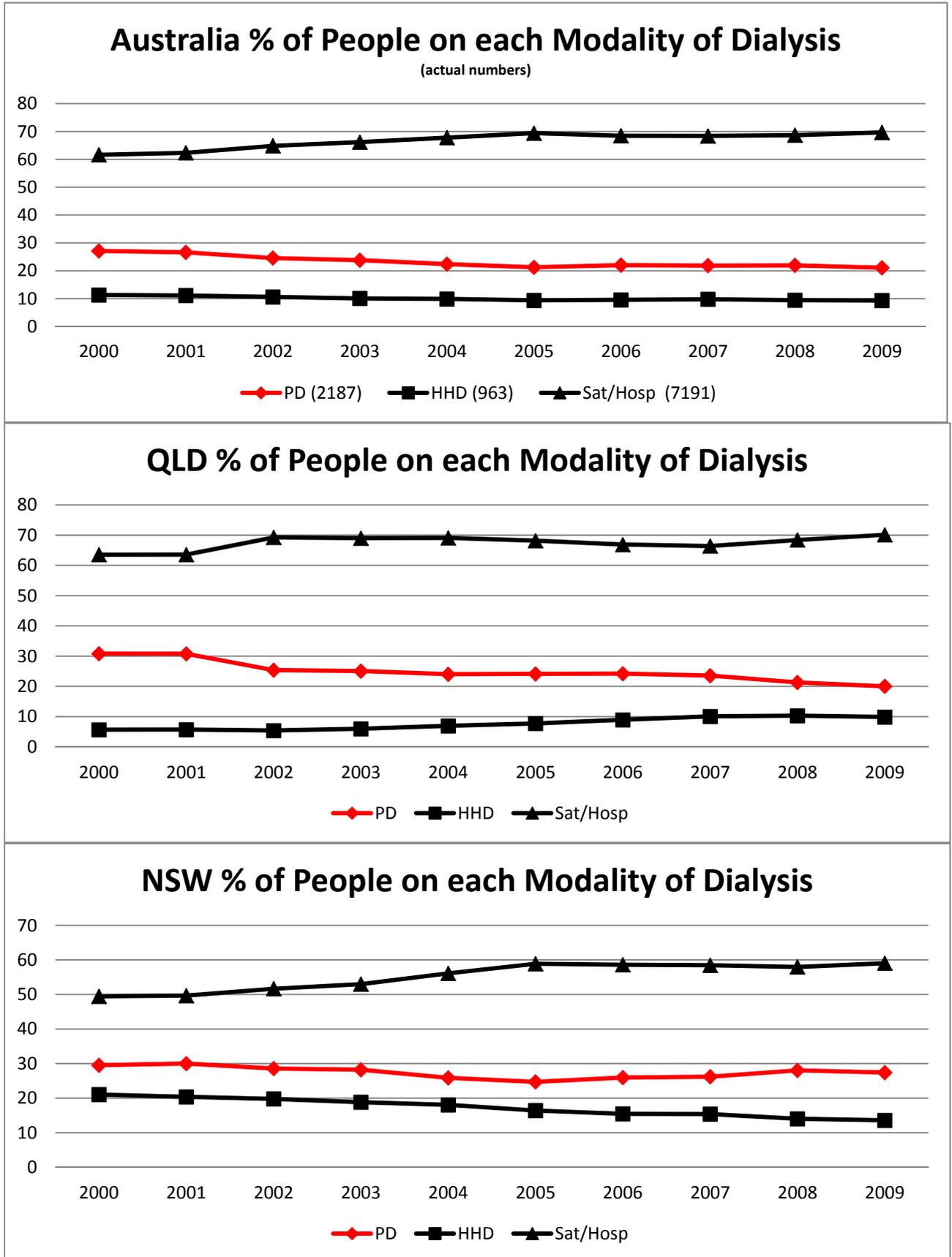
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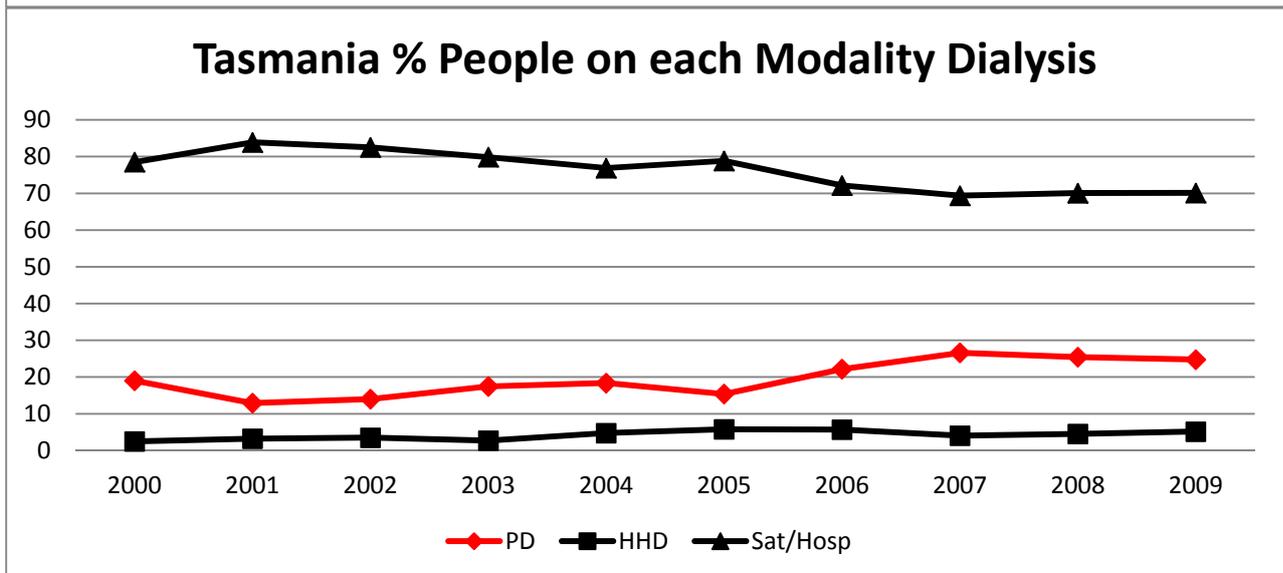
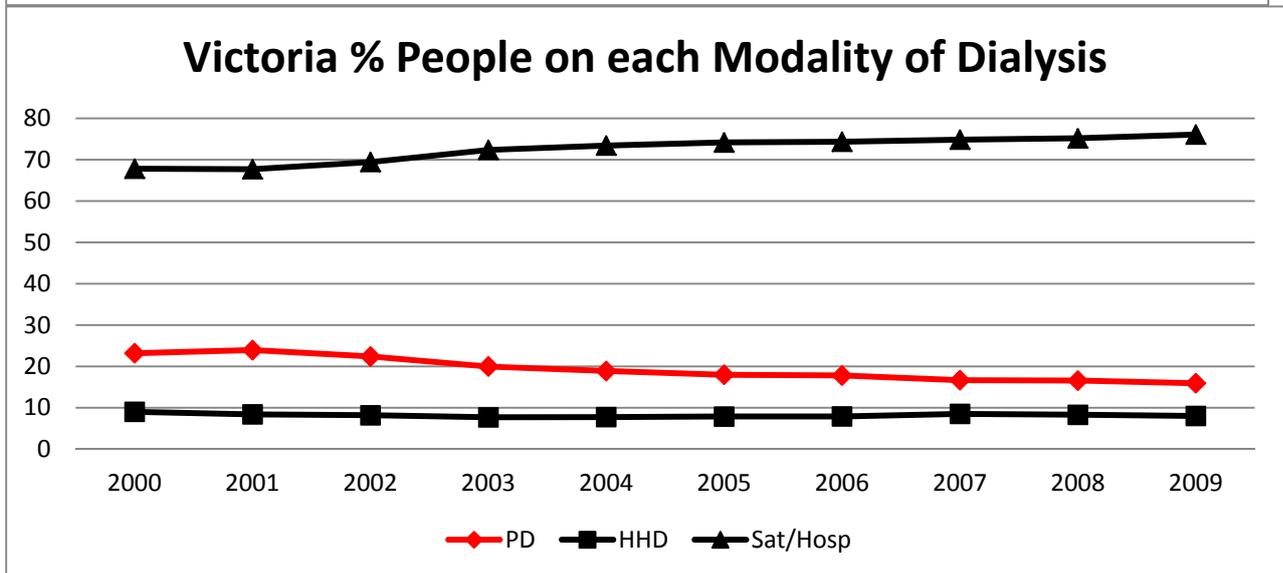
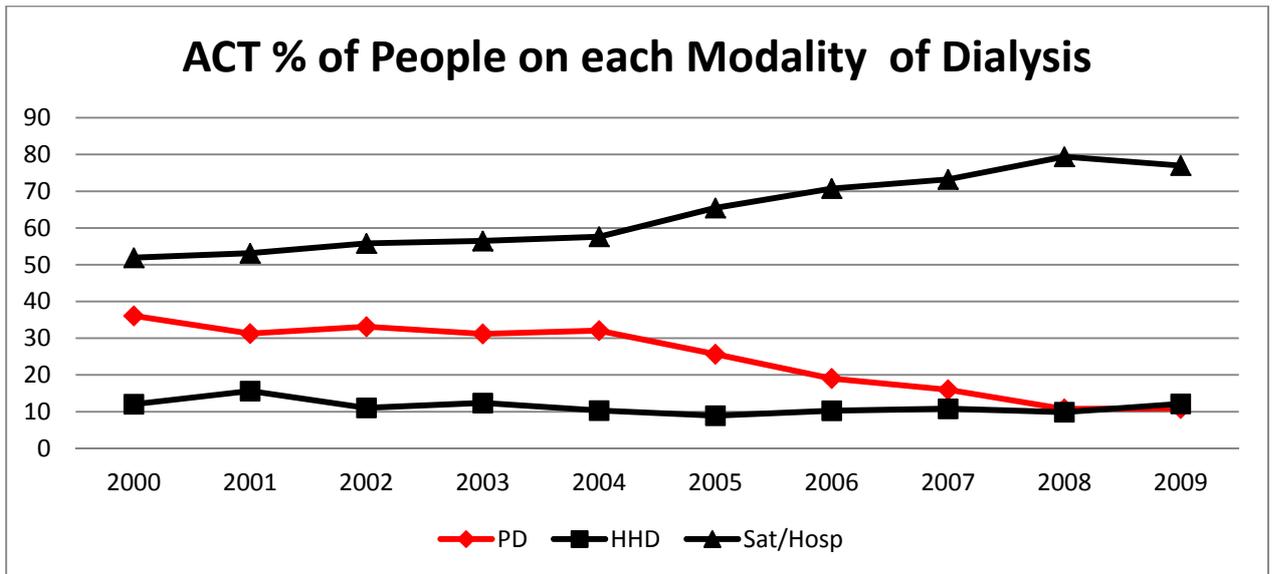
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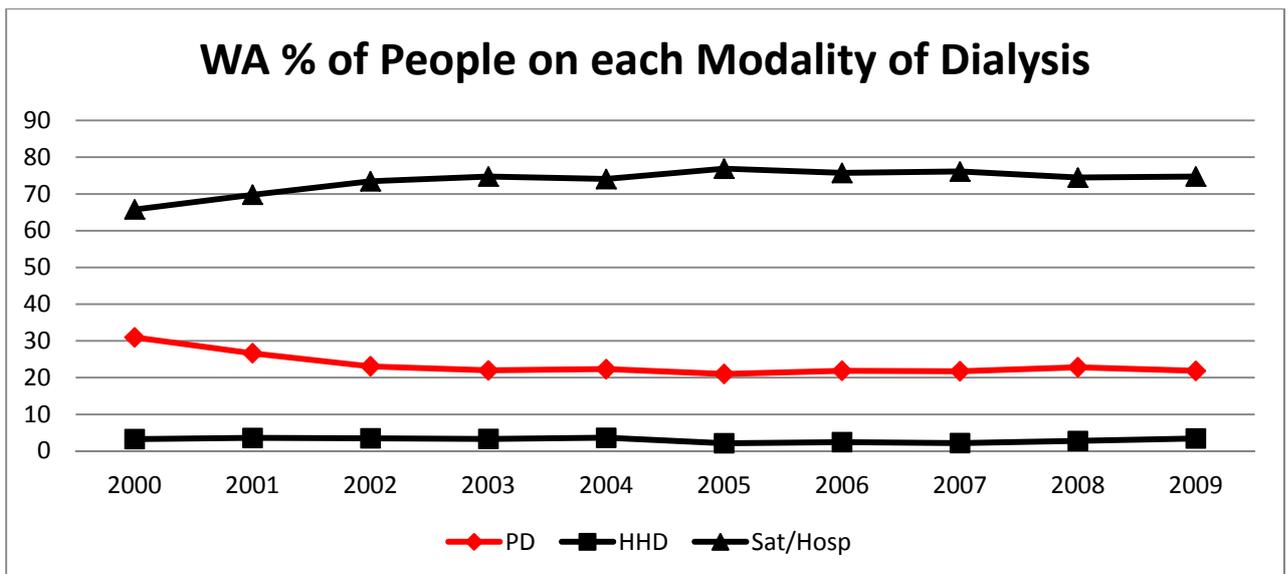
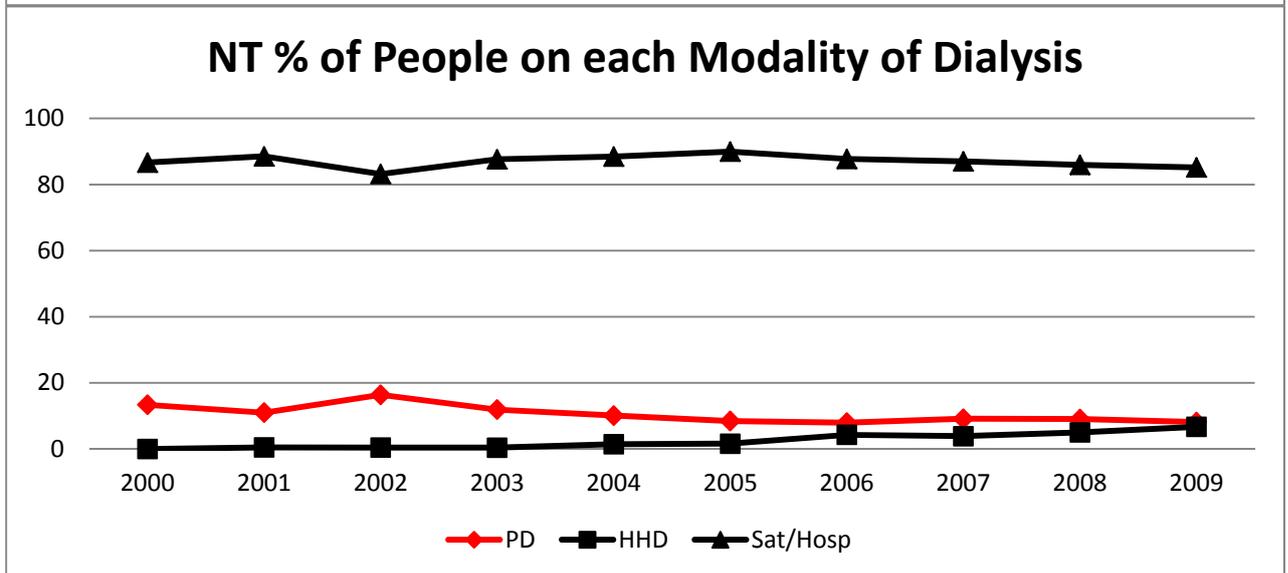
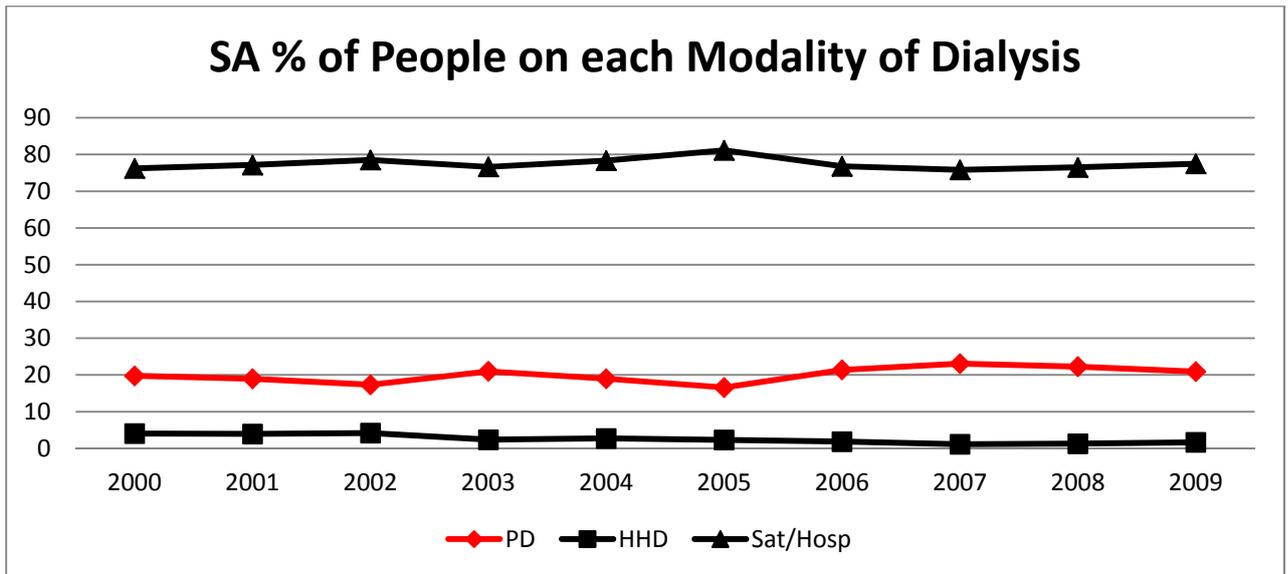
AHS	Area Health Service
ABF	Activity Based Funding
ACT	Australian Capital Territory
ANZDATA	Australian New Zealand Dialysis and Transplant Registry
APD	Automated peritoneal dialysis
CAPD	Continuous ambulatory peritoneal dialysis
CARI	Caring for Australians with Renal Impairment guidelines
CKD	Chronic kidney disease
DVA	Department of Veteran Affairs
FTE	Full time equivalents
GP	General Practitioner
HD	Haemodialysis
HDF	Haemodiafiltration
HHD	Home haemodialysis
HTU	Home training unit
ISPD	International Society of Peritoneal Dialysis
IT	Information technology
KCAT	Kidney Check Australian Taskforce
KDIGO	Kidney Disease Improving Global Outcomes
KHA	Kidney Health Australia
KPI	Key Performance Indicator
NKFKDOQI	National Kidney Foundation Kidney Disease Outcomes Quality Initiative
NSW	New South Wales
NT	Northern Territory
PD	Peritoneal dialysis
PPT	Price per treatment
QI	Quality Improvement
QLD	Queensland
SA	South Australia
SHD	Satellite Haemodialysis
SHDF	Satellite Haemodiafiltration
TGA	Therapeutic Goods Administration Authority
UK	United Kingdom
USA	United States of America
VIC	Victoria
WA	Western Australia

