

Service Improvement theme

**Evaluation of Case Study Sites for Home Therapies for People with
Chronic Kidney Disease**

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1. EXECUTIVE SUMMARY

This report presents a case study evaluation of how four hospitals have been working to increase the uptake of home therapies by patients with chronic kidney disease. The evaluation was a two-year study starting in April 2011 and was part of a wider programme of work within the West Midlands Central Health Innovation and Education Cluster (the HIEC) at the University of Birmingham. The aims of the research were to describe and track what renal teams were doing to increase the uptake of home therapies from the perspective of both staff and patients, to consider how this might influence the uptake of home therapies, and to identify lessons for the future.

Patients with chronic kidney disease are grouped according to a number of stages, as set out in national guidance. At stage 5, when patients are nearing end-stage renal failure, they are offered a number of treatment options. The best option in terms of patient outcomes is transplantation. Patients who are unable or do not wish to have a transplant or are waiting for a suitable donor, are offered a number of other treatment choices: peritoneal dialysis, haemodialysis, or conservative care. Peritoneal dialysis (PD) is done by patients at home as continuous ambulatory PD during the day, or overnight automated PD. Haemodialysis can be done at home with patients responsible for their own treatment, or in a hospital or satellite unit where care is provided by nurses.

In the West Midlands, the specialised services commissioner of dialysis services introduced an ambitious five-year target in April 2010 for providers to increase the uptake of home therapies (PD and home haemodialysis), with the aim of having 35% of patients on a home therapy by March 2015. This was a CQUIN target within Trusts' contracts with the commissioner, which had financial penalties attached if annual interim home therapy targets were not met. Home therapy uptake levels in the West Midlands averaged 17.3% at the end of December 2009, just prior to the start of the 5-year target period. This initiative from the commissioner provided a unique opportunity to study how local hospitals approached the challenge of doubling the uptake of home therapies over a five year period.

Following discussion with renal consultants, all seven West Midlands renal services were invited to express interest in the evaluation. Four were selected in order to get maximum variation in geography and size of unit. Fieldwork data were collected over a 12-month period from September 2011 to August 2012. At the point when data collection began, the hospitals had been working for 18 months on ways of increasing the uptake of home therapies. Home therapy uptake rates were tracked from a baseline in December 2009 for three years through to December 2012.

The research used a realistic approach to the evaluation, which aimed to identify the local context and factors influencing change in each setting or organisation. Findings from two recent systematic reviews were used to identify significant factors for the sustainability of innovation in the health service, and success factors in shifting hospital care into community settings. These factors were applied to renal services and mapped to the four levels of

Ferlie and Shortell's (2001) model for successful health system change, in order to provide an evaluative framework for the research.

Two linked studies were undertaken. Study 1 was a qualitative evaluation undertaken in the four hospitals with staff and patients. Study 2 was a smaller-scale observational study which picked up issues from study 1 for more detailed study in one of the four hospitals.

For study 1, face-to-face qualitative interviews were undertaken with 96 staff working in clinical renal roles, along with renal managers and Trust senior managers. Ninety-three patients who had gone onto their current dialysis treatment within the last two years were interviewed by telephone about their experience of the services. Interview data were analysed within the research framework to identify themes related to: the dialysis pathway and individual patients and clinicians; the renal team and how it is organised, trained and led; the hospital Trust; and factors related to the wider health system. Changes in the uptake of home therapies during the study period were also monitored and compared with other hospitals in the West Midlands and the rest of England.

For study 2, pre-dialysis patients were observed in 123 routine out-patient appointments and home visits. The 42 appointments where dialysis was discussed were then analysed in detail, looking at the strategies that staff use to overcome barriers to home therapies, the perspectives that staff and patients have on home therapies, and the range of communication styles which staff use when discussing dialysis with patients.

