

Improving Choice: Home Therapies

1. Executive Summary

We are moving towards a very interesting time in healthcare. The recent change of government, along with the challenges of the economic climate and its inevitable financial constraints on public sector spending, are reinventing the way we look at healthcare provision. The new white paper *Equity and Excellence: Liberating the NHS* upholds the founding principles of the NHS – free to all, based upon clinical need – and also supporting patient choice at the heart of decision making, with the pledge: *no decision about me without me*.

Self care, care at home and home dialysis offer real benefits for kidney patients and link closely to the vision of an NHS that is organised around patients, giving them more choice, convenience and control over their care. During 2010 NHS Kidney Care has been engaging directly with home dialysis patients and local care teams to influence service redesign with a series of nationwide events designed for “Improving Choice for Kidney Patients”. There have been 10 events, one in each Specialised Commissioning Group Patch, to promote choice for kidney patients within the planning and commissioning of kidney services.

In total, 326 delegates attended the ten events, representing 83 different NHS Trusts and 10 Specialised Commissioning Groups. The majority of delegates represented hospital trusts with primary care represented in six of the ten regions (North West, Yorkshire and the Humber, South West, South East Coast, West Midlands and East of England). During the half-day workshop presentations were heard from local clinical champions and commissioners followed by interactive sessions undertaking a gap analysis specific to the local needs and services currently available.

Valuable as these presentations and discussions were, one of the most powerful parts of each of the ten events was the personal story told by a resident from each region of his or her personal experience of home dialysis. In some cases the partner of the person who dialyses at home also spoke about the impact home dialysis has on their lives.

With permission from the people who described their experience nine of the home dialysis patient stories have been captured, either by recording them at the event, and/or by interviewing the person shortly afterwards. NHS Kidney Care has published these stories to highlight the experiences of home dialysis. A summary of these patient stories is included in this report. http://www.kidneycare.nhs.uk/_Ourworkprogrammes-Improvingchoice.aspx

In 2011 NHS Kidney Care hosted an eleventh “Improving Choice” event specifically for patients and carers. Home Haemodialysis patients gave presentations to illustrate their experiences of dialysis at home. Workshops were conducted with delegates in order to further understand their support and information needs, and examine how services can be improved to meet their requirements. Workshops focussed on the following areas:

- Engaging patients in the commissioning of home therapy services
- Measuring quality of life for kidney patients
- Shared decision making and care planning
- Making renal data accessible to patients and the public.

As a result of this opportunity to focus on outcomes, action plans for each patch are now developed with sign off from each Kidney Care Network Board which will enable us to measure the local and national impact of enabling genuine choice for kidney patients.

The big question:

Where would you like to have your dialysis?
At hospital or at home?

Dr Richard Fluck, Consultant Nephrologist, Derby

2. Background

2.1 Changing choices

Home Haemodialysis started in the 1960s and for a time was the most common form of dialysis. Since then, there has been a move away from home haemodialysis with treatment in hospital and satellite units being the fastest growing dialysis location. This is due to a number of factors, including:

- increased transplantation rates
- a continuous rise in the number of patients with end stage renal disease (7,000 to 45,000 between 1982 and present), and an associated significant increase in the median age of the dialysis population
- the emergence of continuous ambulatory peritoneal dialysis (CAPD)
- .-availability of ring-fenced capital

2.2 National trends

Nationally there is wide variation in uptake of home dialysis. Current Trends (2008 UK data)^{Ref 2009 UKRR} indicate that:

- In-centre dialysis is rising at 5.9%
- Peritoneal dialysis is down by 9.2%
- Home haemodialysis shows modest increases – but some units have limited or no programme