Appendices

Appendix 1 State Percentages of Dialysis modalities – Source – ANZDATA 2000-2010 Reports







Appendix 2 Distribution of Home Dialysis Units across Australia (Dec 2011)

Health service/Unit Name	Location	Postcode	Parent Hospital	HHD	PD	Satellite	Incentre	Self-care HHD
Sydney Local Health (Statewide renal service)	Camperdown	2050	Royal Prince Alfred, Wagga	X	X	X	X	
Nth Sydney Central Coast (Sydney Dialysis Centre - SDC)	St Leonards	2065	Royal North Shore	X	X	X	X	
Nth Sydney Central Coast	Gosford	2250	Gosford	X (+SDC)	X	X		
West Sydney AHS	Blacktown	2148	Westmead/Blacktown	X	X		X	
South West Sydney LH Service	Liverpool	2170	Liverpool/Bankstown	X	X	X	X	X
South East Sydney & Illawarra	Kogarah	2217	St George	X (+SDC)	X		X	
South East Sydney & Illawarra	Waverley	2024	Prince of Wales	X	X	X		
South East Sydney & Illawarra	Woolongong	2500	Woolongong	X	X		X	
Hunter New England	Charlestown	2290	Newcastle (John Hunter)	X	X			
North Coast Area Health Service	Ballina	2478	Ballina/Lismore	X		X		
North Coast Area Health Service	Lismore	2480	Ballina/Lismore		X		X	
Great South Area Health Service	Wagga Wagga	2650	Wagga Wagga	No service		X		
Rural Regional Western AHS	Dubbo	2830	Dubbo Base	X	X		X	
Canberra	Garran (2 sites)	2605	Canberra	X	X	X		
Western Health	St Albans	3021	Sunshine Hospital	X	X		X	
North West Dialysis service	Parkville	3052	Royal Melbourne	X	X			
St Vincents	Fitzroy	3065	St Vincents	X	X	X		
PANCH	Preston	3072	Austin Health	X		X		
Austin	Heidelberg	3084	Austin Health		X		X	
Eastern Health Int Renal Service	Box Hill	3128	Box Hill	X	X		X	
Alfred Health	Caulfield	3162	Alfred	X	X		X	
Southern Health	Clayton	3168	Monash		X		X	
Southern Health	Dandenong	3175	Monash	X		X		
South Geelong	Sth Geelong	3220	Geelong		X	X		
Geelong	Geelong	3220	Geelong	X				