Before considering the findings, it is important to note that the very large majority of patients were overwhelmingly grateful and positive about the dialysis services, and particularly about the support and care they had received from staff. The comments they made about improvements were made in this context, with the very large majority of patients wanting staff to be aware of how supported and cared for they felt. Table 1.1 illustrates with quotes from patients the main points the patient interviews raised in the study. These are incorporated into the main findings which follow and which are summarised in six themes. The report concludes with a discussion of how home therapy uptake rates had changed, success factors for increasing the uptake of home therapies and implications for commissioning

TABLE 1.1 : SUMMARY OF PATIENT PERSPECTIVES

“I mean the staff are great, always there for you if you want them.” Home haemodialysis patient

“To be honest, with the renal unit I think they are absolutely first class and they talk you through everything and, you know, I can’t see that they can improve.” PD patient

“Speaking directly to someone who has had it [dialysis], so you’re getting all the unfiltered information...it was useful to be able to speak to a person who had gone through that to give us, you know, warts and all what’s going to happen, so that was good.” PD patient

“The actual going onto dialysis and actually accepting it [was the hardest part] - knowing for over twenty years that the likelihood of it as happening is one thing, but the actual reality of it...” Home haemodialysis patient

“...they were explaining to me but it just didn’t go through me head that I was going to get ill, like. I mean they were very, very nice but I was just too scared.” In-centre haemodialysis patient

“I had the feeling sometimes that if I had been able to put my kidneys on a plate and send them into the hospital it probably would have worked as well really. He [the consultant] didn’t seem to be particularly kind of interested to talk to me about the kind of wider implications of dialysis and kidney failure.... I think that the transition to that kind of life is extremely traumatic.” Home haemodialysis patient

“So ward x then, the support is top notch. They’re at the end of the phone if you’re worried about anything and I have used that a couple of times and it’s good.” PD patient

“You get tossed between your doctor [GP] and the hospital. The doctor won’t see you or treat you – they might see you but they won’t treat you because you’re a renal patient... the doctor at the hospital won’t treat you because you’ve not seen your GP...” Home therapy patient

“I suppose more having it [home therapies] more visible... more patient information in the outpatient areas and stuff like that... there was nothing that screamed out at me as if to say oh have you thought of a home therapy?” In-centre haemodialysis patient

“...it was actually one of the health care assistants, I was asking her about something to do with the [haemodialysis] machine and she said “Oh I don’t know what you’re bothered about asking for, you’re not going home, you wouldn’t be going home on one of these machines anyway” and I was completely if you like shot down in flames over it.” Home haemodialysis patient.

“What I’d like to see more of ‘though is people being able to erm, do self-care within the unit.” In-centre haemodialysis patient

The dialysis pathway

The dialysis pathway in all four sites covered three phases of care for patients with stage 5 chronic kidney disease. Pre-dialysis for many patients covered the 9-12 months prior to starting dialysis, when patients' kidney function was declining and they were offered pre-dialysis education to help them consider their treatment options. Training was then provided for patients who opted for PD or home haemodialysis, prior to them starting treatment. On-going care and support was provided to patients on dialysis through out-patient appointments and/or home visits. Although the majority of patients experienced a gradual decline in their kidney function which allowed their care to be planned over a number of months, some patients had acute kidney failure and needed to start treatment very quickly. All sites had separate acute pathways for these patients.

Pre-dialysis was the part of the pathway which varied the most across the four sites. It was also the part of the pathway which attracted the most comments from both patients and staff. In contrast, once patients had opted for a home therapy, both the training to undertake dialysis at home and the on-going care and support arrangements for home patients were seen to be working very well, with only minor suggestions for improvement. The main difficulties for patients once they were on dialysis were getting access to psychological support or counselling and poor continuity of care with GP practices, particularly in relation to changes to medication. Although this did not impact directly on home therapy uptake, it was a source of considerable frustration and time-wasting for the minority of patients affected, and for this reason it is recommended that continuity of care between hospitals and GP practices improves.

