RENAL ASSOCIATION WORKING PARTY ON PERITONEAL DIALYSIS

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MEMBERS OF WORKING PARTY

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Background

Home dialysis, peritoneal dialysis (PD) or haemodialysis (HD), has many advantages for patients requiring dialysis therapy as patients are enabled to take control of their own medical treatment and thereby improve their sense of well-being. Home therapies also use fewer resources in terms of space required, numbers of nurses and reliance on hospital transport. Historically, the majority of patients in the UK dialysed at home – using HD in the 1970s and early 80s and then PD from the late 80s. Since around 2000, the number of patients on home dialysis has declined, so that currently, only 1-2% dialysis patients are on home HD and numbers starting on PD have declined from 40% in 2000 to 20% of dialysis patients in 2006 (1). Furthermore, there is huge variation with many centres in the UK having no or hardly any patients on home HD and less than 10% patients on PD. A wide spectrum of utilisation of home dialysis modalities is also seen within other countries and the national and international differences in the prevalence of home dialysis cannot be ascribed primarily to patient case-mix.

PD has many advantages for patients starting on dialysis. It enables patients to continue working, travel, socialise, care for other family members, etc, and as a home therapy, requires less adaptation to the home and is less intrusive than HD. PD may also permit carers and family members to help older and/or frail patients to have their treatment at home avoiding the disruption of 3 times a week travel to and from a HD unit.

The median age of patients starting on dialysis in the UK in 2006 was 65 years. Transplantation rates are rising with increasing numbers of living donor transplants, but many older patients have comorbidities making them unsuitable for transplantation and/or do not have suitable donors. This means that with an ageing population, the number of older
patients requiring dialysis will continue to rise. Proportionately fewer older patients, however, start on PD; in 2006 in the UK 30% patients <65 years old started on PD compared to only 17% of patients >65 years old. With the predicted increasing number of older patients, this trend will result in expanding HD numbers requiring more HD units and specialist HD nurses.

The decline in utilisation of PD is occurring in most Western countries. Several reasons have been suggested for this: lack of patient education, physician bias, belief that patient survival is poorer on PD, inadequate education and/or exposure of trainee nephrologists to PD, a belief that older patients cannot cope with a home treatment, and increasing numbers of more frail elderly patients who would require assistance from family or community-based healthcare workers. The situation is also confounded by the economic need to fill HD spaces once a unit exists – this is particularly important in private healthcare systems.

The English Department of Health recently established a working group entitled “National Specification for PD”. This working group had the following aims:

- To maintain the number of competitive providers in the PD market
- To maintain availability of the full range of PD products and services
- To achieve national consistency in pricing across England
- To achieve equity in patient access to all treatment modalities
- To set standards for quality of care and outcomes

Their report can be found at http://www.kidneycare.nhs.uk/IL/assets/Commissioning_of_PD_Pathway_Oct_09.pdf and should be read in conjunction with this Renal Association document.

Objectives of Renal Association Peritoneal Dialysis working party

The specific aim of the working party was to provide advice on how (within the UK) numbers of patients starting on PD could be optimised to ensure the patient receives the most appropriate therapy.

Where possible professional advice and guidance has been provided on the following issues:

- What are the advantages of home dialysis and PD in particular?
- How are patients educated to choose dialysis?
- Is the percentage of patients starting on PD a measure of quality of patient choice – and if so, how should this be monitored in a way which could reassure commissioners that patients are being provided with high quality care?
- What is the impact of the increase in pre-emptive transplantation in the number of patients starting on PD?
- How relevant are economic considerations?
- Is there evidence for physician bias and if so, what are the reasons?

Methodology

A literature review was performed by the working party. The working party met once and corresponded by email to produce a draft report which was posted on the Renal Association
website for comment by members. All comments were considered by the Clinical Affairs Board and the draft report amended to reflect the comments of members where it was appropriate. The working party subsequently reviewed and approved the final report.