Health service/Unit Name	Location	Postcode	Parent Hospital	HHD	PD	Satellite	Incentre	Self-care
Royal Brisbane	Bowen Hills	4006	Royal Brisbane	X	X			X
Royal Brisbane	Wooloongabba	4102	Princess Alexandra	X	X		X	
Logan Home Dialysis	Meadowbrook	4131	Logan	X	X			
Gold Coast Health Service	Southport	4214	Gold Coast Hospital		X		X	
Gold Coast Health Service	Robina	4226	Robina hosp	X			X	
Toowoomba	Toowoomba	4350	Toowoomba	X	X	X		X
Sunshine Coast	Nambour	4560	Nambour, Caloundra	X	X	X		X
Fraser Coast Renal Service	Maryborough	4650	MaryBorough/Hervey Bay	X	X	X		
Bundaberg	Bundaberg	4670	Bundaberg	X	X		X	X
Rockhampton	Rockhampton	4700	Rockhampton	X	X	X		X
Townsville	Townsville	4810	Townsville	X	X	X		
Cairns HHD	Nth Cairns	4870	Cairns Base	X				
Cairns PD	Cairns	4870	Cairns Base		X		X	
Central North Adelaide renal & Transplant service	Woodville Sth	5011	Queen Elizabeth, Royal Adelaide	X (all S/A)	X		X	
Flinders Medical Centre	Bedford Park	5042	Flinders Medical centre		X		X	
Royal Perth PD Unit	Perth	6001	Royal Perth		X		X	
Sir Charles Gairdner PD Unit	Nedlands	6009	Sir Charles Gairdner		X		X	
Warwick (Fresenius)	Warwick	6024	FH, RPH, SCGH	X	X			
Fremantle PD Unit	Fremantle	6160	Fremantle		X		X	
Coolbellup (Fresenius)	Coolbellup	6163	FH, RPH, SCGH	X	X			
Kimberley (KAMSC)	Broome	6725	Royal Perth		X	X		
Karingal renal education centre	Hobart	7000	Hobart	X	X			X
Launceston	Kings Meadow	7249	Launceston		X		X	
Launceston	Launceston	7250	Launceston	X			X	
Nightcliffe Renal Unit	Nightcliffe	0810	Darwin	X	X		X	
Katherine District Hospital	Katherine	0852	Darwin	X	X	X		
Flynn Drive Renal Unit	Alice Springs	0870	Alice Springs	X	X	X		

Appendix 3 Patient Testimonies

These are a small sample of the multitude of positive stories that are on the internet. Many are also available as videos.

Peritoneal Dialysis:

Last year we went away for a fortnight in Cornwall and of course I took my dialysis equipment with me. With home dialysis I am completely unrestricted, and can even travel abroad with a bit of forward planning. I'm lucky because I am in complete control of my treatment and I feel like there is nothing I can't do.

http://www.idratherbeathome.org/pamela_story.html

I can now continue with my hobbies and spend my time at home, instead of having to do a 220-mile round trip three times a week to receive my treatment, which would have tired me out.

http://www.idratherbeathome.org/hugh_story.html

After being diagnosed I felt very isolated. Now I realise that with my home treatment I do not have to alter my plans too much – I can still work, visit my grandchildren and daughters, and travel. I'm a regular extra on Eastenders and sometimes have to work 10 hour days. I was in the latest Harry Potter film, and my scene took two whole days of filming. APD at home is really flexible and allows me to do this – after all I can always take my machine with me.

http://www.idratherbeathome.org/gwyneth_story.html

Nocturnal Haemodialysis

"The nocturnal dialysis program allows me work and go to my practices and games. On nights that I do dialysis, I go in around 11:00 p.m., leave the centre around 6:00 a.m., go to work and then coach. Thanks to DaVita's nocturnal dialysis program, I have the extra energy to keep up with a hectic schedule and extremely active athletes," shares Donavon.

<http://www.davita.com/treatment-options/in-center-nocturnal-dialysis/nocturnal-testimonials/>

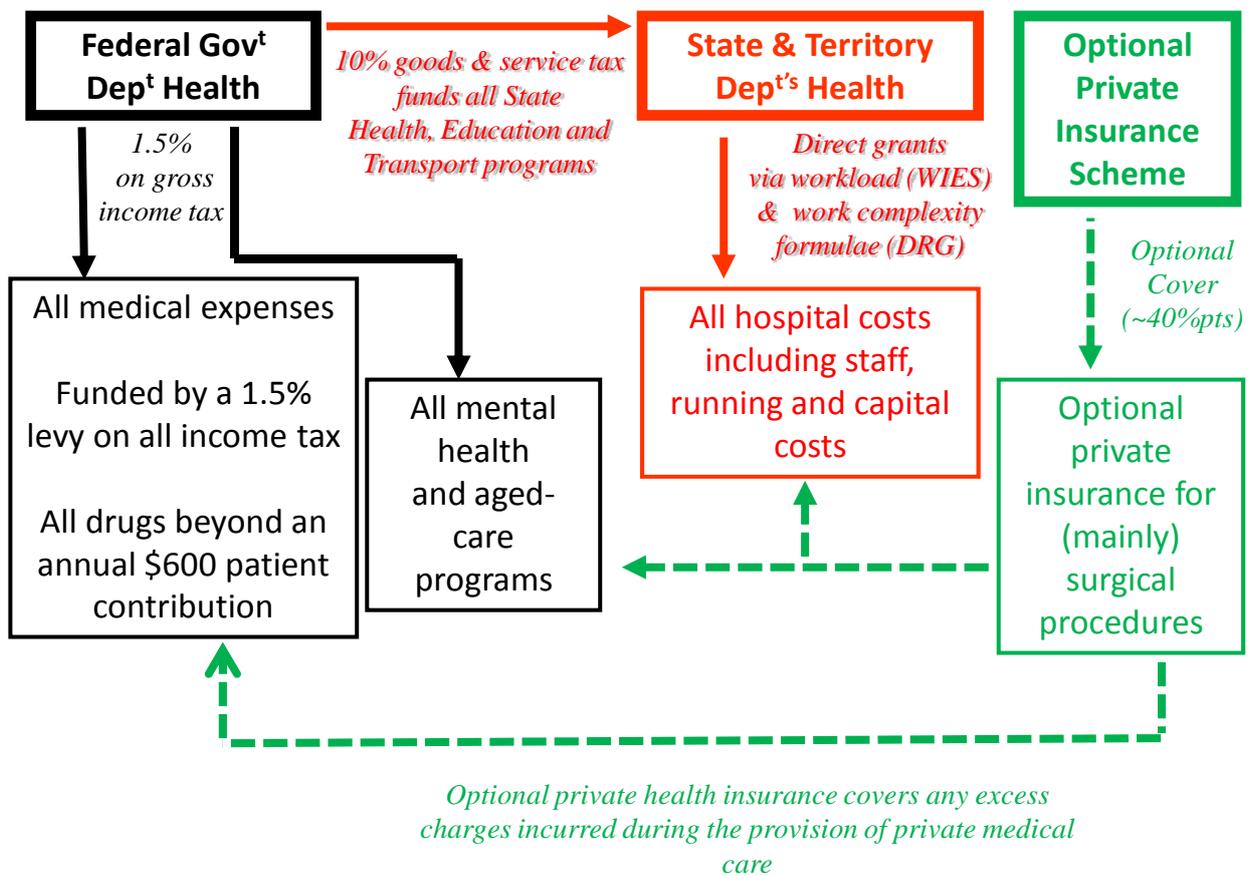
Daily Haemodialysis

Everette had been undergoing in-centre dialysis treatments when he learned about daily home hemodialysis with **. "For the past seven years, the ** has given me the freedom to live my life closer to the way I want to live it and allowed me to dedicate more time to my hobbies and business dreams," he said. Thanks in part to ** and dialyzing more frequently, I feel more healthy and active. I've come off several blood pressure medications and play basketball twice a week while spearheading my online clothing store.