Patient barriers to home therapies

Although very small numbers of patients faced practical barriers to home therapies, related to housing, space or lack of support at home, most of the barriers identified by staff and patients were to do with patient motivation, myths and misunderstandings about treatment, difficulties in understanding complex information and making decisions, and a number of psychological and emotional issues. Study 2 found a high degree of skill among staff in the one site involved, in tackling practical barriers and finding solutions wherever possible. The study recommended that renal services and pre-dialysis education should draw on psychological skills and techniques to help patients overcome barriers to home therapies.

Pre-dialysis education

Feedback from patients suggested that pre-dialysis education was not working optimally and could improve in a number of ways. Both studies found that many patients appeared to find choice of dialysis treatment very difficult. The reasons for this were quite complex, but patient feedback suggested that some fairly simple changes to teaching and learning methods and the use of information would help some patients engage more with the process. This included employing a wider range of teaching methods, and particularly more

active learning methods such as handling dialysis equipment or talking to patients already on dialysis.

Some patients described having “information overload” because of the number and complexity of treatment options they need to think about. Study 2 highlighted that although staff had considerable skill in providing information to patients, less emphasis was given to helping patients apply the information to their own lives. Patients talked about wanting treatments to be made ‘real’ to them and their own circumstances, and appeared to want a more individualised approach to pre-dialysis education. Opportunities to have contact with other dialysis patients, was one of the most frequent improvements suggested by patients.

There was also a difference of view between staff and patients about the role of information in patient decision-making. Staff described a fairly rational weighing of treatment options based on information, whilst patients described a more personal approach of thinking about their own lives and how different options might work for them.

The study concluded that a more individualised approach to pre-dialysis education is needed, where the focus for specialist staff is less on providing information and more on discussing with patients what is important to them, what they value and how any hindrances to self-care can be overcome. This is more like counselling than education. Study 2 suggested that staff will also need to adapt their dominant communication styles in order to take more of a counselling approach to pre-dialysis.

Study 1 found that some patients only become open to home therapies once they are established on dialysis, suggesting that routine reviews of treatment choice could be helpful. Study 2 also noted that many patients seem unprepared for making treatment decisions, and suggested that patients could perhaps be prepared for making this important decision if they had opportunities for making lower level decisions earlier on in the CKD pathway.

Recommendations include: using a wider range of teaching materials and methods, and matching these to patients’ preferred learning styles; reducing the amount of time spent on information-giving by providing patients with information ahead of pre-dialysis sessions; taking a more individualised approach to dialysis education which includes a two-way exploration of treatment options and considers emotional and psychological barriers to home treatment; providing opportunities for all patients to talk to established dialysis patients; exploring the reasons behind patients’ choice of treatment and undertaking periodic reviews of treatment choice; providing counselling skills training for pre-dialysis nurses; and preparing patients for the complex choice of renal replacement therapy, by providing lower level choices earlier on in the CKD pathway.

Patients’ unmet psychological and emotional needs

The research found that there are considerable unmet needs amongst dialysis patients related to their psychological and emotional adjustment before and after they start on

dialysis. Although this was not something the study set out to explore, just over a third of patients talked about the transition to dialysis as a scary and traumatic experience. Very few staff raised this issue and some patients were very critical of the medical focus of staff which often excluded discussion about wider needs. Some patients thought that their high distress levels meant they had been unable to engage properly with treatment choices, suggesting that they would benefit from re-visiting treatment options once they are established on dialysis.

Overall, the study suggests that there are relatively large numbers of patients who would benefit from some kind of psychological support during and after the transition to end-stage renal failure. This would provide support to patients, but also has the potential to reduce any adverse impacts on patients' ability to make treatment decisions. Given the number of patients who have unmet psychological support needs, one option would be for staff to build regular checks on patients' emotional well-being into routine appointments. However, Study 2 suggests that staff will need to be trained for this option to work well.

Recommendations include: building support for patients into existing pathways; undertaking research into low level interventions which might be helpful for patients; and undertaking research into the impact of psychological distress on patients' decision-making about their treatment.