**Patient survival on Peritoneal Dialysis and Haemodialysis**

There are numerous registry based studies from US, Europe and Australia comparing survival on HD and PD. All are confounded by the different case mix of patients choosing the 2 modalities. Attempts can be made to correct for these confounding factors by statistical adjustments for comorbidities, age, sex and cause of primary renal disease but there are other differences which are more difficult to make statistical adjustments for, e.g., social support, ability to work. Most studies suggest that survival on PD may be better during the first 2 years but thereafter any survival benefit is lost and survival on HD may become better with longer duration of dialysis. Any survival rate differences however are small and are hard to relate to the management of an individual patient. Vonesh in 2006 concluded from his review of recent publications and additional analyses of US Medicare data (2) that overall patient survival is similar for HD and PD, but there are differences within select subgroups of patients related to age and diabetes. These differences, though, were confounded by small numbers in some groups, and the differences in survival were small with limited clinical significance.

**CONCLUSION:** There is no convincing evidence for clinically significant differences in survival of cohorts of patients starting on either PD or HD.

**Technique Survival**

Technique survival is lower for patients on PD and is accepted as being 50-60% at 2 years (data from UK Renal Registry and NECOSAD study (3,4); i.e., 40-50% patients who remain alive and who are not transplanted will transfer to HD by 2 years. In a recent study of 3269 incident PD patients in the UK during 1999-2004 with a mean age of 59.9 years technique survival was <50% at 2 years (4). More dramatically this study observed a 45% technique failure rate over a mean observation of 430 days.

In contrast, in the NECOSAD study only 9% of HD patients transferred to PD after 2 years. Few HD patients are transferred to PD despite frequent problems with lack of reliable vascular access or inability to dialyse effectively because of symptomatic hypotension. Such patients appear to continue on HD rather than be transferred to PD despite multiple attempts at creating vascular access, often with limited longer term success.

**CONCLUSION:** Lower technique survival should not prevent patients being offered PD, though this information should be given as part of patient education. Longer technique survival is not necessarily the principal objective for many patients starting dialysis as many patients in clinical practice will be transplanted (younger patients) or will die (older patients) within 2 years of starting PD. Furthermore, the integrated care concept (5) demonstrates how PD as first line therapy can be utilised to provide good clinical outcomes.

**Quality of life, rehabilitation and satisfaction with treatment**

Studies on quality of life have looked at the dialysis population as a whole and have not been restricted to specific age groups. In all studies, PD patients are more likely to be younger, Caucasian, better educated, employed and have less co-morbidity. This creates
great difficulty in comparing quality of life outcomes on different dialysis modalities. Data from the CHOICE study shows that patients on PD are more satisfied with their treatment at 1 year (6), but overall most studies show that some items on questionnaires score better for PD and some other items score higher for HD (7, 8). No studies have specifically focused on how older patients cope with dialysis; this is being examined by BOLDE (Broadening Options for Long-term Dialysis in the Elderly) which is comparing several measures in matched patients on HD and PD (lead investigator, E Brown; funded by Kidney Research UK, results expected in 2009).

CONCLUSION: It is hard to capture “living with dialysis” with quality of life studies. Patients and families should be given realistic guidance how each modality will impact on their individual lifestyles.

Cost-effectiveness of haemodialysis and peritoneal dialysis

Only one study (9) has formally measured costs of dialysis in the UK, but this was based on stated supplier price lists and not contracted prices. “Payment by Results” tariffs for dialysis are expected to be introduced in 2010/11, so a systematic cost effective analysis was not possible. However, it was generally agreed that costs of PD treatment are less than standard HD for several reasons:

- fewer nurses needed
- lower capital costs
- greatly reduced costs for patient transport
- less erythropoietin used in PD (10)

CONCLUSION: A higher proportion of patients placed appropriately on PD with a concomitant reduction in the proportion of patients on hospital HD would reduce overall expenditure on renal replacement therapy. Ultimately this would release funds which could support the anticipated future growth in renal replacement programs or other healthcare initiatives or requirements.

Patient choice and education

Patient choice is enshrined in the National Service Frameworks for renal disease. Education is essential to enable patients to make choice, but there are no UK guidelines how this should be delivered and what information should be given to patients. Education is mostly given by predialysis nurses, but it was recognised that subliminal bias of clinicians can make patients feel that they have no choice. The role of the predialysis nurse has emerged over the last decade; there is no formal training for the role and there is no professional group overseeing objectives and standards of education. This issue was also considered by the “National Specification for PD” working group.

Manns et al (11) showed in a randomised control trial that one-to-one education enables patients to make a choice; indeed, in this study, 80% patients in the intervention group chose a home therapy.