The following graphs show the current national treatment trends

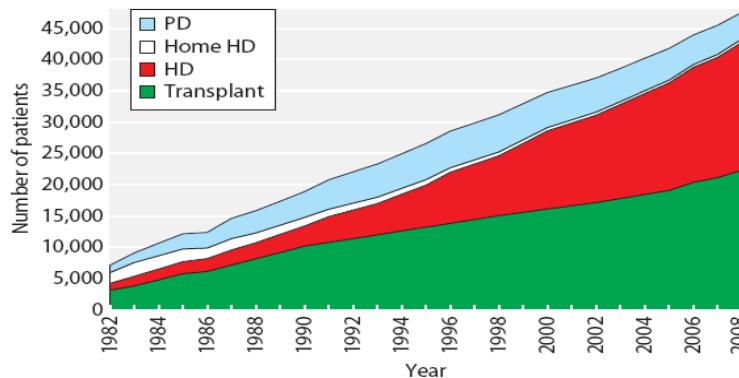
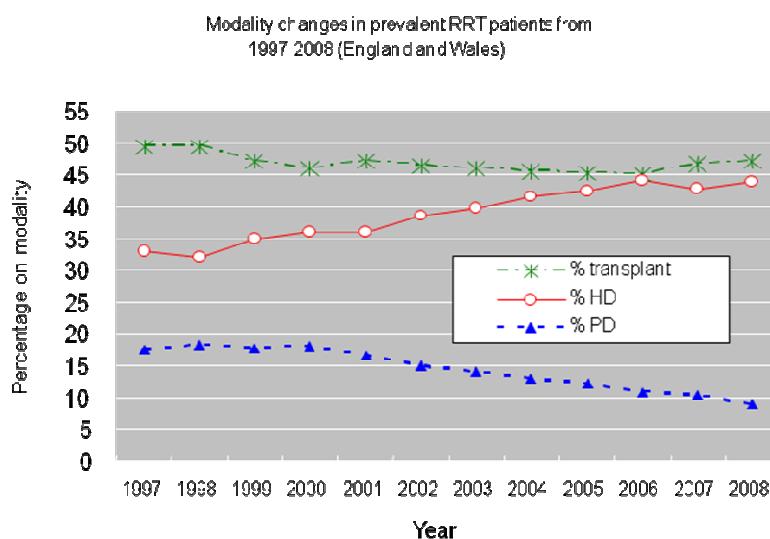


Fig. 4.3. Growth in prevalent patients, by treatment modality at the end of each year 1982–2008



2.3 Drivers for change

The key national and local drivers for change that underpin commissioning decisions to support home dialysis are listed below:

- Equity and Excellence: Liberating the NHS
- NHS From Good to Great- Preventative, People Centred, Productive
- Quality, Innovation, Productivity & Prevention (QIPP)
- Achieving Excellence in Kidney Care
- Improving Choice: NHS Kidney Care Report.
- Improving Choice: Toolkit for Home Haemodialysis
- NHS Kidney Care Peritoneal Dialysis Specification
- End of Life Care for AKD: A framework for Implementation
- National Institute for Clinical Excellence “Guidance on home compared with hospital haemodialysis for patients with end stage renal failure”
- Financial forecast

Patients report real benefits and improved outcomes from home dialysis including

- Better quality of life.
- Increased freedom
- Reduced travel
- Reduced dietary and fluid restrictions
- Reduced symptom and medication burden
- Improved recovery time
- Ability to continue in employment

There is strong evidence that more frequent daily haemodialysis, especially nocturnal haemodialysis, offers better quality of life, morbidity and mortality benefits compared with three times weekly haemodialysis. NHS Kidney Care has produced short films wherein home haemodialysis patients detail the clinical and psychosocial benefits of dialysing at home. http://www.kidneycare.nhs.uk/_Ourworkprogrammes-Improvingchoice.aspx

We know that the population needs for dialysis and transplants will grow. Home dialysis provides a solution to providing more capacity, alleviating the need for more buildings and infrastructure. Home dialysis is both a clinically and cost effective option. This will not be an option for everyone but we need to promote the opportunity to self care.

The current centralised model of kidney care represents a serious drain on NHS resources. Despite representing just 0.1% of the population, 2% of the NHS budget is spent on services for dialysis and transplantation patients.