" <http://www.prnewswire.com/news-releases/first-nxstage-home-hemodialysis-patients-celebrate-seven-year-anniversary-111990404.html>

Appendix 4 Summary of Australian Funding Mechanism for Renal Replacement Therapy

John Agar – Beijing presentation 2009



Appendix 5 Victoria Funding Model - General Information

Victorian funding model accessed in August 2011 at <http://www.health.vic.gov.au/renaldialysis/funding.htm>

The Government will spend \$150 million dollars in 2010-11 to provide maintenance dialysis (MD) services across Victoria. The annual recurrent budget for MD is paid through a two-tier funding model that includes a capitation grant that is paid to the hub hospitals and a variable (WIES) payment that is paid directly to the in-centre and satellite providers. Under the current policy, renal dialysis payments are paid to actual so that all patients requiring renal dialysis receive it.

While renal targets (capitation and WIES) are set for health services, their renal budget will be updated as a prior year adjustment to reflect actual activity (either positively or negatively). Health services are encouraged to quarantine their renal budgets until this final wrap up has occurred. Any funding that is recalled will be re-distributed within the MD service system. For the 2010-11 financial year the case payment is calculated on the number of annual attendances, the weight associated with the Diagnosis Related Group (DRG) of 'Renal Dialysis' and the payment per Weighted Inlier Equivalent Separation (WIES). This payment is made directly to providers of in-centre and satellite services. The Case Payment covers the costs of:

- Nurse care
- Waste management
- Power, water, domestic/cleaning services
- Supply of some linen
- Limited catering
- Receiving goods
- Provision of some equipment, eg. chairs, dressing trolleys
- Telecommunications
- Medical records
- Patient transport (inter hospital)

Capitation Grants are payable to the hub providers to cover a set of costs that are not covered by the Case Payment and are associated with treatment provided to the patients treated and managed within their service network. The Capitation Payment covers the costs of:

- Haemodialysis consumables
- Medical care, review and 24 hour call service, including emergency
- Acute dialysis treatments
- Nurse training
- Provision of 24 hour support to nurses
- Provision of allied health services – dietetics and social work
- In-patient pharmacy
- Pathology
- Provision and maintenance of dialysers, lines, and associated ancillary fittings, including all plumbing fittings
- On-call service of equipment
- Water quality testing
- Recovery of machine usage fee from other hub units that use the satellite service

Funding Model 2009-10

Following a Renal Dialysis Costing and Funding Review in 2006-07, a new funding model for maintenance dialysis services was implemented on 1 January 2008. This model included the use of three capitation grants and a single WIES payment rate.

In 2010-11, the funding model will continue to use three capitation grants and a single WIES payment rate. The capitation grant includes, in 2010-11:

- a \$10,383 incentive payment to hub services for each home haemodialysis patient;
- an additional \$2,686 payment to hub services for each peritoneal dialysis patient;
- patient payment, as below, to hub services which will be administered by hub services:
 - for home peritoneal dialysis - \$489 per patient per annum; and
 - for home haemodialysis - \$1,289 per patient per annum

The total capitation grant rates for 2010-11, which includes the components listed above, are in the table below.

Table 1. Victorian Maintenance Dialysis Program, Capitation Grant Payments in 2010-11

	Facility dialysis	Home Haemodialysis	Home peritoneal dialysis
Capitation grant	\$29,608	\$52,092	\$46,968

WIES rates are available from the Policy and Funding Guidelines, 2010-11.

Reporting will continue to occur through the Victorian Admitted Episodes Dataset (VAED) and the Agency Information Management System (AIMS).

Reports

 [Renal Dialysis Costing and Funding Review Report \(draft\) - December 2006 \(pdf, 1.69mb\)](#) (consultants report)

 [Report on Outcomes of the Renal Dialysis Costing and Funding Review \(pdf, 90k\)](#) (department's response to consultant's report)

Appendix 6 CARI Guidelines

<http://www.cari.org.au/DIALYSIS>

Peritoneal dialysis versus haemodialysis (adult)

Final submission: March 2009

Author: Melissa Stanley

GUIDELINES

No recommendations possible based on Level I or II evidence

SUGGESTIONS FOR CLINICAL CARE

(Suggestions are based on Level III and IV evidence)

- - Treatment starting with peritoneal dialysis (PD) may lead to more favourable survival in the first 1–2 years compared to starting treatment with haemodialysis (HD)(Level II evidence, small RCT).
 - Peritoneal dialysis compared with conventional HD is associated with equivalent or better survival in the first few years, especially with respect to residual renal function (RRF) (Level III evidence)
 - With loss of RRF, PD may lead to worse outcomes than HD (Level III evidence)
 - Haemodialysis is associated with improved long-term survival (Level III evidence)
 - A timely transfer from PD to HD may improve patient survival (Level IV evidence)
 - Renal programs should include an integrated PD/HD program where therapies are not competitive but rather complementary (Opinion)
 - Survival according to modality should be considered in the context of life quality as perceived by the patient when they are choosing HD or PD as initial therapy (Opinion)

Predialysis education

Date written: December 2004

Final submission: June 2005

GUIDELINES

No recommendations possible based on Level I or II evidence

SUGGESTIONS FOR CLINICAL CARE

(Suggestions are based on Level III and IV evidence)

Patients and their families or carers should receive sufficient information and education regarding the nature of end stage kidney disease (ESKD), and the options for the treatment to allow them to make an informed decision about the management of their ESKD (Level III evidence). The use of multidisciplinary clinics with input from medical, nursing and allied health personnel using standardised protocols for the preparation of patients for dialysis is one way of achieving this outcome. Pre-dialysis education programmes providing information about kidney disease, options for the management of chronic kidney disease (CKD) prior to dialysis (including pharmacological and dietary management) and the options for renal replacement therapy may also be beneficial. These clinics or education programmes should incorporate a mechanism for the timely referral of patients for the creation of an access for dialysis. Existing data suggest that these clinics and education programmes may facilitate the improved medical care of patients (for example, better control of anaemia and hypertension), greater patient involvement in the selection of the mode of dialysis, a reduction in the need for 'urgent start' dialysis, and improved short-term survival and quality of life after the initiation of dialysis.

