NHS

Kidney Care

No place like home:
Increasing access to home dialysis

March 2013

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Title	**No place like home: Increasing access to home dialysis**
Authors	Clare Beard, programme lead at NHS Kidney Care. Thanks are due to all project groups, as well as Rob Elias and Martin Wilkie for their input.
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Target audience	Nephrologists, renal nurses, renal dialysis technicians, commissioners, CCGs, network managers NKF, BKPA, people with kidney disease.
Circulation list	Nephrologists, renal nurses, renal dialysis technicians, commissioners, CCGs, network managers NKF, BKPA
Description/purpose	This document outlines the key learning and outcomes from locally-led and centrally co-ordinated projects to improve access to home therapies.
Cross Ref	Home dialysis: Who cares for the carer? http://www.kidneycare.nhs.uk/document.php?o=464 Improving choice for kidney patients: The carer and patient viewpoint http://www.kidneycare.nhs.uk/document.php?o=478
Superseded docs	n/a
Action required	Providers and commissioners of kidney services, including renal units, should review the findings outlined in this report, and consider how they can implement the recommendations in order to improve access to home therapies.
Timing	For ongoing review and action
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Foreword

The NHS faces major challenges if it is to improve the quality of the patient care it provides in the face of a difficult financial environment. At the same time there is growing evidence for the value of greater patient involvement in the management of long-term conditions. Home dialysis provides a rare opportunity in health care since it combines important benefits for patients with cost effectiveness. However, for complex reasons, home dialysis has become less commonly used in the UK over recent years. It is against this background that in 2010 NHS Kidney Care initiated a programme to support initiatives focused on increasing the uptake of home dialysis. This opportunity was embraced by a range of networks and renal centres including the Yorkshire and the Humber Renal Network, the West Midlands Renal Network, Epsom and St Helier University Hospitals NHS Trust, Sussex Kidney Unit, Royal Berkshire Foundation Trust, Reading, Oxford University Hospitals and Queen Alexandra Hospital, Portsmouth.

The report summarises the main learning points and resources that have come from this work. Initiatives have included the reorganisation of home therapy teams to improve effectiveness, the preparation of a "choice room" to give patients a greater opportunity to understand their treatment possibilities and the provision of educational resources for patients and staff. Among these are "how to guides" covering practical aspects of home dialysis including solo dialysis and button hole needling, and these are available at www.kidneycare.nhs.uk. Key themes include the importance of patient engagement at the centre of service development and the importance of sharing learning through forums, and accessible resources in written and video format.

Establishing an effective care pathway to deliver home dialysis is complicated. Issues include funding, logistics, patient and staff training, cultural change and providing adequate support to people dialysing at home. This NHS Kidney Care-supported programme has given teams the opportunity to explore these challenges in sufficient detail to be able to address the components necessary to effect change. This work forms part of a strong dialogue within the UK renal community which recognises the importance of patient-centred care in the context of progressive, supportive networks. It is difficult to measure the impact of the diverse initiatives contained in this report, in particular since it takes time before changes in clinical culture feed through to increased numbers of patients dialysing at home. However, it is encouraging to see a modest increase in the uptake of home HD reported by the UK Renal Registry.

It has been my privilege to be involved in this important programme – that experience has opened my eyes to the central role of renal patients as experts in the development and delivery of high quality care. I commend the resources and materials that are contained in this report to be used to support the continuing development of sustainable programmes in which patients can be true partners in their own treatment.

Dr Martin Wilkie
Consultant renal physician, Sheffield Teaching Hospitals NHS
Yorkshire and Humber Renal Network

1. Executive summary

Giving patients greater choice over how they are treated is a key commitment in the recent healthcare reforms. Both the NHS Outcomes Framework and the Mandate for the NHS emphasise the point that "The NHS needs to become dramatically better at involving patients and their carers and empowering them to manage and make decisions about their own care and treatment. This means people should be empowered to develop the knowledge, skills and confidence to manage their own health, so they can live their lives to the full." Other clear commitments include "people should expect the right support to help them manage their long term conditions so that they do not end up in hospital needlessly" and "supporting people with ongoing health problems to live healthily and independently, with much better control over the care they receive."

Home dialysis fits in with these commitments perfectly. Not every patient will be suitable for home dialysis; however every suitable patient should be offered this choice. For those who are suitable, home dialysis provides undoubted benefits both in terms of quality of life and life expectancy. It is cheaper and arguably necessary to cope with rising demand. The expansion of home dialysis services addresses the challenge to the NHS to make major efficiency savings while improving the quality of a patient-focused health service.

In 2010 and 2011, NHS Kidney Care commissioned project groups across England to establish home therapies projects in their respective coverage areas. This report summarises the key findings from all the project groups 'end of project' reports.

A number of key themes have emerged across all the home therapy projects which should inform future successful service improvement. These include:

- **Plan and engage with key stakeholders**. Time needs to be spent planning projects.
- **Involve patients and carers in development, design and delivery**. Patient and carer involvement in all stages of the project was identified as vital to the success of projects.
- **Recruit motivated clinical champions**. Having highly motivated clinical champions was essential to promote the service and drive up acceptance among staff and patients.
- **Engage with all key stakeholders to raise awareness and build strong relationships**. This needs to be done from the start in order to create local enthusiasm and to ensure the project meets its objectives.
- **Engage fully with staff**. Healthcare professionals have a key role in supporting patient choice including dialysis at home.
- **Consider any service changes that may be needed such as combining the home dialysis departments**.
- **Be flexible to accommodate patients with complex and diverse needs**.
- **Involve your local communications team**.
- **Identify in advance what you will achieve and how you will measure success**.
- **Anticipate potential difficulties around data collection**. It will be important to consider how process measures in particular can be used effectively in the future.
- **Make use of any available national and local support**. The support of NHS Kidney Care was seen as invaluable in this work.
- **Set up a forum to share resources and protocols**. This avoids unnecessary duplication and maximises spread of service improvements.

1. Executive summary

This project demonstrates that it is possible to develop a range of innovative new approaches and resources to support dialysis at home.

The home therapies projects have delivered very real service improvements for people who want to dialyse at home. Some project groups significantly increased the uptake of home therapies during this project – for example, Sussex increased the number of kidney patients dialysing at home from 25.5% to 36%. Coventry grew numbers on home dialysis from 22% to 28%. Other improvements have focused on increasing self-care amongst haemodialysis patients, and better identification of those patients who might benefit most from home dialysis. A range of strategies have been used to achieve these changes despite facing significant constraints of capacity and resources. These strategies are set out in this report.

The changes have not just been at a regional level. National figures from the NHS Kidney Care Dialysis Capacity Survey show that between 2009 and 2011 the numbers of kidney patients receiving hospital dialysis was **down 6%**, satellite dialysis was **up 16%**, and home therapies were **up 5%**. It is possible that the work of the NHS Kidney Care home therapies project groups contributed to this. The learning from this work now needs to be shared across all kidney units in England and beyond. It also begs the question that if many kidney patients can successfully manage to undertake a complex treatment modality such as dialysis at home, then what other long-term conditions could adopt similar approaches? The potential is clearly there for many more patients to benefit. The challenge for the NHS now is to build on this work and embed real and lasting change.