In the 2002 guidance NICE advocated home dialysis as a more cost-effective treatment than hospital dialysis and its expansion as an opportunity to ease the capacity burden on hospitals. NICE have stated that up to 30% of patients (Haemodialysis and peritoneal dialysis) would be suitable for, and should receive, home dialysis but this has not been implemented at a local level.

3. Evaluation of Roadshows

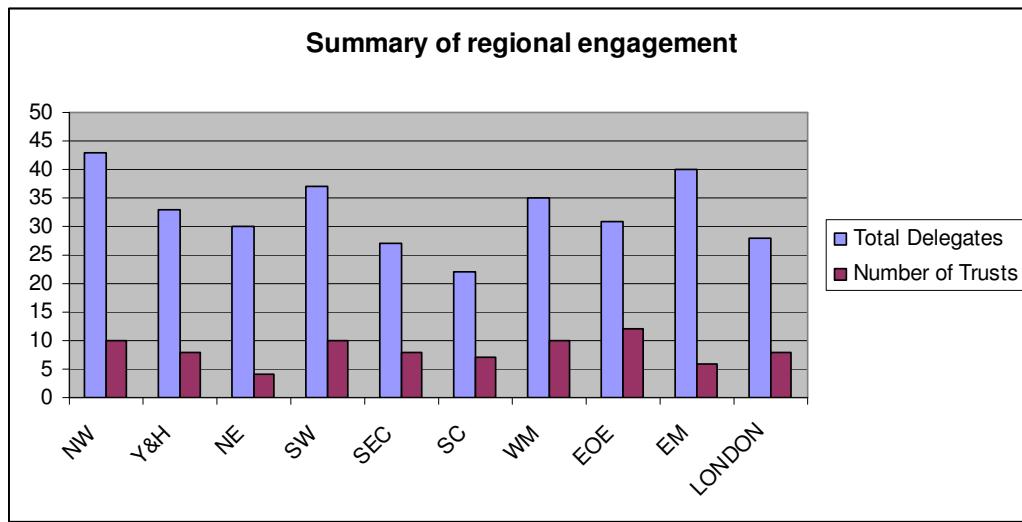
3.1 Summary of reach of engagement.

The ten NHS Kidney Care events, conducted between April and September 2010 in the specialised commissioning group regions, were evaluated in two ways;

1. Data were collected to develop a profile of delegates. This involved recording the job title and employing trust or organization of each attendee.
2. End of day evaluation forms were completed by delegates, to gauge how useful they found the event

In total 326 delegates attended the ten events, including NHS Kidney Care and Department of Health representatives. Attendance at each event ranged from 22 to 43 delegates, with the mean attendance being 32.6 delegates and the median 32. Delegates came from 83 different NHS Trusts and 10 Specialised Commissioning Groups. The majority of attendees worked for Hospital Trusts. Primary Care was represented in six of the ten regions (North West, Yorkshire and the Humber, South West, South East Coast, West Midlands and East of England) but not in the North East, South Central, East Midlands and London regions.

Figure 1. Number of delegates (n=326) and number of NHS Trusts (n=83) by region.