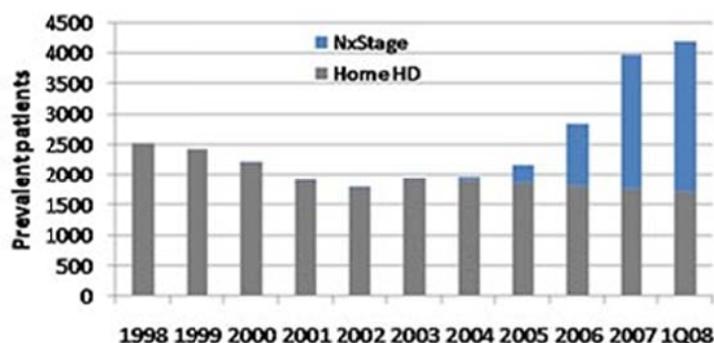
Appendix 7 NxStage and Impact on Home Dialysis in the US

http://www.nxstage.com/chronic_renal_care/registry/overview.cfm

Why At Home Today?

During the 30 years between 1975 and 2005, home hemodialysis nearly disappeared as an option for patients. The NxStage System One's FDA home clearance in 2005 has led to a new wave of clinical adoption of home hemodialysis. NxStage is leading a movement to improve patient care, and has been told that the community could benefit from timely insight into this progress.

Home dialysis growth in the US



Source: USRDS ADR and NxStage Public Disclosures. Non-NxStage Home HD numbers for 2005 through 2008 are estimated based on historical trends.

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JRM2710, Rev. A



Traditional data registries on dialysis care such as the USRDS and the ESRD Networks cannot structurally provide timely reports on this movement. This is due to data lags (2 years) as well as coding inconsistencies that make capture of information on home hemodialysis and the frequency in which it is delivered challenging. And, home hemodialysis still comprises less than a one percent of the patient population. Particularly during these early years of this rebirth of home dialysis and its enabling technologies, more timely and focused information can be insightful.

From the beginning, NxStage implemented and has maintained a thorough internal database capturing its therapy experience.¹ Thousands of patients and over one million home treatments have added to this insight. The company reviews this information regularly with its [Scientific Advisory Board](#) to allow for continuous improvement and education on the therapy. In keeping with NxStage's commitment to innovate, educate, and advocate, our Scientific Advisory Board recommended that NxStage should make summaries of this information available in a readily accessible, updated format so that folks may be better informed as home daily dialysis clinical adoption spreads through the community.

It is our commitment to the kidney care community to update this information on a regular basis, and to make the data available for public use to those who desire for as long as it is valuable.

References:

1. Australian Institute of Health and Welfare, 2009, *An overview of chronic kidney disease in Australia*, 2009, cat no. PHE 111. Canberra AIHW, p. vi.
2. AIHW 2011. *Projections of the incidence of treated end-stage kidney disease in Australia, 2010-2020*. Cat. no. PHE 150. Canberra: AIHW. Viewed 14 October 2011 <<http://www.aihw.gov.au/publication-detail/?id=10737419875>>.
3. ANZDATA 2010 report www.ANZdata.org.au Accessed Aug 2011
4. Kidney Health Australia - *Economic Impact of End-Stage Kidney Disease in Australia - Projections to 2020* <http://www.kidney.org.au/LinkClick.aspx?fileticket=vave4WFH73U%3d&tabid=635&mid=1837> Accessed August 2011, Graphs copied from presentation by KHA Medical Director Tim Matthew
5. Rosner, MH. Home Hemodialysis: *Present State of the Evidence*. Dialysis and Transplantation Aug 2010 p330-333 DOI 10.1002/dat.20477
6. Kidney Health Australia. *Consumer Perspectives on Dialysis: First National Census*. Melbourne, 2011, <http://www.kidney.org.au/LinkClick.aspx?fileticket=JfvirIbNWxA%3d&tabid=618&mid=854> Accessed Aug 2011
7. Agar, JWM. *Home Hemodialysis in Australia and New Zealand: Practical problems and solutions* Hemodialysis International 2008 12:S26-S32
8. Queensland Government (2007) *Queensland Statewide Renal Health Services Plan, 2008–17, Part One: The Way Forward*, Queensland Government, Brisbane.
9. Australian Capital Territory Government *Renal health service plan 2010-2015*
10. Blagg, C. *The future of Home Hemodialysis Dialysis and Transplantation* 2010, vol 39 (8) p335-337
11. Kam-Tao, Li P., Cheung, WL., Lui, SL., Blagg, C., Cass, A. et Al. *Increasing home based dialysis therapies to tackle dialysis burden around the world*. 2011 <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1797.2010.01418.x/full>
12. Western Australia. *Chronic Kidney Disease Model of Care*. Perth: Health Networks Branch, Department of Health, Western Australia; 2008.
13. Yerbury, B. & King, K. *Analysis of the funding and delivery of renal disease services in NSW and suggestions to address future demand* Baxter Healthcare May 2011.
14. Blagg, C.R. *The renaissance of home hemodialysis: Where we are, why we got here, what is happening in the United States and elsewhere* Haemodialysis International 2008; 12:S2-S5
15. Agar JW, Hawley CM, George CR, Mathew TH, McDonald SP, Kerr PG. *Home haemodialysis in Australia - is the wheel turning full circle?* Medical Journal of Australia 2010;192(7):pp403-6.
16. Kepler, J. (2010) USRDS Annual Data Report. Chapter 12 – International comparisons
17. Agar 2009 – Agar, J. *International variations and trends in Home Haemodialysis*. *Advances in Chronic Kidney Disease*, Vol 16, No 3(May), 2009: pp205-214
18. NHS *Improving choice for kidney patient* <http://www.kidneycare.nhs.uk/Library/ImprovingChoiceforKidneyPatients> HomeHaemodialysis Report Feb2010.pdf Accessed Aug 2011
19. Kam-Tao Li, P., Czeto, C.C., Piraino, B., Bernardini, J., Figueiredo, A.E., Gupta, A., Johnson, D., Kuijper, E.J., Lye, W., Salzer, W., Schaefer, F. & Struijk, D.G. *ISPD guidelines/recommendations –Peritoneal Dialysis-related infections recommendations* 2010 update Peritoneal Dialysis International 30(4); pp393-423
20. Kidney Health Australia *The national CKD strategy*, <http://www.kidney.org.au/> Accessed Aug 2011
21. Nocturnal Haemodialysis Agar, J., Geelong hospital: <http://www.nocturnaldialysis.org/>
22. Sinclair P. *Home haemodialysis: a literature review*. Ren Soc Aust J 2008;5(1):9-15.
23. Peckham, B. *On dialysis will travel*. Dialysis and Transplantation 2010, vol 39 (8) p321
24. Ludlow MJ, George CRP, Hawley CM, Mathew TH, Agar JW, Kerr PG, et al. *How Australian nephrologists view home dialysis: Results of a national survey*. Nephrology 2011;16:pp446-52.
25. Jaber, B et al. On behalf of the Freedom study group. *Daily Hemodialysis Reduces the Need for Anti-hypertensive Medications*. Abstract presented as poster at American Society of Nephrology Conference, October 31, 2009.
26. Marshall, MR., Hawley, CM., George, CR., Mathew, TH., McDonald, SP., & Kerr PG. *Home Dialysis and Mortality risk in Australian and New Zealand populations*. American Journal of Kidney Disease. Nov 2011, Vol 58(5) p782-793
27. The FHN trial group. *In-Center Hemodialysis Six Times per Week versus Three Times per Week*
28. Mowatt G, Vale L, MacLeod A. *Systematic review of the effectiveness of home versus hospital or satellite unit haemodialysis for people with endstage renal failure*. International Journal of Technology Assessment in Health Care 2004;20(3):258-68.
29. Foley, R.N., Gilbertson, D.T., Murray, T. & Collins, A.J. *Long Interdialytic Interval and Mortality among Patients Receiving Hemodialysis*. N Engl J Med 365;pp1099-107
30. Ecran O, Soner D, Gulay A, Murat T, Ozen O, Meral K, et al. *Comparison of 4-h and 8-h dialysis sessions in thrice-weekly in-centre haemodialysis*. Nephrol Dial Transplant 2011;26:pp1287-96.
31. Vale, L., Cody, J.D., Wallace, S.A., Daly, C., Campbell, M.K., Grant, A., Khan, I., MacLeod, A.M. *Continuous ambulatory peritoneal dialysis (CAPD) versus hospital or home haemodialysis for end-stage renal disease in adults* Cochrane Renal Group Published Online: 8 JUL 2009
32. Jaar, B.G., Coresh, J., Plantignia, L.C., Fink, N., Klag, M.J., Levey, A.S., Levin, N.W., Sadler, J.H., Klinger, A. & Powe, N.R. *Comparing the Risk for Death with Peritoneal Dialysis and Hemodialysis in a National Cohort of Patients with Chronic Kidney Disease* Annals of internal medicine August 2, 2005 vol. 143 no.3 pp174-183
33. Jaber, B.L et al on behalf of the Freedom study group. *Effect of daily hemodialysis on depressive symptoms and post dialysis recovery time*. AJKD Vol 56 (3), sep 2010 pp531-539