2. Introduction

In 2010 and 2011, NHS Kidney Care commissioned project groups across England to establish home therapies projects in their respective coverage areas. This report summarises the key findings from all the project groups 'end of project' reports. It incorporates findings from the following project groups; the Yorkshire and the Humber Renal Network (six main renal dialysis units), the West Midlands Renal Network (seven main renal dialysis units), Epsom and St Helier University Hospitals NHS Trust, Sussex Kidney Unit, and interim reports from Royal Berkshire Foundation Trust, Reading, Oxford University Hospitals and Queen Alexandra Hospital, Portsmouth. It draws together the evidence and learning from the work undertaken by the renal units and networks, focusing on the shared learning about change and approaches to increasing home therapies.

2.1 Background and rationale

Home dialysis provides undoubted clinical benefits to patients as it allows for more frequent, longer and slower dialysis, improving kidney function. This has positive effects on both quality of life and life expectancy. It is cheaper and arguably necessary to cope with rising demand. It enables people with kidney disease to have greater independence and more control of their condition. The expansion of home dialysis services addresses the challenge to the NHS to make major efficiency savings while improving the quality of a patient-focused health service. For too long, renal care has benefited hospitals, not patients, but home dialysis is exactly the kind of cost-effective innovation that will represent a major step forward both for patients and the NHS itself. Not every patient will be suitable for home dialysis; however every suitable patient should be offered this choice.

Benefits of home haemodialysis (HHD) from a patient's perspective include:

- Better quality of life
- Greater patient independence
- Increased freedom and easier travel
- Reduced dietary and fluid restrictions
- Reduced symptom and medication burden
- Improved recovery time following dialysis sessions
- Better able to continue in employment
- Increased duration or frequency of dialysis is associated with improved survival.

2. Introduction

2.1 Background and rationale

Policy context

This work addresses the NHS Outcome Framework domain 2: Enhancing quality of life for people with long-term conditions; and domain 4: Ensuring that people have a positive experience of care (2012/13)[1]. The NHS mandate[2] which sets out the strategic direction for the NHS Commissioning Board corresponds to these domains and underlines the importance of 'supporting people with multiple long-term physical and mental health conditions, particularly by embracing opportunities created by technology.'

The National Service Framework for Renal Services published in 2004[3] and 2005[4] set out five standards and four quality requirements. These include the following which relate to home therapies:

- Standard One: all patients have access to information that enables them to make informed decisions and encourages joint decision making
- Standard Two: Maximise patient choice of clinically appropriate treatment options
- Standard Four: Renal Services are to ensure the delivery of high quality clinically appropriate forms of dialysis which are designed around individual needs and preferences and are available to patients of all ages throughout their lives.

In its 2002 guidance, the National Institute for Health and Clinical Excellence (NICE)[5] 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 recommends all suitable patients should be offered a choice regarding the location of their care. This has clear implications for service planning "making the assumption that 10% to 15% of dialysis patients, given the choice, would opt for home haemodialysis, expansion of the services to support home haemodialysis will be required."[5]

National trends

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 52 trusts in England that offer dialysis services, up to 50% of their patient transport service costs are accounted for by dialysis.

As more people develop kidney disease, demand for dialysis and other treatments is forecast to increase. Home therapies may be a fundamental component in how this demand in met in the future.

In 2010 transplantation was the most common treatment modality (48%) for prevalent Renal Replacement Therapy (RRT) patients, followed closely by centre-based HD (44%) in either hospital centre (22%) or satellite unit (21%) (see figure 1 below*). Home therapies made up the remaining 9% of treatment therapies, largely PD in its different formats (8%) which was similar to 2009.

Home therapies are now being used by 17.6% of prevalent dialysis patients (2.9% home HD and 14.7% PD – see figure 2 below*). The number of patients on home HD has stopped falling in recent years, rising 23% since 2009 (636 to 780 patients – see figure 3 below*). (UK Renal Registry report, 2011)[6]. The Renal Registry noted wide variation in home therapies access and uptake with a 13-fold variation between centres.

*The data reported here have been supplied by the UK Renal Registry of the Renal Association. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the UK Renal Registry or the Renal Association.