3.2 Delegates represented

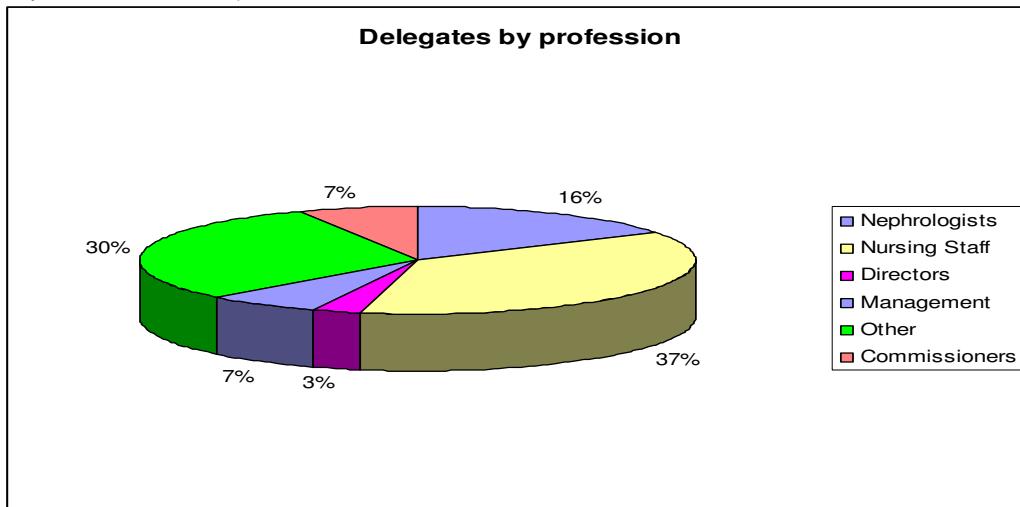
There has been a healthy variety of delegates attending the events. The majority of attendees have been nursing staff, with consultant nephrologists making up eleven per cent of the total delegates (n=41). This level of clinical engagement is encouraging, and is possible evidence of local clinicians acting as champions for home therapies.

One in ten delegates was a Director or at Senior Management level. Representation from commissioners has been high with Specialised Commissioners present at each event. In addition, the events facilitate engagement with many professionals associated with all aspects of home therapies including psychologists, dieticians, technicians, public health specialists, patient advocates, patients, carers, training managers and supplies managers.

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Three of the “Improving Choice” events have been attended by a member of the Renal Policy Team from the Department of Health. The Head of Branch of the Vascular Programme at the Department of Health attended the London event. Events have also been attended by Chair of the Kidney Alliance, by academics and by patient advocates from the National Kidney Federation.

Figure 2. Percentage of delegates by profession (excluding representatives of NHS Kidney Care and Department of Health)

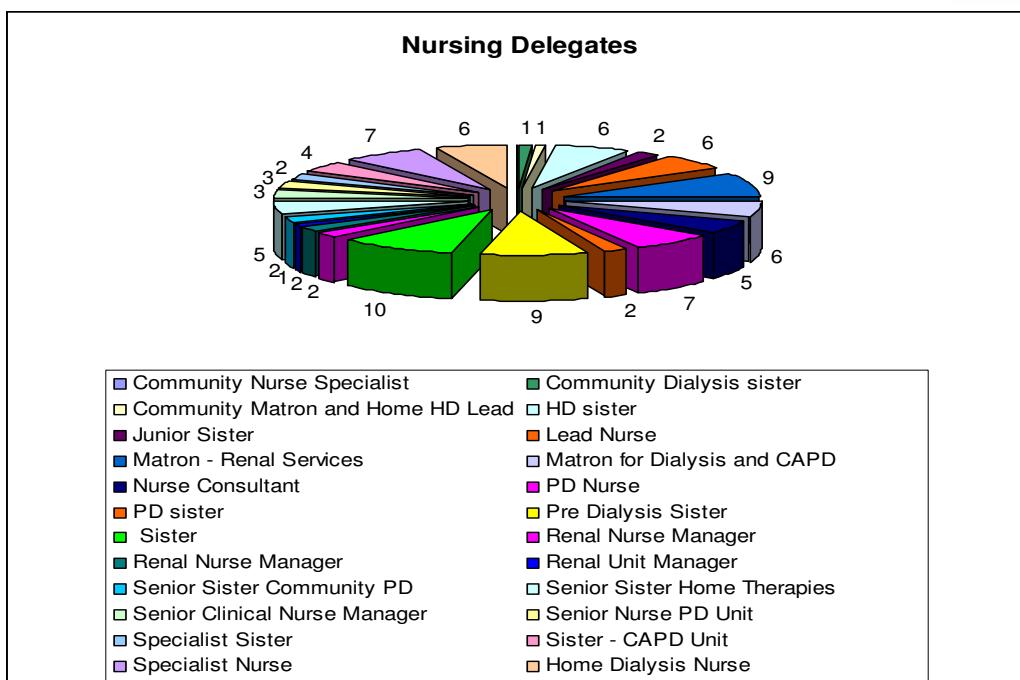


“Other” indicates allied health professionals such as dieticians and technicians, patients and carers, academics, clinical scientists and engineers.