How dialysis education is delivered varies considerably across the UK; some units offer group sessions only, while others offer individual sessions in the hospital or in the patient’s home. Predialysis nurses also take on other roles, such as anaemia management, management of conservative care patients, and so with increasing numbers of predialysis patients, many have little time for education outside the clinic setting. Furthermore, many patients approaching dialysis are elderly, often with a degree of cognitive impairment, and
many will have hearing or visual problems making it difficult to follow information. These patients, and the many patients from ethnic minorities with a poor understanding of English, will often not attend group sessions and will need their education tailored to their special needs – this tends not to happen.

Two studies have looked at outcomes when patients are enabled to make free choice. The first, and largest, comes from the NECOSAD study (12); this was set up to perform a randomised study of HD compared to PD; only 38 patients agreed to enter the study. Of the remaining 1347 patients, about a third was deemed not to be suitable for medical or social reasons to be able to make a choice. Of the 64% who could make a choice, half chose PD and half chose HD. The other study comes from Toronto (13); in this group of patients, 58% of those assessed as able to make an informed choice of dialysis modality selected PD. The results of these 2 studies are therefore similar, suggesting that around 50% of informed patients able to make a choice of dialysis modality will select PD.

Which patients select PD? The NECOSAD study looked at this in detail and showed that patients choosing HD tended to be older, live alone, have vascular renal disease, have more comorbidity, be less likely to have predialysis care, be unemployed and have lower educational level. These are the same categories of patients who are often assessed as unable to make a choice of their dialysis modality.

Despite all the above observations, the experience of working party members suggests that education as currently provided does not always enhance selection of home treatment by patients. This was thought partly due to information overload, inappropriate style of education (written and oral), and discrepant information given about PD and HD.

There are a number of qualitative studies examining specifically how patients make choices and their perceived role in the process (14). All highlight how choice changes over time, the importance of trust and the need for accurate information, but also the importance of understanding the patient’s perceptions and roles they want to play which clinicians need to identify and review regularly. Some studies have also identified the role that physicians play in guiding decisions (15).

CONCLUSION: With appropriate education, studies show that 50% of patients who are deemed able to choose a dialysis modality will opt for PD and up to 80% will select home dialysis (peritoneal and home HD). Patient education should focus on the choice between home versus hospital based treatments, and then discuss PD versus HD only once patients have discussed where they would prefer their treatment to take place. The lack of UK guidelines for dialysis education should be rectified.

Patient awareness of the complications of peritoneal dialysis and haemodialysis

The main complications of PD and HD should be discussed with patients before they make a choice of dialysis modality.

All patients considering opting for PD should be aware of:

1. Risk of peritonitis (one episode of peritonitis every 20 months of PD in Scottish audit 2002-2007)
2. 50% risk of technique failure and switching to HD after 2 years
3. Possible development of Encapsulating Peritoneal Sclerosis during or after stopping PD (incidence of 3.5% after 3-4 years of PD and 8% after 4-5 years of PD in incident Scottish PD patients 2000-2007) (16)
Similarly all patients thinking of opting for HD should be aware of:

1. Risk of local infection of the vascular access and bacteraemia, especially with the use of central venous dialysis catheters (e.g. 1 episode of catheter related bacteraemia every 12.6 catheter months in a prospective audit at Glasgow Royal Infirmary 2005-2007).

2. Risk of developing infective endocarditis and metastatic bacterial infection of the spine and joints complicating local infection of the vascular access or bacteraemia.

3. Small risk of technique failure and switching to PD

4. Risk of bleeding complications from the regular use of anticoagulation during HD

Encapsulating Peritoneal Sclerosis (EPS) is well recognised as a severe complication of long-term PD, occurring in around 8% of patients who have been on PD for 4-5 years (16). HD also has severe complications (complications of line infections, e.g. endocarditis, discitis, venous thrombosis, need for multiple and increasingly complex vascular access procedures), though their rates are not as well documented as for PD. EPS is increasingly being used as a reason for not putting patients on PD, partly because many nephrologists see the few inpatients with EPS in each unit much more frequently than the many more healthy outpatients on PD.