2. Introduction

2.1 Background and rationale

Figure 1: Treatment modality in prevalent RRT patients on 31/12/10

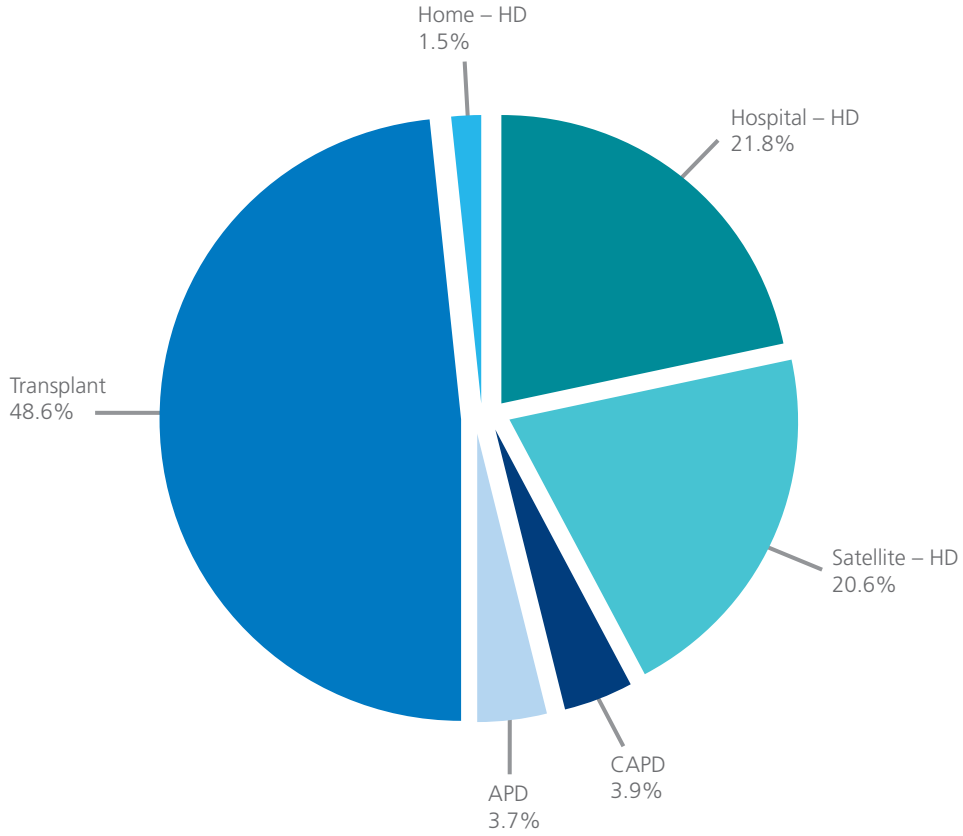
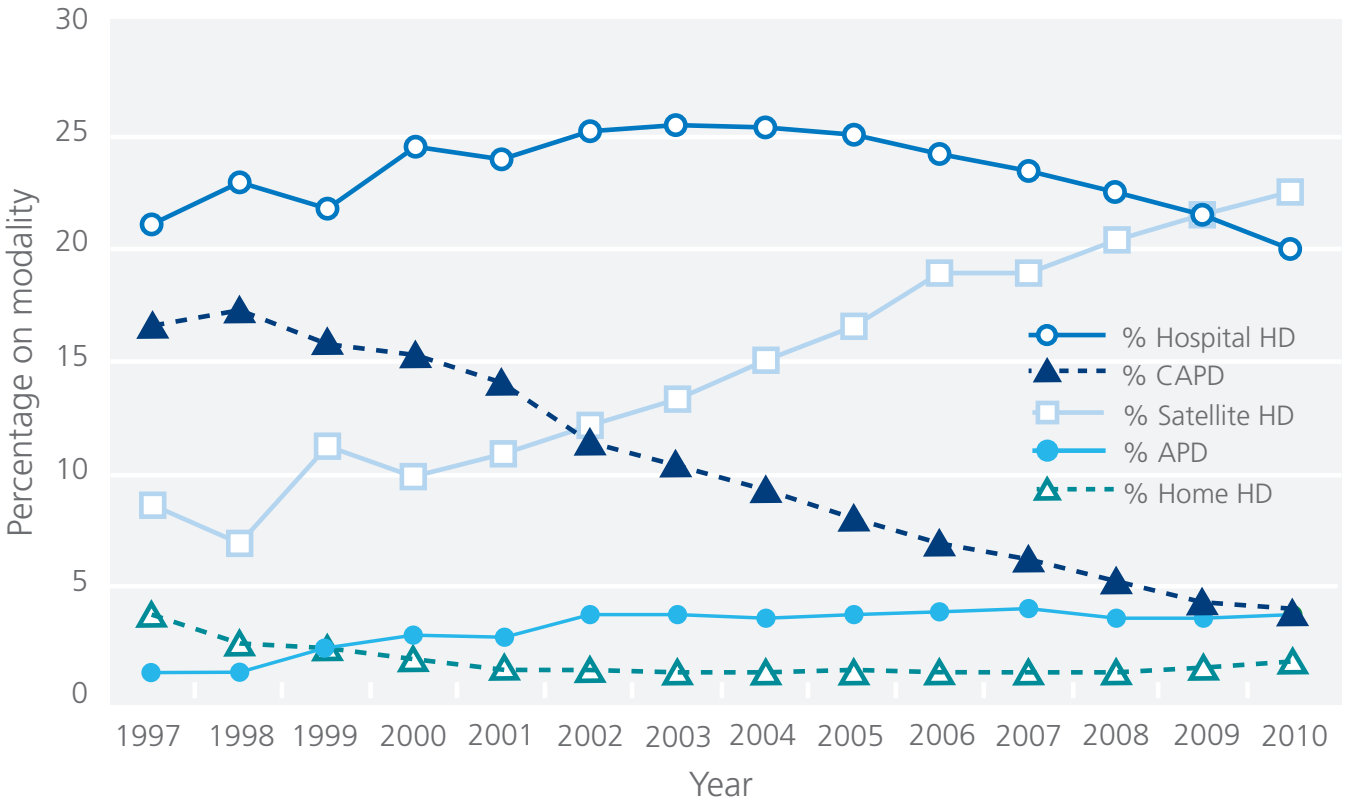


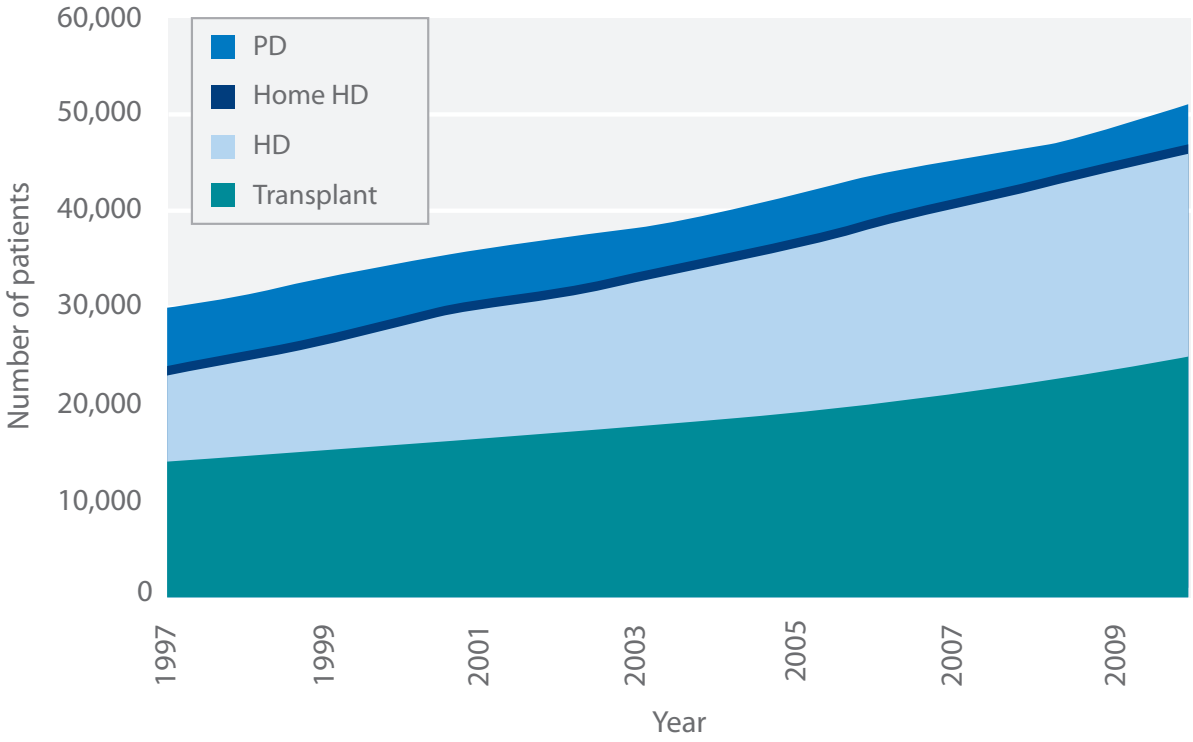
Figure 2: Detailed dialysis modality changes in prevalent RRT patients from 1997–2010



2. Introduction

2.1 Background and rationale

Figure 3: Growth in prevalent patients by treatment at the end of each year 1997–2010



The 2011 Dialysis Capacity Survey reports on home therapies in each region of England[7]. Key findings included that 'the number of people receiving home therapies (excluding Yorkshire & Humber) has increased from 3,430 in 2009 to 3,811 in 2011, up 11%. However, home therapies have only increased slightly from 18% of people having dialysis in the 2009 and 2010 surveys to 19% in the 2011 survey. South East Coast has the highest rate with 33% of people on home therapies. Very few areas have substantial numbers of patients on Assisted PD (as a preparation for home therapy) apart from London (19%) and the North East (17%).' In the 2011 survey there is a planned increase of 27% in home therapy patients over the next 5 years. This is up on the 12% growth planned in 2009 and 20% growth planned in the 2010 survey.

The number of people on dialysis at any one time is significantly affected by survival rates. Survival rates have traditionally been long for HHD. The number of people on dialysis will be reduced by increasing transplantation rates. It will be further affected by extending dialysis to more complex patients previously thought unsuitable for dialysis at home as these patients may not live as long as traditional HHD patients. It is important that there is an idea of how many patients are required to be trained per year in order to maintain a programme of a particular size. In Yorkshire and the Humber it has been estimated that to achieve a prevalence of 10% of patients receiving home HD, they would have to be training 57 patients per year across the region.