3.3 Nursing Delegates by job title

Nursing professionals represented nearly 25% of the total number of delegates (n=101). A wide variety of nursing staff attended the events, including nine Pre-Dialysis sisters and nine Renal Service Matrons. Both Home Haemodialysis and Peritoneal Dialysis nurses were represented across the 10 regions, indicating the importance of recognising both modalities when discussing choice in Home Therapies.

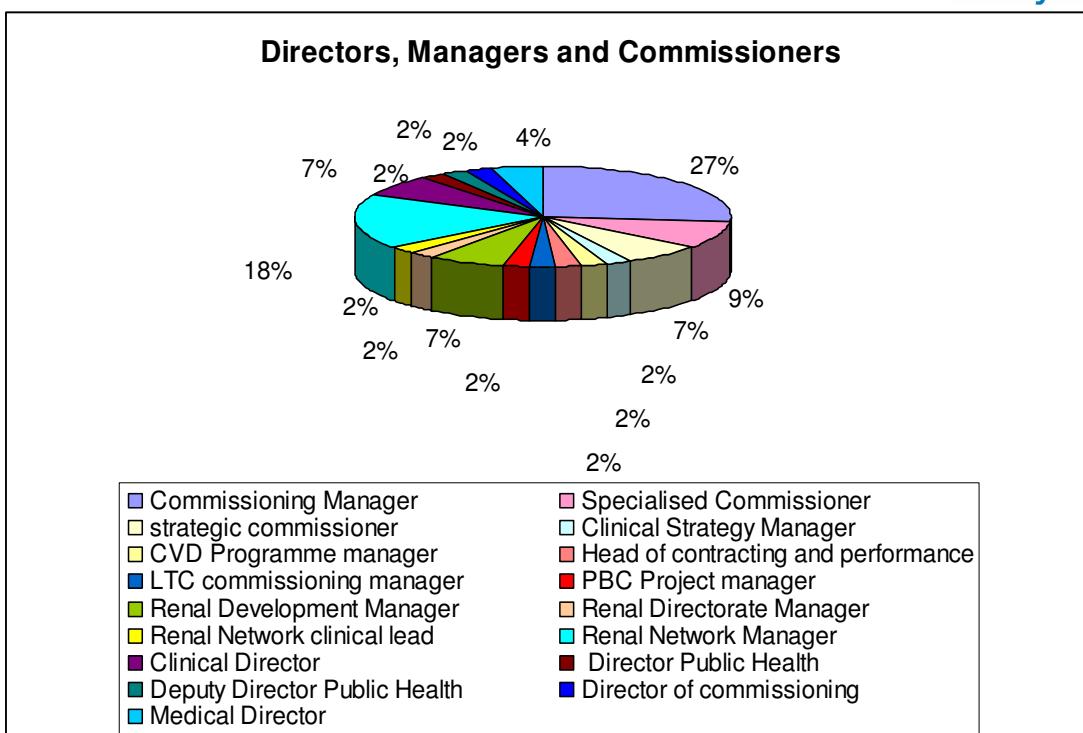
Figure 3. Breakdown of total nursing (n=101) delegates by job title



3.4 Directors, Managers and Commissioners

The majority of delegates in this category defined themselves as “Commissioning Managers”. There has been a high managerial/policy and commissioning presence at each of the ten events.