CONCLUSION: Patients should be told that both dialysis modalities have complications which can be severe and life-threatening. The risk of EPS, itself, is not a reason to avoid using PD. The majority of patients will be transplanted, will have transferred to HD or will have died within 5 years of starting PD. PD teams should be pro-active and provide appropriate guidance about the risk of developing EPS before and after starting PD and especially as patients approach 5 years on PD. Any information (oral or written) should be carefully considered, consistent and appropriate.

Patient selection for home dialysis

In all studies, it is recognised that various medical and social factors are barriers to home dialysis and that therefore not all patients can be realistically given choice. It is well recognised that there are more barriers preventing PD than HD. Social factors preventing home dialysis are more frequent amongst older patients (e.g., lack of social support, availability of assistance if the patient is unable to do dialysis independently because of impaired manual dexterity, cognitive problems or physical frailty) and in areas with poor housing accommodation with overcrowding and lack of space to perform the dialysis or store supplies. In published studies (12,13,17), 20-36% patients were designated as not suitable for PD for such reasons.

Inevitably there will be significant variation among units depending on social factors, e.g., age and social mix of population, proportion of ethnic minorities with a poor command of English, living in crowded accommodation, availability of home assistance with treatment. Review of Renal Registry data, though, shows that high rates of patients starting on PD can be achieved in areas with a high proportion of patients from ethnic minorities (e.g., Barts and the London, Leicester) (18). Therefore the factors influencing selection for home therapy are complex. It is likely that clinician bias for or against home treatment also impacts on proportion of patients thought to be unsuitable for home treatment (19,20).

CONCLUSION: Although studies show that only a third of patients are not suitable for PD, allowance needs to be made for areas of the UK where there are large numbers of ethnic minorities, poor housing and a high proportion of frail elderly. The opinion of the working
Impact of pre-emptive transplantation

It is often suggested that the increase in pre-emptive transplantation is one of the reasons for the observed decline in patients starting on PD. This is not necessarily true as many UK centres with high rates of pre-emptive transplantation also achieve an average or even above average percentage of incident patients starting on PD (1). However an increase in living donor transplantation may impact on the prevalent rates of PD.

CONCLUSION: Pre-emptive transplantation will lower the number of patients who may otherwise start on PD but is not a reason for a low uptake of PD.

‘Crashlanders’ and acute start peritoneal dialysis

Up to 30% of patients starting dialysis do so unexpectedly, either because of late referral and/or presentation, or because of more rapid decline in renal function than expected. Such patients are mostly started on HD with central venous dialysis catheters. Some units are proactive about subsequent education and choice of modality but in the majority of units such patients are given little or no education about dialysis in the HD unit and therefore have no or little choice of modality. Although HD is the optimal modality for patients with a severely metabolically disturbed acute presentation of end-stage kidney disease, there is no reason why more stable patients could not be started directly on PD. Historically, this happened very successfully, and a few units are introducing a programme of “acute start PD”. There is evidence that outcomes are identical for late presenting patients starting on PD and HD (21). The main factor limiting the use of acute PD is the difficulty of getting a peritoneal catheter inserted. This may be especially the case in units where nephrologists do not insert catheters themselves and are therefore dependent on surgical colleagues.

CONCLUSIONS: Enabling ‘late presenters’ with irreversible renal failure to start directly on PD will increase the number of patients eventually choosing PD. All patients who present late and start dialysis urgently should receive individualised education within 3 months of starting treatment.

Restarting dialysis after transplant failure

It is important that patients with failing grafts are as well managed as patients with similar levels of renal function in low clearance clinics. There is anecdotal evidence that this may not always be the case. In particular, it is often assumed that they know about dialysis and choice of modality is not discussed with them. However, some will not have been on dialysis previously and for many their last experience of dialysis will have been many years previously. The majority of patients with a failing transplant are started on HD, despite evidence that outcome is at least as good amongst patients starting on PD after failure of a transplant (22).