A consultation project undertaken in 2011 by the West Midlands Central Health Innovation Education Cluster (WMC-HIEC)[8] with renal centres in the West Midlands highlighted that each centre had a distinctive culture and mix of caseload. All were undertaking a range of approaches for increasing the uptake of home therapies. Discussion at the visits highlighted a range of perceived barriers to the uptake of home therapies which were closely aligned to those identified in a literature review undertaken.

2. Introduction

2.1 Background and rationale

These included:

- clinician and patient communication
- lack of social support for some patients
- risk averse culture
- clinician and patient resistance to change
- resource and budgetary constraints
- need for consistent early pre-dialysis preparation
- lack of training space
- patient concerns.

The influence of clinicians' attitudes to treatment modalities on patient choice including home therapies has been widely acknowledged. A survey by the UK Renal Registry demonstrated that clinician enthusiasm for a particular modality is a strong determinant of how many patients are treated with that modality in a centre[9]. Wide variation between centres in the percentage of patients treated with a home dialysis modality is likely to be multifactorial. It has been shown that the percentage of patients deemed unsuitable for home dialysis varied with clinician practice patterns but that of patients given a fully informed choice, around 50% will choose a home dialysis modality over in-centre HD.

Other relevant factors that can impact on home dialysis include demographic trends, costs of home adaptation, suitability and tenure of patient accommodation, social factors including family and carers' involvement[10], respite, and holiday dialysis away from base.

Health economics of dialysis

This work has clear links to the Quality, Innovation, Productivity and Prevention (QIPP) programme which aims to improve the quality of care the NHS delivers while making up to £20billion of efficiency savings by 2014–15, which will be reinvested in frontline care. Home therapies are the subject of a five year Commissioning for Quality and Innovation (CQUIN) programme championed by NHS Kidney Care: 'all trusts to achieve a 35% rate of dialysis patients utilising home therapies by 2015. The 35% target comprises:

- 10% Home haemodialysis
- 25% Peritoneal Dialysis (including CAPD, APD, aAPD)
- Both these groups can include self-care (patients who are self-caring should be able to do completely independent of nursing support).'

Home haemodialysis is a cost effective treatment strategy for eligible patients producing a cost saving and improvement in health related quality of life when compared with hospital based and satellite unit based haemodialysis (NHS Purchasing and Supply Agency (PASA) report, 2010)[11]. Home haemodialysis allows the dialysis regime (timing, length and frequency) to be tailored to suit individual patient choices and consequently improves the patient experience. There is also a corresponding gain in the Quality Adjusted Life Years (QALY) for home haemodialysis when compared with hospital and satellite unit based models of care delivery[12]. Estimated savings in the PASA report[11] show savings of £20,700 per patient over 10 years when the modality of treatment moves from hospital based to home based delivery. However, health economic analysis of home therapies has to consider initial costs of set up in patient home as well as on-going costs.

2. Introduction

2.1 Background and rationale

NICE (2011)[13] has suggested that "if the number of adults on peritoneal dialysis in England increases from current levels of approximately 15% (Renal Registry 2010) to the optimal level of 39% (NHS Kidney Care 2009 and expert clinical opinion), there may be annual savings of approximately £20 million nationally."

In 2011 NHS Kidney Care surveyed all adult renal units in England to inform the development of a best practice tariff for home haemodialysis introduced from April 2012, and to inform other interested parties, such as commissioners[14].

The project group in St Helier identified cost savings from the second year on home dialysis, when compared with in-satellite dialysis via a fistula.

2.2 NHS Kidney Care approach

2.2.1 The initiative

NHS Kidney Care commissioned a number of projects across England that aim to support patient choice and home dialysis. These projects were diverse in nature, and included:

- Staff education and training to develop skills in various processes, including buttonhole formation
- Expansion of home therapy services with an agreed pathway
- Creating 'choice rooms' for patients (designated training spaces for people with kidney disease and their carers to find out more about treatment options and try them out)
- Providing updated patient information and educational materials about dialysis at home including DVDs, and satellite unit road shows
- Supporting patients who dialyse at home and their families by providing training and using technology to improve confidence and competence.

2.2.2 The support

Alongside funding, NHS Kidney Care provided a package of support to the project teams which offered them opportunities to access specialist advice, and share experiences and knowledge with others. This was intended to ensure a long-lasting impact and success of the initiative, as well as ensuring the various projects remain motivated as they progress towards project delivery. This support involved the input of the NHS Kidney Care Programme Lead for the Home Therapies projects, who provided regular coaching contact and project progress monitoring to the projects. NHS Kidney Care also set up a monthly reporting system which helped the project teams to document their progress and key learning from the project implementation, address exceptions and risks, and escalate where appropriate. Other support included:

- **Learning network and forum**
  NHS Kidney Care created and facilitated a learning network for the project leads which provided opportunities for the project groups to interact with each other to share common concerns and experiences. This group met via regular e-seminars held to monitor progress and facilitate sharing of learning and good practice. This was supported by a learning on-line forum that allowed the sharing of key resources. Project leads acknowledged the value of this support in driving the project forward, avoiding duplication and maximising spread of innovation.

- **Presentations at professional meetings**
  As an acknowledgement of the important work being carried out by the various project teams, NHS Kidney Care encouraged the project teams to submit abstracts and present posters in major academic and professional conferences. These presentations offered opportunities for the aims and objectives of the initiative and the variety of approaches by the individual project teams to be communicated widely.

- **Dataset**
  All home therapies groups are participating in an evaluation of their projects, using an agreed set of measures. These measures were developed by NHS Kidney Care's evaluation team, in discussion with project leads. These data are presented in appendix 1.

2.2 NHS Kidney Care approach

2.2.2 The support

- **Communications and dissemination**
  NHS Kidney Care has disseminated the project resources and key lessons widely, integrating learning with other work programmes such as peer support and care planning. This has included production of how to guides and making resources available on the NHS Kidney Care website. External e-seminars were held on specific topics to disseminate learning widely across England.
- **Buttonholing how to guide:**
  http://www.kidneycare.nhs.uk/howto_guides1/buttonhole_needle_technique/
- **Tray approach how to guide:**
  http://www.kidneycare.nhs.uk/howto_guides1/tray_approach_makes_home_conversions_for_dialysis_easier_and_more_cost_effective/
- **Solo dialysis how to guide:**
  http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/home_therapies/howto_guides1/solo_dialysis_more_freedom_and_control_for_patients_living_alone/
- **Haemodialysis at home how to guide:**
  http://www.kidneycare.nhs.uk/howto_guides1/haemodialysis_at_home/
- **Renal Patient*View* how to guide:**
  http://www.kidneycare.nhs.uk/howto_guides1/renal_patient_view_helping_dialysis_patients_live_life_to_the_full/

3. The project learning and outcomes

3.1 Overview of coverage

The project groups participating in the programme were located across England.