34. Jaber, B.L et al on behalf of the Freedom study group – *Impact of at Home Short Daily Haemodialysis on Restless Legs Symptoms and Sleep Disturbance* Clin J Am Soc Nephrol 6; 2011. doi: 10.2215/CJN.10451110
35. Feidhlim-Woods, H. *The influx of dialysis patients, what does the future hold?* Fresenius Home Therapies Conference 2010 – Presentation
36. Connor, A., Lillywhite, R., Cooke, M.W. *The Carbon footprints of Home and in-center Maintenance hemodialysis in the United Kingdom* Haemodialysis International. 2011 pp1-13 DOI:10.1111/j.1542-4758.2010.00523
37. Agar, J. Simmonds, R. Magoffin, J. Knight, R. *Simple but essential new water-conservation practices for home-based dialysis services.* Hemodialysis International 2008; 12:p121
38. Agar, J.W. *Conserving water in and applying solar power to haemodialysis: 'green-dialysis' through wiser resource utilization.* *Nephrology (Carlton)*. 2010 Jun;15(4):pp448-53.
39. Oliver, M.J., Quinn R.R., Richardson E.P., Kiss A.J., Lamping D.L., & Manns B.J. *Home care assistance and the utilization of peritoneal dialysis* Kidney International (2007) 71, pp673–678
40. Medicare item 13104. <http://www9.health.gov.au/mbs/search.cfm?q=Dialysis&sopt=S> Accessed Nov 11
41. Medicare Funding for nurses at <http://www.medicareaustralia.gov.au/provider/other-healthcare/nurse-midwives.jsp>. Accessed Nov 2011
42. Activity based funding http://www.health.nsw.gov.au/resources/hospitals/pdf/abf_series_1_funding.pdf Accessed Aug 2011
43. WA activity based funding <http://www.health.wa.gov.au/activity/home/> Accessed Aug 2011
44. Neil N, Guest S, Wong L, Inglese G, Bhattacharyya SK, Gehr T, Walker DR, Golper *The financial implications for Medicare of greater use of peritoneal dialysis.* *Clin Ther.* 2009 Apr;31(4):pp880-8.
45. Central Australia Report [http://www.health.gov.au/internet/main/publishing.nsf/Content/A7B443D6D3F55E67CA2578B100831F9A/\\$File/Final%20Report%20Central%20Australia%20Renal%20Study.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/A7B443D6D3F55E67CA2578B100831F9A/$File/Final%20Report%20Central%20Australia%20Renal%20Study.pdf) Accessed Aug 2011
46. Agar, J., Knight, R.J., Simmonds, R.E., Boddington, J.M., Waldron, C.M., & Somerville, C.A. *Nocturnal Haemodialysis: An Australian cost comparison with conventional satellite haemodialysis* Nephrology 2005; 10, pp557-570
47. Kroeker, A., Clark, W.F., Heidenheim, A.P., Kuenzig, L., Leitch, R., Meyette, M., et al (2003) *An operating cost comparison between conventional and home quotidian haemodialysis.* American Journal of Kidney Disease 42 (suppl. 1), pp49-55
48. Komenda, P., Copland, M., Makwana, J., Djurdjev, O., Manish M. & Levin, A. *The cost of starting and maintaining a large home hemodialysis program* Kidney International (2010) 77, pp1039–1045
49. McFarlane, P.A., Bayoumi, A.M., Pierratos, A., & Redelmeier, D.A. (2003) *The quality of life and cost utility of home nocturnal and conventional in-centre hemodialysis.* Kidney International, 64, 1004-1011
50. Oreopoulos, D.G., Thodis E., Passadakis, P., Vargemezis V. *Home dialysis as a first option: a new paradigm.* International Urology and Nephrology. Dordrecht: 2009. Vol. 41, Iss. 3; pg. 595-606
51. Morton, R.L., Howard, K., Webster, A.C. & Snelling, P. *Patient information about options for treatment (PINOT): a prospective national study of information given to incident CKD stage 5 Patients.* Nephrology, Dial Transplant (2010) 1:9 Doi: 10.1093/ndt/gfq555
52. Yorkshire & the Humber Kidney Care. *Home Therapies and share Haemodialysis care strategy 2011-2013*
53. Berdanini, J. Price, V. & Figueiredo, A. *ISPD guidelines/recommendations – Peritoneal Dialysis Training.* 2006 Peritoneal Dialysis International, vol 26: pp625-632
54. Nephrology Advanced Training Curriculum <http://www.racp.edu.au/index.cfm?objectid=52520B8F-F2D2-359D-28C1A650FB9E39D5> Accessed Oct 2011
55. Nxstage http://www.nxstage.com/chronic_renal_care/registry/overview.cfm http://nxstage.com/our_community/chronic_community.cfm Accessed Oct 2011
56. Schatel, D. *Five practical steps you can take to promote successful home dialysis.* Dialysis and Transplantation 2010, vol 39 (8) pp326-327
57. AWAK – Portable PD http://online.wsj.com/article/SB10001424053111903454504576489293290757586.html?mod=googlenews_wsj accessed Aug 2011
58. Lauder, J, Ludlow, M.J, Hawley, C.M., Richardson E.P, Mathew, T, Munro, C.E *Australian Nephrology nurses views on home dialysis: A national survey.* Renal Society of Australian Journal 7(1)
59. CARI guidelines. <http://www.cari.org.au/guidelines.php> Accessed July 2011
60. KDOQI guidelines. <http://www.kidney.org/professionals/kdoqi/guidelines.cfm> Accessed Aug 2011
61. KDIGO. <http://www.kdigo.org/> Accessed Aug 2011
62. ISPD guidelines. <http://www.ispd.org/lang-en/treatmentguidelines/guidelines> Accessed July 2010
63. Stewart, S., Brown, J.B., Donner, A., McWhinney, I.R., Oates, J., Weston, W.W., Jordan, J. *The Impact of Patient-Centred Care on Outcomes* The journal of family practice September 2000 · Vol. 49, No. 9
64. Maddux, F.W. & Maddux D.W. *Characterising the ideal clinical office system for Nephrology* *Advances in chronic kidney disease* 2008 Vol 15:1, pp 64-72
65. Audit 4 <http://www.s4s.com.au/> Accessed Aug 2011
66. MMEX <http://www.mmex.net.au/> Accessed Aug 2011
67. Morton R.L, Tong A, Webster A.C, Snelling P, Howard K. *Characteristics of dialysis important to patients and family caregivers: a mixed methods approach.* *Nephrol Dial Transplant.* 2011 Apr 11. [Epub ahead of print]