CONCLUSION: Patients with failing transplants should have access to education about dialysis modality choice.
Elderly and assisted peritoneal dialysis

The median age of patients presenting with end-stage kidney disease in the UK is now 65 years. Many such patients will have barriers to PD as discussed by Oliver et al (13). These include medical factors (e.g., visual and hearing problems, arthritis, frailty) and psychosocial factors (e.g., depression, needing residential care, cognitive problems). Using a multidisciplinary approach, it is possible to overcome many of these barriers so that the majority of patients can be considered as eligible for home treatment and therefore enabled to choose PD (23). In Oliver’s experience, access to home care assistance increases eligibility further with up to 80% of patients (median age 72 years) considered as suitable for PD. This has been standard practice in France, where PD at home with the assistance of community nurses, is considered as the optimal method of providing dialysis to frail older patients, with the result that the age distribution of PD is considerably skewed to over 70 years and upwards (24). Assisted PD has recently been introduced into the UK by utilising healthcare assistants from a private healthcare agency. This greatly increases the cost of PD such as it approached that of centre HD. However, it can reduce transport costs which can be considerable as many frail patients would need ambulance transport to the main centre dialysis unit rather than to a local satellite unit. The costs of assisted PD are currently not recognised by the commissioning process.

CONCLUSIONS: It is important to recognise the potential advantages of home treatment for the quality of life for older patients – particularly the avoidance of the need for transport to and from a HD unit, which is the commonest source of complaints from HD patients. Dialysis education should be tailored to the patient so that individual barriers can be discussed. The development of home assistance will enable more older and/or frail patients to dialyse at home, but this needs to be appropriately funded and recognised in the current development of “Payment by Results”.

Staffing of peritoneal dialysis units

Staffing structures for PD around the UK vary depending on local factors. In some units, there is a consultant in charge of PD patients and the nursing team work solely on the PD unit. In other units, patients remain under the care of their referring consultant, or are allocated a consultant depending on where they live. Nurses may also rotate in and out of the PD unit or may have roles in other areas. The model of a consultant and senior nurses in charge of PD provides local champions who can promote knowledge and training about PD (medical, nursing and patient) and can ensure high quality care in patients established on PD

CONCLUSION: There should be identified local medical and nursing leads in PD

Medical training in peritoneal dialysis

Many trainees have limited exposure to PD during their training programs. This may be one of the factors leading to a decline in its use. Many trainees only see inpatients with major complications of PD and do not review fit outpatients on PD. This problem was recently discussed by the PD leads in London who produced a document specifying a range of training recommendations. These have been endorsed by the North and South Thames training committees and submitted to the SAC for their consideration.
CONCLUSION: A lack of medical expertise in PD will pose a significant challenge to the use of home therapies in the future. Requirements for training in PD should be strengthened by the SAC in the renal speciality curriculum, to ensure all trainees have undergone the necessary training and have achieved the necessary competencies to allow them to manage patients on PD.

Training for nurses in peritoneal dialysis

Nurses in HD units or on renal wards often know little about PD. Renal courses may often only contain 2-3 weeks dedicated to PD. This means that patients who are finding HD difficult or find themselves on HD after “crashlanding” may be given no or inaccurate information about PD. Furthermore, programmes are needed to update PD knowledge and skills for ward nurses to ensure that PD patients are appropriately managed while inpatients to reduce their risk of acquiring peritonitis at a time when they cannot manage their own dialysis.

CONCLUSION: All renal course nurse students should gain adequate PD experience including home visits and attending PD patient clinics. PD knowledge skills in ward and HD teams should be maintained by continuing education. Rotational posts into the PD team should also be considered

RECOMMENDATIONS

1) Dialysis education for patients
   a) UK guidelines for delivery of dialysis and transplantation education are urgently needed
   b) There should be an accredited course designed to teach predialysis nurses the principles and practice of patient centred education
   c) Consideration should be given to understanding and costing the necessary resources to provide good quality predialysis education to enable adequate reimbursement.
   d) Appropriate education about transplantation and all modes of dialysis should be delivered to all patients – i.e. patients at predialysis clinics, patients with failing transplants and late presenters
   e) All patients (including patients with failing transplants) should have a one-to-one education session away from the predialysis clinic or dialysis unit
   f) Written information should be based on a nationally recognised and peer reviewed template

2) The percentage of patients starting home dialysis should be reported by the UK Renal Registry
   a) All patients suitable for home treatment should be offered the choice of home dialysis
   b) Equity of access to home therapies should be provided regardless of ethnicity, social disadvantage and age
      i) Guidance should be developed regarding clinical and social suitability for PD (to be used for patient assessment and for additional assistance that may be required for individual patients)
ii) Resources for disadvantaged social groups should be identified, developed and commissioned

c) Patients failing PD should be offered home HD to enable them to continue on home treatment

d) All units should report the initial modality of dialysis of incident patients and their modality of dialysis at 6 months after starting dialysis to the UK Renal Registry to permit audit of their performance against their peers (see appendix 1)

e) The UK Renal Registry will provide comparative data on the prevalence of home therapies to renal units and commissioners

f) An education process for renal commissioners should be developed to enable them to scrutinise and challenge the performance of provider units

g) Commissioners should review the performance of their local providers and should develop a view on a prevalence of patients on home therapies which would be appropriate for the patients they serve.