- Yorkshire and the Humber Renal Network worked to increase the clinical support for home-based therapies and self-care, subsequently to increase the number of patients undertaking home-based therapies and engaging with self-care. The network has appointed a clinical lead and nurse educators to champion the benefits and develop a robust strategy for a consistent approach across Yorkshire and the Humber. A Home Therapies and Self-Care Forum has been established, with a Yorkshire and Humber Home Therapies and Self-Care Strategy agreed for 2011-2013. This project has evolved to encompass shared care developments.
- West Midlands Renal Network developed a regional service to improve access and facilitate the development of home therapies, increasing patient numbers for home dialysis, and implementing shared decision making. This group has looked at service procurement, and are working with Advancing Quality Alliance (AQuA) to examine shared decision making and Health Innovation and Education Cluster (HIEC) to review education programmes.
- Sussex Kidney Unit worked to increase the number of home haemodialysis (HHD) patients at the unit, by enhanced recruitment to home haemodialysis, improved quality of home dialysis training and long-term maintenance of patients on home haemodialysis. This group has introduced modular training and reviewed their choice room provision.
- St Helier set out to ensure equal access for all patients to home based therapies and to increase the number of home haemodialysis patients so all patients who want to dialyse at home can do so. This project group developed a film about dialysis at home for pre-dialysis and dialysis patients and their families.
- Royal Berkshire Foundation Trust (Reading) is seeking to offer a full range of RRT modalities by embedding a culture that values RRT closer to home where appropriate, and improving patient experience. This project seeks to expand the current assisted automated peritoneal dialysis (aAPD) service and create a sustainable home haemodialysis service by focusing on staff training and improving the range of educational resources available.
- Oxford University Hospitals are looking at new and creative ways to improve the number of patients accessing home therapies and how to sustain these patients on their chosen home therapy. This includes exploring obstacles to home treatment with existing patients who undertake high levels of self-care in unit. Other developments include 'buddy' training for patients and training for satellite unit staff about home therapies.
- Queen Alexandra Hospital in Portsmouth is working towards offering a full range of treatment modalities to its patients. This project group plan to expand the number of patients on a home therapy rather than in-centre or satellite therapy by offering education and promoting choice. They are considering how patients dialysing at home are most effectively supported.

3. The project learning and outcomes

3.2 Project engagement

During 2010 NHS Kidney Care held a series of nationwide "Improving Choice for Kidney Patients" events with home dialysis patients and local care teams to influence service redesign. Ten of these events were held – one in each Specialised Commissioning Group area – to promote choice for kidney patients within the planning and commissioning of kidney services. At each event a local action plan was drawn up. Following these events, networks were invited to apply for implementation funding. From the responses received a number of projects were commissioned to undertake this work.

3.3 Common challenges and solutions

The groups achieved substantial service improvements, developing a range of innovative approaches. They demonstrated that it is possible to support high quality decision making, patient choice and improve uptake of home therapies. Project groups had to tackle the wider barriers to dialysis at home, such as cost issues, suitability of accommodation, social factors, and hygiene issues, particularly when promoting button hole needling. Despite this, those units that reported baseline and repeated data collections demonstrated increases in home therapies uptake; see appendix 1. The resources and approaches developed have been informed by local geography, population and infrastructure. Although participating groups addressed different challenges in order to achieve their project aims, some common challenges and solutions have emerged which could serve as key learning points:

Project planning

Those who had successfully submitted a project proposal were charged with developing detailed project profiles and delivery plans with explicit milestones and timescales. Some submissions had been made by a single individual or small group, due to the timescales involved. It was essential to engage a wider group of stakeholders to plan projects but this was not always straightforward. Renal network managers and other network staff including lead nurses and project staff played a key role in driving projects forward across a whole network area. They may be more familiar with project planning principles and costs. Establishing a multi-disciplinary steering group, which met regularly and involved stakeholders, working collaboratively with shared focus to develop and improve home therapy services, appeared to be the most successful approach.

Dedicated clinical champions

Motivated clinical champions committed to the projects were very important in this work. For example the Yorkshire and Humber Renal Network obtained funding from NHS Kidney Care for a Clinical Lead for Home-Based Therapies and Shared Haemodialysis Care, and this post has been pivotal in the strategic development of home therapies in this region. Much of the development focused on cultural changes, so engaging key stakeholders including staff and patients was essential. Project groups had to respond appropriately to challenges such as reconfiguring staff teams. Some project groups found they lacked adequate clinical champion capacity and at times this constrained their ability to deliver as planned.

Engagement with staff

It was fundamental to engage staff, across all disciplines, to actively plan how to develop these initiatives. Several project groups noted challenges relating to staff engagement, particularly where there was a tradition of staff assigned to one treatment modality or another. There was reluctance to promote alternative forms of dialysis in areas perceived as dedicated to one form alone. It was essential to agree a shared purpose focusing on patient choice and quality of care. Often, project champions had a key role here, responding appropriately to challenges.

3. The project learning and outcomes

3.3 Common challenges and solutions

Before the project the Sussex Kidney Unit had separate departments with patients in training and separate, dedicated nursing teams. Patient recruitment, home visits and general aspects of home support were markedly different between PD and HHD patients. Unused HHD training slots were re-allocated to the chronic dialysis programme. During their project, services were revised so that patient recruitment, training and follow-up support to both PD and HHD were pooled in a new department that brings together a vision and appeal for dialysis at home, regardless of therapy. Patients can change therapies, remaining at home, supported by the same team. Nursing and medical staff are combined, to improve cross-cover and management of resources, with full cross-training. This has increased the breadth of staff skills, enhancing employment prospects. A formal process of consultation with staff and patients was undertaken.

In Yorkshire and the Humber, a Home Therapies Forum was established in 2010. The aim of this interactive, multidisciplinary group is to share best practice, review progress and to hear regional and national updates. The forum is also used to discuss the development of a regional strategy for home therapies and self-care. The quarterly forum meetings which move around units in the region are extremely well attended by multidisciplinary healthcare professionals, as well as people with kidney disease and carers.

Central and unique to Yorkshire and the Humber's shared care programme is a nurse training course. Matrons, clinical nurse educators and a patient lead were involved in developing the course curriculum, nursing journal and a portfolio of course materials for staff targeted at all levels. It was externally reviewed and is now running recurrently within the region. The course focuses on giving dialysis nurses the skills they require to train and support patients to take a greater role in their own care. The three-day course focuses on adult learning techniques, motivational interviewing, practical microteaching and working with patients using the educational materials.

Patient and carers involvement

Project groups recognised the central importance of involving patients and carers in their projects. Some felt, on reflection, that they should have engaged patients and carers at an earlier stage of their work so they could influence planning at the outset. The Sussex team reported that patients want to be consulted and are prepared to offer many insights from their experience of training for home dialysis, on-going support and transfer to other modalities. They used approaches including a patient satisfaction survey, as well as developing clips which were posted on YouTube. The St Helier group found involving patients and carers in resource development was an effective engagement approach.

Yorkshire and the Humber's Shared Haemodialysis Care project aimed to support patients to have a greater role in the management of their own kidney condition. Patient involvement was therefore central to the programme. This has been successfully achieved in a number of ways including patient partners engaged in the funding application process. A patient survey tool was developed to gauge satisfaction with the service. This has been embedded to be undertaken annually across the network. The group were awarded a grant from the Health Foundation as part of their Closing the Gap through Changing Relationships programme.