Figure 4. Breakdown of total Directorial, Managerial and Commissioning delegates (n=71) by job title



3.5 Key findings from the End of Day evaluation.

In total, 217 delegates completed end of day evaluation forms, representing 67% of all attendees (mean completion = 21.7 completed forms per event.).

Feedback from clinicians, nursing staff and managers at all ten events has highlighted the importance and value placed on the patient and/or carer presentations. The presentations by patients and carers were consistently rated very positively by delegates in each region. More than 20 patients and carers attended in total.

Overall the workshop sessions have been rated as “useful” or “very useful” in all regions, and delegates have provided constructive feedback around the organization of each event and the suitability of each venue. Delegates agreed that the events were well organized and found them interesting and informative. On several occasions delegates have commented that local follow up events would be welcomed.

3.6 Samples of feedback from delegates:

“An excellent forum to initiate discussions on the case for expanding home therapies”

“The patient was excellent, very emotive, highlighting the need for more peer support”

“Very informative, highlighted many areas of resources available, much needed information, would very much like a repeat please to review progress”

“The event was not long enough- a full day is needed to allow for Question and Answer time”

“Providing consistent and real choice requires collaboration between patients and clinicians”

“This was a local meeting and could begin earlier and last for the whole day. We needed more Question and Answer time and a session to share best practice”.

4. Patient stories

Perhaps the most powerful parts of each of the ten events were the personal stories told by home dialysis patients and their partners.

With permission from the people who described their experience, nine of the home dialysis patient stories have been captured, either by recording them at the event, and/or by interviewing the person shortly afterwards. Information from these stories paints a powerful and personal account of the situations, options and implications relating to home dialysis, for those who dialyse and for those closest to them.

NHS Kidney Care has published a report of these stories

<http://www.kidneycare.nhs.uk/Library/ImprovingChoiceListeningtoPatientStoriesFINAL.pdf>,

highlighting the experiences of home dialysis under the following headings:

- How do people discover home dialysis?
- What factors influence the decision to dialyse at home?
- What training is required for home dialysis?
- What adaptation is required for home dialysis?
- What are the advantages of dialysing at home?
- What are the costs and challenges of dialysing at home?
- What improvements are yet to be made?
- What advice would those using home dialysis give to those considering it?

Below is a summary of the full report.

A wide range of people dialyse at home; there is no typical age or health history for home dialysis. Despite these differences there was much commonality in the views and experiences of the nine people on whom the report is based.

4.1 How do people discover home dialysis?

Different hospitals take very different approaches to home dialysis. In some areas hospitals proactively offer home dialysis to patients while in other areas dialysis patients who are interested in home dialysis have to request, demand or push for it.

4.2 What factors influence the decision to dialyse at home?

A range of considerations influence a dialysis patient's decision whether or not to dialyse at home. People sometimes change their mind about the significance of the factors over time, and/or their circumstances may change. Influential factors include:

- feeling daunted if new to dialysis
- wanting to keep dialysis separate from home life
- not wanting to lose the sociability of dialysing with others at a unit

- the convenience or inconvenience of their current dialysis arrangements
- the views and concerns of their partner.

4.3 What training and adaptation is required for home dialysis?

The experience of training for dialysis highlighted areas for comment and/or improvement. People who learn to self-care as part of their regular dialysis practice tend to make the transition to home dialysis most smoothly. Training is most effective when it takes place in a calm and relatively quiet environment, at a speed at which people feel comfortable and unhurried. Training that is only available in working hours creates a significant challenge to people who are working, and/or for their partners who may be working. More time and attention is needed during the early decision and training stages for partners of those who dialyse at home and/or for those who support home dialysis patients to ensure that they are aware of the implications for their lives and that they are well supported to address concerns. Some home dialysis patients depend on their partners for the process of dialysis and their partners are involved in the training; others are completely self-caring. Even partners not directly involved in the process of dialysis should be offered the opportunity to consider and discuss the implications of home dialysis for their life. If partners are involved in the dialysis process it is essential that they receive enough information, training and support to feel confident in what they are doing.