h) Where the performance of a provider unit is significantly different from their peers (as alerted by the UKRR) or significantly different from commissioner expectations the unit should be asked by the commissioners to provide an explanation for this variance

i) Commissioners should support (with financial incentives if required) the providers to develop 3 year plans to achieve a prevalence of patients on home therapies which has been agreed to be appropriate for their area

3) Physician and Nursing lead for PD
   a) There should be a designated physician and nursing lead for PD in each renal unit. These leads should act as clinical champions for PD and ensure that appropriate protocols and training are in place to support the PD program

4) Assisted Peritoneal Dialysis
   a) Further research into the benefits and cost effectiveness of assisted PD are urgently required, recognising that assisted PD is already being used in some centres.

   b) If the evidence supports its use, an appropriate tariff should be developed through the Payment by Results process to support the implementation of assisted PD

5) Dialysis related complications
   a) The Renal Association should define a dataset of major complications associated with the use of PD which could be collected by the UKRR (alongside a set of complications for HD). Accurate data around serious dialysis-related complications will result in:
      i) Appropriate clinical management decisions for patients regarding dialysis modality and the need for change
      ii) Accurate information becoming available to patients regarding risk of treatment
      iii) Identification of the impact of severe complications on cost of treatment
Local data regarding major complications of PD (alongside those of HD) should be collected and made available to commissioners. This will enable monitoring of quality and patient outcomes.

6) **Medical Training in Peritoneal Dialysis**

   a) The SAC should strengthen their training recommendations for nephrology trainees along the lines already agreed by the London Deanery. Specifically all trainees should:

   i) attend a minimum of 15 PD clinics during their training
   
   ii) attend a national course or local dialysis training day which includes a component about PD
   
   iii) complete a miniCEX and CBD (case based discussion) on PD
   
   iv) complete the Renal Association sponsored PD e-module during their training and produce a certificate at their next RITA.
   
   v) visit a PD or home HD patient at home at least once during their training

7) **Training Nurses in Peritoneal Dialysis**

   a) Renal course nurses should spend longer training in PD (e.g., up to 6 weeks), experience home visits and PD patient clinics

   b) PD skills should be maintained in HD and ward nursing teams by ongoing training which could include rotation into the PD unit where locally feasible

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**REFERENCES**


Conflicts of interest

Dr Robert Mactier has been local principle investigator for multicentre studies conducted by Roche, Amgen and Baxter, was a member of the clinical advisory board for Baxter in 2005 and has received support to attend scientific meetings from Amgen, Leo, Roche and Baxter.

Prof Edwina Brown has received speaker and consultancy fees from Baxter Healthcare.

Dr Stan Fan has received travel expenses and speaker fees from Baxter Healthcare and Fresenius Medical Care. His department have received educational grants from Baxter Healthcare and Fresenius Medical Care.

Appendix 1

The appropriate percentage of incident patients on home dialysis at 6 months after starting dialysis is likely to vary from area to area depending on patient demographics, social deprivation and other socio-economic factors. The working party therefore did not feel that it was appropriate to set a specific target for the percentage of incident patients on home dialysis.

However the Working Party considered that across the UK as a whole, a figure of 25% of incident patients on a home therapy at 6 months after starting renal replacement therapy would be a realistic minimum figure. This proportion of incident patients is derived from data from the literature on patient choice of dialysis modality (11-13) as follows:

iv) 10% patients may receive pre-emptive transplants

v) 90% therefore will start treatment on dialysis; at least 50% of these will be eligible for home treatment i.e. 45% of total population

vi) 60% of patients eligible for home treatment will choose a home treatment if they are given appropriate education and an approach to overcoming barriers is adopted i.e. 25% total population.

The timeline for auditing the proportion of patients on home dialysis was chosen to allow late presenters to be established on the dialysis modality of their choice and provide adequate time for patients to complete training on home HD.