Promoting home therapies to people with kidney disease

In order to produce net growth in home therapies, despite patient drop-out due to hospital-based dialysis, transplantation and death, projects groups sought to promote home therapies to patients, including those at pre-dialysis stage and those already on dialysis. The St Helier team developed a DVD supported by posters centred on the benefits of dialysing at home. This was not meant to explain how to carry out either home haemodialysis or

peritoneal dialysis, but to be a taster, introducing patients to the idea of dialysing at home. There were a number of steps in developing the DVD including developing and agreeing a clear brief, identifying suitable company, preparation for filming including patient recruitment and consent, filming and editing. This group found it essential to involve their trust communications team and recognise the time required to develop high quality resources. The DVD is available at: http://www.kidneycare.nhs.uk/resources_old/short_films/st_helier_home_dialysis_video/

Groups sought, in addition to traditional resources including posters and leaflets, to provide resources via newer media including the internet. The Sussex Kidney Unit posted several short clips of between one and twelve minutes on topics relating to home dialysis including hand washing, and exit site dressing. An evaluation of usage at 30 October 2012 showed that in eighteen months there were over six thousand views of a clip on APD. The clips are available at: http://www.youtube.com/user/BuckfieldDialysis.

Choice room

Several units established choice rooms or training spaces for dialysis at home. For one project group, service needs led to relocation of the choice room to an open plan area, initially in a corner of the outpatients waiting area, and later in the dialysis waiting area. This resulted in several formal complaints from people who felt it was 'too much naked reality'. Comments received included:

> 'wrong to have it on display reminding me of the spectre of dialysis'
>
> 'I can't cope being faced with the equipment and reminder of dialysis, without having someone with me to explain'
>
> 'I don't like it and gives me another reason to avoid coming in, now that I have my transplant I just want to forget those dreadful dialysis days'.

As a result, the group has identified an area to re-instate a separate, dedicated four-walled choice room. They have developed a 'home-like' feeling, with images of patients dialysing at home.

Training for dialysis at home

Adequate training and preparation is essential for effective dialysis at home[15]. Traditionally the average time required to train a patient is between five and seven weeks of four hours three times per week. It is recognised that training should be flexible around patient needs e.g. 7 am until 6 pm, training two patients at the same time or offering support for an established patient while training another. In February 2012 the Sussex Kidney Unit introduced modular training for home haemodialysis. This initiative built on previous notable increases in the proportion of prevalent dialysis patients on home HD in 2008 compared with 2009 in Sussex (5.7% vs. 8.2%)[16]. The modular training programme was adapted from the 'Self-Care Guide' produced under the Guy's Modernisation Initiative (2007)[17]. The default training programme is offered as two hours, five days a week for four weeks although depending on the patient's circumstances and abilities, a personal training plan can be negotiated. The training programme consists of twelve modules, each with a set of competencies attached. Once each competency is achieved, both the patient and staff member sign that module off. There is no particular order in which to complete the modules, it depends on the priorities negotiated between the patient and staff member. Learning is assessed by dedicated home dialysis staff with progress being monitored on a regular basis. As a group, the patients are followed up by a dedicated consultant who takes over their care from the moment they choose home haemodialysis, following their progress from training to long-term home dialysis. The aim is successful, safe training in a timely manner with sustained support at home.

3. The project learning and outcomes

3.3 Common challenges and solutions

Feedback so far has been positive from both patients and staff. This approach focuses on learning achievement with an individualised approach as each learner finds different modules easier. It also supports people who have impaired vision, fear of technology, cognitive impairment, and dexterity difficulties. It allows the learner to see gradual progress and celebrate achievements. It also enables staff to observe the patient's ability to safely carry out all tasks and focus on those that appear more difficult to learn. Previously, some patients were daunted by the overall learning required, extending the training times and making it unclear whether home haemodialysis would prove unrealistic. A modular programme of training, supported by use of equipment such as handheld scanners for ease of needling and simulation mannequins to practice technique is helpful to build learner confidence. When supported by an individual learning plan with scope to train over three or five days and dialyse solo, it becomes a flexible choice for patients depending on lifestyle. One possible drawback is the number of competencies to achieve within each module. It requires time to learn and time to assess. In practice patients and nurses have found that it is not possible to complete a module in isolation. Learning becomes more integrated when tasks related to different modules are assessed at the same time such as preparing the dialysis machine and weekly maintenance of the Reverse Osmosis machine.

Project groups were keen to minimise infection risks and therefore provided aseptic techniques training with regular refresher sessions.

In Yorkshire and the Humber, nurse educators were recruited with a role to develop and adapt existing educational materials and curricula to be used for education of patients and health care professionals. This has included a purpose-designed 14 competency patient handbook (http://www.health.org.uk/media_manager/public/75/programme_library_docs/Sharing%20Haemodialysis%20Care%20-%20Patient_Handbook.pdf). Patients are trained in competencies according to their level of interest and ability and these are documented in the patient handbook. These competencies range from patients undertaking self-observations, hygiene (infection control), preparing the basic pack, lining and priming a dialysis machine to needling their fistula.

Complex needs, diverse needs

The group at St Helier developed a training manual specific to the machine used by their patients at home. The manual is picture based since some patients do not speak English as their first language or have limited reading skills. The manuals are mainly used to train people, although they can be taken home if patients want them as a reminder. The group have also promoted solo dialysis without a carer at home, a nocturnal dialysis program and made smaller more portable home haemodialysis machines available for patients with limited space or for those who wished to travel frequently. The number of patients dialysing solo has increased considerably from two to seven true solo patients dialysing independently and frequently without someone else in the house, and a further two patients who dialyse independently although with another person available if needed. This work has resulted in 45% of home haemodialysis patients trained to dialyse as solo patients.

The Sussex team successfully developed a range of training regimes increasing the appeal of training for home dialysis to patients holding jobs and raising families, including devoting 60 consecutive training days to a local nursing home, in order to dialyse a man with learning difficulties, opening further scope to dialyse future clients as home dialysis patients who need nursing home respite or residency, without travelling for in-centre dialysis. Other project groups also considered a range of complex needs including dialysis in prison.

3. The project learning and outcomes

3.3 Common challenges and solutions

Vascular access

Project groups recognised that the biggest single obstacle for anyone contemplating home haemodialysis is probably needling their own fistula. Buttonholing, whereby patients use dull rather than sharp needles and insert the needle into the same track each time rather than pierce the skin afresh, can make this process much easier. Button holing also has other benefits for patients who have a short or difficult to needle fistula or when aneurysms are developing within fistulae. The formation of the track however can be difficult and staff can find this much easier if they are able to visualise the vessel under the skin. This helps them choose the optimum site and to gauge the depth the needles should be inserted. In patients who are learning to needle their own fistula, but not intending to button hole, being able to visualise the fistula can also have enormous benefits.

Several groups focused on buttonholing whilst recognising challenges including difficulties establishing buttonhole tracks in some cases. The main issue is difficulty in needling the venous track after it is initially formed. Taking time to get the direction and depth of the track and using the scanner has helped in some cases but not in all. Other problems arose when buttonholes failed due to patients being admitted to hospital for a long period and the buttonhole was left unused. It was also reported that when patients went on holiday or dialysed at different units, there was a reluctance to use the buttonhole. One unit's approach to delivering buttonholing is described in a How to Guide:
http://www.kidneycare.nhs.uk/howto_guides1/buttonhole_needle_technique/

A key challenge project groups had to address were concerns from some healthcare professionals about infection risks[18]. Current studies have suggested contrasting evidence[19] but project groups addressed this by using careful patient selection and training.