68. W.A. GP referral to nephrologist http://www.healthnetworks.health.wa.gov.au/projects/kidney_disease.cfm W.A. GP referral algorithm http://www.healthnetworks.health.wa.gov.au/docs/CKD_Algorithm_RDHN.pdf accessed Aug 2011
69. KHA KCAT <http://www.kidney.org.au/HealthProfessionals/tabid/582/Default.aspx> Accessed Aug 2011 at
70. Lee A, Gudex,C., Povlsen JV.,Bonnievie B., Nielsen CP. *Patients' views regarding choice of dialysis modality* Nephrol Dial Transplant (2008) 1 of 7. Doi: 10.1093/ndt/gfn365
71. Schatell, D. *Home Dialysis, Home Dialysis Central, and What YOU Can Do Today* Nephrology Nursing Journal; Mar/Apr 2005; 32, 2; Health & Medical Complete pg. 235
72. Winterbottom, AE., Bekker,HL., Conner M. & Mooney AF. *Leeds Patient stories about their dialysis experience biases others' choices regardless of doctor's advice: an experimental study* Nephrol Dial Transplant (2011) 0: 1–7 Doi: 10.1093/ndt/gfr266
73. Western Australia Renal Nurse Educator group, Royal Perth Hospital, Sir Charles Gairdner Hospital & Fremantle Hospital
74. Match D <http://forums.homedialysis.org/showthread.php/1631-MATCH-D-New-Home-Dialysis-Tool> Accessed Aug 2011
75. Liaw, T., Lau P.,Pyett P., Furler J., Burchill M. Rowley K., Kelaher M., *Successful chronic disease care for Aboriginal Australians requires cultural competency* Australian and New Zealand Journal of Public Health Volume 35, Issue 3, pages 238–248, June 2011
76. Figueiredo, A., Goh B., Jenkins, S., Johnson, D.W., Mactier, R., Ramalakshmi, S et al *ISPD guidelines/recommendations – Clinical practical guidelines for Peritoneal Access*. 2010 Peritoneal Dialysis International, vol 30(4) : pp424-429
77. QLD State-wide renal clinical network workforce recommendations, June 2010
78. Victorian Maintenance renal Dialysis programme. Funding model – general information. <http://www.health.vic.gov.au/renaldialysis/funding.htm> (accessed Aug 2011)
79. Patient transport and accommodations <http://www.kidney.org.au/ForPatients/Finances/tabid/614/Default.aspx> accessed Aug 2011
80. Kidney Health Australia <http://www.kidney.org.au>
81. Therapeutic Goods Administration Australia <http://www.tga.gov.au/> Accessed Oct 2011
82. Agar, JWM. *Review: Understanding sorbent dialysis systems*. Nephrology 15 (2010) 406-411
83. NHS buyers guide for home haemodialysis <http://www.kidneycare.nhs.uk/Library/CEP10061.pdf> Accessed Aug 2011
84. Australian and New Zealand Electrical Guidelines for dialysis AS/NZS 3003:2011 <http://infostore.saiglobal.com/store/details.aspx?ProductID=1458596> Accessed Oct 2011
85. Policy and procedure for water testing, Section G Policy and procedure files. Western Australia Home Dialysis programme (Fresenius), 2009
86. NSW water for home dialysis http://www.healthfacilityguidelines.com.au/hfg_content/guidelines/WaterPreTreatmentHaemodialysisAT-HOME.pdf Accessed Aug 2011
87. QLD Government *State-wide renal network renal dialysis water sampling handbook*. The State of Queensland (Queensland Health) 2009. Accessed Aug 2011 at http://www.health.qld.gov.au/cpic/documents/water_samplingv2.pdf
88. Quality of dialysis fluid for haemodialysis and related therapies ISO11663:2009. <http://www.iso.org> Accessed Oct 2011
89. Agar, JWM. *Conserving water in and applying solar power to haemodialysis: 'Green Dialysis' through wiser resource utilization'*. Nephrology 15 (2010) 448-453
90. Fresenius Medical Care <http://www.fmc-ag.com/97.htm>
91. The HOME Network, sponsored by Roche and Kidney Health Australia email membership@thohomenetwork.com.au
92. Canada Standards Association Z364.5-10 *Safe installation and operation of hemodialysis and peritoneal dialysis in a home setting* <http://shop.csa.ca/en/canada/kidney-dialysis/z3645-10/inv/27031622010/> Accessed Oct 2011
93. Clinical and Related Waste Management policy. 2009 Government of Western Australia Department of Health
94. Booklet - Health Management Plan For End Stage Kidney Disease http://www.renalresource.com/booklets/HMPESKD_Guide.php#isurveillance Accessed July 2011
95. St George Palliative care <http://stgrenal.med.unsw.edu.au/StGRenalWeb.nsf/page/Palliative%20Care%20Section?Open> Accessed Aug 2011
96. Dialysis Escape Line <http://www.dialysisescapeline.com/>
97. Kidney Health Australia. Financial fact sheets. www.kidney.org.au Accessed Nov 2011
98. Centrelink. www.centrelink.gov.au
99. Kidney health Australia Consumer networks <http://www.kidney.org.au/ForPatients/ConsumerParticipation/tabid/606/Default.aspx> Accessed Oct 2011
100. Kidney Organisation UK Consumer groups <http://www.kidney.org.uk/> Accessed Aug 2011
101. Disaster planning: www.nxstage.com/are_you_ready Accessed July 2011
102. Business continuity plan WA <http://www.health.wa.gov.au/circularsnew/attachments/519.pdf> Accessed Aug 2011 at
103. Tam, P. *Peritoneal dialysis and preservation of residual renal function* Perit Dial Int 29(Supplement_2): 108-110 2009
104. North, K. *Correlation of stenosis with cannulation difficulties* Presentation at WA renal seminar day - Fresenius Midland Dialysis Unit, Perth. Not published.

105. Tattersal, J. *Bioimpedance analysis in dialysis: State of the art and what we can expect* Blood Purification, Vol. 27, No. 1. (2009), pp. 70-74.
 106. KDQOL36 <http://www.kdqol-complete.org/pdfs/KDQOL-Complete-Brochure.pdf> Accessed Aug 2011
 107. Labriola, L., Crott, R., Desmet, C., Andre, G., Jadoul, M. *Infectious complications following conversion to buttonhome cannulation of native arteriovenous fistulas: A quality Improvement report.* AJKD, 57:3. pp442-448
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