4.5 What are the advantages of dialysing at home?

The following advantages were mentioned by people who dialyse at home:

- improved health from more frequent dialysis in both short and longer term
- flexibility of choosing when to dialyse and the freedom that brings
- for those who previously lived a long distance from their dialysis unit, less time spent
- more relaxed fluid and dietary restrictions
- the satisfaction of taking personal responsibility for their own health.

Nocturnal dialysis brings added benefits of freeing up more time and even greater health improvements.

4.6 What are the costs and challenges of dialysing at home?

Costs and challenges of home dialysis are the extra time involved, not only through more frequent dialysis but also time spent on cleaning and maintenance. Space is needed for equipment and storage; confining and containing dialysis to avoid it being too constant a presence can be a challenge. Constraints on water use in the house while dialysis is in process can create difficulties for the household. Home dialysis creates large amounts of non-recyclable waste. Some people experience considerable anxiety when unable to quickly access technical support, especially outside business hours. Home dialysis inevitably places additional pressure on partners of those who dialyse, especially if they play a crucial role in the dialysis process.

4.7 What improvements are yet to be made?

Improvements suggested for home dialysis include ensuring a fast response when technical support is needed, even if after hours, and ensuring that home dialysis patients and those who support them feel confident in their ability to cope with technical difficulties, and better able to believe that adequate support will be available when they need it. In some areas home dialysis and the skills of those who dialyse at home could be more efficiently

integrated into the rest of the health system. There are missed opportunities in some dialysis units where, instead of fostering self reliance, processes appear to support dependence. Opportunities could be developed to enable those on home dialysis to communicate with each other electronically and/or at occasional meetings. People want access to mobile dialysis units. Nocturnal dialysis offers better health outcomes and creates more free time; some people see access to nocturnal dialysis as their best solution. Ongoing attention should be paid to partners and those who support people who dialyse at home, ensuring they are given adequate information and support at the outset and in an ongoing way, offering opportunities to ask questions, express emotions, increase understanding and access support. It was suggested that a proactive service should offer support and respite as a matter of course, rather than in response to requests.

4.8 What advice would you give to those considering home dialysis?

Advice to those considering home dialysis from those already doing it was to seriously consider the potential benefits and to talk to people who are doing it to hear the advantages and disadvantages.

5. Summary

There is significant variability in the current provision of home haemodialysis across England, with some renal units having no service provision. The prevalence of home haemodialysis within the total dialysis modality population remains relatively consistent, whilst in centre haemodialysis increases and peritoneal dialysis decreases. More significantly patients have raised concerns regarding access and availability of home haemodialysis in their locality. Evidence suggests that self care, care at home and home dialysis offer real clinical and psychosocial benefits for kidney patients and links closely to the vision of an NHS that is organised around patients, giving them more choice, convenience and control over their care. Increasing access to home therapies is vital to enable our patients to lead lives with greater freedom and control, with the additional benefit of being more cost effective and addressing future capacity challenges. This work demonstrates the importance of local designed strategies and the value of listening to patients and those affected by kidney disease in order to support the commissioning of quality kidney services



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APPENDIX 1: NHS KIDNEY CARE HOME THERAPIES ACTION PLAN 2011/2012

This Action Plan summarises the key issues consistently raised at the Improving Choice for Kidney Patients events. The action plan will be audited against a colour coded assessment of progress by NHS Kidney Care

Red	Action not on target and/or significant risks identified.
Amber	Action on target but risks identified.
Green	Action on target and no risks identified.