In the West Midlands, a HIEC simulated fistula project set out to support patients to overcome self-needling barriers for home haemodialysis. Consultations with staff and patients regarding design of a simulated fistula led to development of prototypes for trial. These were tested with Royal Wolverhampton Hospitals who used the device to facilitate self-needling in all their HD patients.

Self-care and shared care

Project groups were keen to consider how to promote self-care. In Yorkshire and The Humber the term 'Shared Haemodialysis Care' was agreed for use in place of self-care to emphasise the partnership between patients and staff. The option of shared haemodialysis care on a medical unit provides a 'half-way house' between hospital dialysis and home haemodialysis, offering patients the opportunity to manage some of their treatment for themselves, with the support of clinical staff where they need it. It is anticipated that for some patients shared care will develop into dialysis at home, but not in every case. The network has seen increases in flow onto home haemodialysis; however, it is not known whether this is cause and effect, since there are several initiatives occurring simultaneously to increase the uptake. Measurement is difficult as not all patients who express intent will end up on the therapy and some patients will receive a renal transplant. The impact on home haemodialysis numbers has not been marked up to the present time.

Another project group found that the percentage of patients carrying out one or more element of self-care decreased in one satellite unit, which prior to the project had encouraged all patients to put out their own packs and then other patients to take on further responsibilities. Unfortunately this initiative had not been continued as new patients started in the unit, mainly because teaching self-care is not included in the contracts set up with the companies providing dialysis. This highlights the need for teaching on greater patient involvement in dialysis to form part of the renal nursing curriculum and to become a recognised competency.

3. The project learning and outcomes

3.3 Common challenges and solutions

Technological support for home dialysis

Project groups reported that the purchase equipment such as the introduction of hand-held Doppler scanners played an important part in improving self-cannulation and confidence, whilst enuresis alarms that detect any blood leakage from lines have supported patients dialysing solo who wish to use them.

Private units

Project groups sought to share their initiatives with satellite units including those privately run. One challenge was where self-care training is not included in initial contracts with these companies. Project groups had to persuade companies of the long term advantages, with their current staff and financial limits. Involving management in privately run satellite units in any healthcare professional education or events is a crucial step to setting up self-care and home therapy programmes.

Regional procurement of home haemodialysis services

The West Midlands Renal Network (WMRN) collaborated with seven renal centres to lead a regional procurement for home haemodialysis. This aimed to establish a regional home therapies service to increase the numbers of patients dialysing within their home environment; and to support all West Midland renal units to establish robust local home therapy services in order to reduce variation across the region. Initial discussions regarding a regional procurement for home therapies were under the proviso of 'any willing provider'. This meant significant implications for providers should they not win a contract, albeit this appeared nationally to be the preferred procurement route for commissioners. Following discussions with providers and a more detailed assessment of the impact of this decision, the nature of the procurement changed to ensure the outcome would only deliver benefits for units across the region. WMRN engaged stakeholders in order to progress a regional tendering exercise for home therapies and this identified that the procurement was also being pursued by Health Trust Europe (HTE); an organisation that specialises in tendering healthcare services. From this point, both WMRN and HTE worked in partnership to embark on a procurement process. Subsequently, the nature of the original objective slightly changed, from the WMRN leading the regional tender for home haemodialysis to Health Trust Europe leading the exercise. Following this, the WMRN soon realised that clinical leads who at first were uncomfortable with the idea of procuring for such services were now much more positive.

A patient representative was recruited and involved as part of the procurement and tender evaluations. In addition, the WMRN were able to perform a gap analysis of the service specifications created by the WMRN project team and HTE. Once completed, this gave the ability to further develop and shape the final service specification that was used for the tendering exercise. It was important to ensure the HTE specification included all key points from the WMRN specification. The tendering exercise via HTE was being conducted on behalf of four trusts. The final framework contract was awarded in May 2012 and sets out volumes for twelve months. Responsibility for the review and monitoring of the framework contract lies with HTE and the respective acute trusts. The WMRN will be made aware of, and will work in collaboration, to resolve any issues following contract meetings.

This work highlights the critical importance of identifying and engaging stakeholders as early as possible, and throughout projects.

3. The project learning and outcomes

3.3 Common challenges and solutions

Data

This project aspired to be evaluated using an agreed set of data measures (see Appendix 1). There were considerable challenges which included the small numbers, limited time period and capacity to collect data. There are a number of key lessons from this project which will inform work in the future with the UK Renal Registry and other key organisations. Whilst project groups could determine outcome data such as numbers of patients dialysing at home and numbers with button hole established, process measures such as numbers of those referred for training or those in training for home dialysis and relating to patient choice were generally not collected. There was some variation in how project groups defined self-care although most used the self-care competencies defined in the 'Self-Care Guide' produced under the Guy's Modernisation Initiative (2007).

Commissioning for Quality and Innovation (CQUIN) targets

An integral element of the West Midlands home therapies work was the introduction of a CQUIN to support an increase in the number of patients dialysing at home. The CQUIN has supported providers to target resources toward improving services within their units and re-structure home therapy teams so they are more effective. At the beginning of the project, the home therapies CQUIN caused tensions between commissioners and providers as it was deemed to be unachievable and would result in the units automatically being penalized for not achieving the targets. Much of this concern resulted from a perception that units lacked the appropriate infrastructure to support the CQUIN. This was largely overcome through merging PD and HHD teams and enabling them to work together more cohesively. The CQUIN has now been in place for three years and the West Midlands has seen an increase in the number of patients dialysing at home as a result.

Working together

Project groups were asked to work together, facilitated by NHS Kidney Care's Learning Network. Project groups have sought to collaborate to address clinical issues by sharing protocols, for example around blood results reporting, nocturnal dialysis as well as training resources on different machines. This has been identified as an on-going need, not only for these project groups but for all units working to increase home therapies uptake. Groups also worked closely with a number of other organisations including Advancing Quality Alliance (AQuA), Health Innovation and Education Clusters (HIEC) and the Health Foundation. Time and capacity constraints were key challenges to sharing learning. This work links to other initiatives including care planning, shared decision making and peer support.