Ref	Core Issue	Action Required	KPI	Timescale	Lead officer	Current Progress	RAG
1	Inequity in treatment options	<ul style="list-style-type: none"> Review of all gap analysis Identify Clinical Champion for Home Therapies across each region Promote change of mind set to eradicate any healthcare professional bias 	Full choice of home therapies available in all areas where possible Clinical champion identified	April 11			

Ref	Core Issue	Action Required	KPI	Timescale	Lead officer	Current Progress	RAG
2	Overcoming barriers and inflexible systems	<ul style="list-style-type: none"> Encourage challenging of decisions and current practice Encourage change in mindset and culture on units – who should stay in hospital NOT who could dialyse at home Develop guidance as to who should be considered for home therapy- enabling clinicians to ask “where would you like your treatment hospital or home?” Patient marketing -Use of “Patient champions” to promote Home therapy Identify closer links with primary care Focus on home therapy rather than modality Develop consistent policy for sole dialyser, remembering all patients have different abilities. 	Service specification developed Register of patient champions Sole home dialysis user policy developed Guidance for suitability for home dialysis	April 11			

Ref	Core Issue	Action Required	KPI	Timescale	Lead officer	Current Progress	RAG
3	Inconsistent pathways	<p>Review current pathway</p> <p>Development of clear streamlined pathway for all home therapies that can be adapted locally</p>	Care pathway developed	April 11			
		<p>Review of funding mechanism and contracts including set up costs for HHD</p> <p>Clarity around number of home sessions funded. No limits should be placed on number of sessions for individual patients</p> <p>Measurable quality indicators must be included in contracts</p>	Development of clear guidelines	Jan 11			
		<p>Monitor CQUIN to ensure quality for home therapy and capacity and availability for home therapies HD and PD is maintained.</p> <p>Ensure patient feedback reports into existing measures</p>	CQUIN monitored Increased patient satisfaction year on year	Jan 11			

Ref	Core Issue	Action Required	KPI	Timescale	Lead officer	Current Progress	RAG
4	Adequate, timely and consistent education	<ul style="list-style-type: none"> Develop training programme for staff including identification of minimum competencies Develop a programme of continuing education for patients and common information pack to strengthen resilience and ensure equity Identify the potential for dedicated lead trainer at each trust Review current training model, options for redesign-collaboration between units. Scope potential for private providers for satellite training Review range of consistent literature and resources available such as interactive, visual (e.g. Brussels) 	Guidance developed for nurse education including minimum competencies Development of a Continuing education programme and common information pack Development of a specification for education Standardised information easily available nationally	March 11			

Ref	Core Issue	Action Required	KPI	Timescale	Lead officer	Current Progress	RAG
5	Robust support for patients and carers,	<ul style="list-style-type: none"> Review patient and carer networks, with potential for separate carer network and Peer support groups Develop online community such as facebook or Renal Patient View with a specific online forum for HHD patients to prevent feeling of isolation Identify patient champions to promote home therapy and support new Patients considering home therapy. Introduce patient seminars where users can ask questions of other users Availability of support information such as how to access Independent living allowance etc Potential for national support telephone line Develop patient and carer strategy 	Patient and carer support networks in place Develop online community support Patient and carer strategy developed	Jan 11			

Ref	Core Issue	Action Required	KPI	Timescale	Lead officer	Current Progress	RAG
6.	Insufficient sharing of knowledge/ common issues	<ul style="list-style-type: none"> Develop regional home therapy nurse forum Share good practice between units Awareness of new technology Develop National patient newsletter Encourage use of renal patient view Use communication teams more effectively Actively promote home therapy through advertising, education etc <p>Including good news stories, Adopt a culture of self care, change dependency culture</p>	<p>Regional home therapy nurse forum established</p> <p>Variety of communication channels available</p>	Jan 11			

Ref	Core Issue	Action Required	KPI	Timescale	Lead officer	Current Progress	RAG
7	Consistent National approach	<ul style="list-style-type: none"> Nationally agreed approach Better communication between centres, share good practice Transparency and benchmarking Review potential for national or Network approach to procurement scope opportunity for bulk purchasing National consistent policy and specification development with local adaptation Develop Home therapies service specification with Metrics for efficiency Ensure easy availability of national/local protocols i.e protocol for solo dialysis , patient competencies/ checklist 	National strategy developed Development of home therapy service specification	April 11			