3. The project learning and outcomes

3.4 Emerging success principles

A number of key themes have emerged across all the home therapy projects which should inform future successful service improvement. These include:

- **Plan and engage with key stakeholders**. Time needs to be spent planning projects. This includes stakeholder engagement, reviewing existing provision and identifying how to address gaps. Utilising group members who have project management skills can greatly assist in this. Projects found they worked best with established multidisciplinary steering groups, including representation from all units involved in the project. Network managers and other network staff made a valuable contribution in supporting projects throughout the project. Senior management, including commissioner support and trust acceptance, may help embed the culture change necessary for sustainability of the project.
- **Involve patients and carers in development, design and delivery**. Patient and carer involvement in all stages of the project was identified as vital to the success of projects. This should be established as early as possible. Project groups found that patients were often keen to share their insights.
- **Recruit motivated clinical champions**. Having highly motivated clinical champions was essential to promote the service and drive up acceptance among staff and patients. Any motivated and experienced member of the kidney healthcare team can take on the clinical champion role; however they need dedicated time and capacity.
- **Engage with all key stakeholders to raise awareness and build strong relationships**. This needs to be done from the start in order to create local enthusiasm and to ensure the project meets its objectives. Utilise the resources that are available – by working with organisations, project groups could focus on many aspects of home therapies such as: the barriers, communication styles, consistency, choice, and shared decision making.
- **Engage fully with staff**. Healthcare professionals have a key role in supporting patient choice including dialysis at home. Staff engagement is fundamental to embedding real service improvements, and some project groups found they had to address considerable resistance to change. This was successfully addressed via credible clinical leadership and staff education. Continuous and relevant communication is needed throughout the project, capturing achievements and outlining next steps. Share learning using a variety of methods such as forums, newsletters, seminars, and presentations.
- **Consider any service changes that may be needed**. Combining the home dialysis departments can produce symbiotic change, embedding sustainable developments such as a revised training format, buttonholes needling for home haemodialysis patients, increased referrals for home dialysis, and ease of modality change whilst remaining on home dialysis.
- **Be flexible to accommodate patients with complex and diverse needs**. Project groups prioritised development of resources that promote home dialysis and training approaches that are flexible to accommodate different learning needs. Approaches suitable for those with more complex needs such as solo dialysis, and nocturnal dialysis for those in employment, living with learning difficulties or co-morbidities need to be further developed.
- **Involve your local communications team**. Key learning about DVD production included allowing adequate time to agree the brief and understand how the film was to be used. This allowed the team to be clear with the company producing the film what they wanted to achieve. Preparation prior to filming patients and staff in the hospital was crucial. The local communications teams were invaluable in assisting with these issues.

3. The project learning and outcomes

3.4 Emerging success principles

- **Identify in advance what you aim to achieve and how you will measure success**. Anticipate potential difficulties around data collection. It will be important to consider how process measures in particular can be used effectively in the future.
- **Make use of any available national and local support**. The support of NHS Kidney Care was seen as invaluable by some project groups, providing opportunities to network with other units. The regular e-seminar meetings enabled learning and sharing of experiences to move the project forward. There was also regular contact with NHS Kidney Care to support elements of the project and inform changes. The communications team supported project groups to successfully submit a number of abstracts and publications to a diverse range of events and journals. Project groups also found that the NHS Kidney Care funding empowered frontline staff to own and lead sustainable change with senior support, building on the talented and committed workforce.
- **Set up a forum to share resources and protocols**. This avoids unnecessary duplication and maximises spread of service improvements. The annual home therapies forum held in Manchester may play a key role in supporting this work going forward.

4. Project implications and future development

This project demonstrates that it is possible to develop a range of innovative new approaches and resources to support dialysis at home. Successful approaches are likely to include initiatives that address all or most of the following key dimensions:

- Promotion of home dialysis to people with kidney disease, including those due to start dialysis and those already on dialysis using appropriate resources and facilities such as 'choice rooms'
- Staff engagement and education to provide choice
- Training for home dialysis
- Best use of technology both to improve self-needling and support dialysis at home
- Financial incentives that drive and support service developments.

In order to raise awareness of existing best practice and to disseminate effective models of care, project groups worked with other kidney care services. These projects have delivered developments in care quality which will stand the test of time and have lasting positive benefits for patients and service providers. Projects have had recognition at local, regional and national levels.

The key principles from this work include transferable learning about approaches to patient choice, promoting self-care and staff engagement which apply to other long term conditions. There are also important issues that relate to work with private healthcare providers and procurement of healthcare.

Key future developments that will impact on dialysis at home include the potential role of smaller dialysis machines that may not necessitate home adaptation and of minimal care units that have been introduced in various locations. Areas where future research would be useful include evaluating the patient experience of HHD; approaches to supporting patient choice and training; and the safety of patient needling.

In conclusion, the home therapies projects have delivered very real service improvements for people who want to dialyse at home. The learning from these groups will be shared to create momentum for change in units across England, and beyond. Project groups have identified a need to ensure that this work is supported during the current NHS organisational developments.

Appendix 1

Unit data

Measure	Royal Wolverhampton		Coventry		North Staffs		Sussex Kidney		St Helier		Yorkshire & the Humber (Sheffield and York)	
	April 2012	Oct 2012	April 2012	Oct 2012	April 2012	Oct 2012	Oct 2011	Oct 2012	Nov 2011	Sept 2012	April 2012	Dec 2012
% of haemodialysis patients undertaking at least one aspect of self-care	6.7	6.5	21	73	80.9	89.2	10	15	15	9.7	87.5	95.5
% of patients on in-centre/satellite haemodialysis who are independent of nursing support	1	1	4	4.2	1.6	1.3	5	5	<1	<1	0	5
% of patients on haemodialysis with a functioning AVF/AVG who are using button-hole technique	6	8.5	12	16	7.7	7.6	6	16	5	7.3	9	4.5
% of planned start patients who have had the opportunity to discuss dialysis options	100	100	100	100	100	100	100	100	97	100	Not collected	Not collected
% of unplanned start patients who have had the opportunity to discuss dialysis options	100	100	100	90	98	100	100	100	45	100	Not collected	Not collected
Number of patients about to start dialysis identified for home dialysis/self-care in the last 4 months	35	30	21	36	11	21	6	12	2	3	15	17
Number of patients about to start dialysis who have completed or are in home dialysis/self-care training in the last 4 months	15	27	28	25	7	5	8	6	1	4	5	34
% of patients dialysing at home (CAPD & home haemodialysis)	23.2	26	22	28	23.4	27.3	25.5	36	14.9	16.2	21	20.5

Appendix 2

Useful resources

The following 'how-to' guides describe how healthcare teams and services can implement new approaches to help improve access to home therapies.

Buttonholing
http://www.kidneycare.nhs.uk/howto_guides1/buttonhole_needle_technique/

Tray approach
http://www.kidneycare.nhs.uk/howto_guides1/tray_approach_makes_home_conversions_for_dialysis_easier_and_more_cost_effective/

Solo dialysis
http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/home_therapies/howto_guides1/solo_dialysis_more_freedom_and_control_for_patients_living_alone/

Haemodialysis at home
http://www.kidneycare.nhs.uk/howto_guides1/haemodialysis_at_home/

Renal Patient*View*
http://www.kidneycare.nhs.uk/howto_guides1/renal_patient_view_helping_dialysis_patients_live_life_to_the_full/
http://www.kidneycare.nhs.uk/howto_guides1/encouraging_patients_to_use_renal_patient_view/

Yorkshire & the Humber's Sharing Haemodialysis Care website:
http://www.yhscg.nhs.uk/Networks/sharing-haemodialysis-care.htm

Further information is contained in this blog:
http://www.health.org.uk/blog/no-more-groundhog-days/

St Helier DVD
The team at St Helier has produced a 10 minute film, which was made with the help of patients who have chosen home dialysis, using their experiences to educate both pre-dialysis and current dialysis patients as well as carers about dialysis at home.
http://www.kidneycare.nhs.uk/resources_old/short_films/st_helier_home_dialysis_video/

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