Staffing issues

Although the large majority of staff expressed support for increasing the uptake of home therapies, staff who did not work in a home therapy role said they lacked confidence when talking to patients about home therapies and wanted to increase their knowledge and experience of both PD and home haemodialysis. Only one site had a structured approach to this, through their induction and training programmes for all staff. Staff emphasised the importance of being able to see patients treating themselves at home, in order that they can talk credibly to other patients about home therapies. The patient interviews highlighted the importance of all staff being 'on message' about home therapies, with patients reporting that they were influenced by how staff answered their casual questions about home therapies, particularly on the wards and in the haemodialysis units. Specialist registrars (SpRs) felt they were poorly trained about home therapies and had little if any experience of home haemodialysis, despite regularly having conversations with patients about treatment options.

Sites varied in how they structured their teams with two sites having separate PD and home haemodialysis teams and two sites having integrated home therapy teams. Although staff advocated the benefits of their existing team structures, this appeared to be less important than team structures being flexible enough to provide staff with experience of both types of home therapy. All sites had successfully secured extra staff resources for home therapies on the back of the CQUIN target, and felt they had sufficient resources to meet targets. None of the sites had forward-looking capacity plans which took them to their April 2015 target. One of the keys to successfully increasing the uptake of home therapies was seen by staff as

strong clinical leads who had championed home therapies, supported by enthusiastic and skilled home therapy teams.

Recommendations included: providing basic home therapy training to all renal staff, to equip them to answer patients' questions and signpost patients to specialist staff; including home therapies in induction, staff appraisals, personal development plans and unit training plans; increasing the home therapy content on the local regional training programmes for SpRs and ensuring this is covered early on in the programme; providing PD and home haemodialysis specialist staff with training and experience of both types of home therapy; and planning for further increases in specialist home therapy staff capacity in order to meet the 2015 CQUIN target.

Home therapies as an example of service change

The research framework, which was developed around the Ferlie and Shortell (2001) model for health service change, suggested that there would need to be supportive actions taken at four levels in order to be successful at increasing the uptake of home therapies: at the individual patient and staff level; at the team level; at the organisational level; and at the level of the wider health system. The research confirmed that this was the case. However some of the findings point to sites being at the early stages of service change, which can be characterised by a small number of highly motivated staff driving forward changes, compared to the later stages when service changes become more embedded and rely less on individual champions.

Earlier sections have reported on the first two levels (individual patients and staff; and teams). At the organisational level, senior management within three of the hospitals were seen as supportive of the goal to increase the uptake of home therapies, which tended to align well with Trusts' strategic plans. At the wider system level, the regional commissioners' CQUIN target appeared to have played a positive role in stimulating the renal services to focus on increasing the uptake of home therapies. Although the process by which the target had been introduced had made it initially unpopular with many clinicians, there were positive effects in raising the profile of home therapies within the service and more widely in the hospitals. However, all four sites queried whether the target of 35% of patients on a home therapy by April 2015 was realistic and achievable.

Changes in the uptake of home therapies

All four sites had introduced assisted PD in order to extend PD to a wider group of patients and had improved their acute PD pathways so that patients on the wards could access PD more rapidly than before. One site was using additional strategies including: self-care in haemodialysis units as a stepping stone to going home; reviewing in-centre patients and transferring some to home haemodialysis; and offering solo home haemodialysis using the NxStage machine.

All four sites had made increases in the uptake of home therapies over the two years since the introduction of the CQUIN target in April 2010, and by the end of 2011, all four were

above the England average, which had remained static. By the end of 2012, the sites had achieved between a 1.8% and 10.5% increase in the uptake of home therapies. Statistical analysis showed that there was no effect on home therapy uptake rates arising from participation in the study. Although there had been changes in the composition of the renal replacement therapy and dialysis populations, which might have influenced home therapy uptake rates, none of these changes were significant when comparing the study sites to the West Midlands and the rest of England (with the exception of one site where its renal replacement therapy patients aged under 65 had increased significantly). It was therefore concluded that the increases in home therapy uptake rates were likely to be attributable to the actions undertaken in each site.

Success factors for increasing the uptake of home therapies

A number of success factors were found in all four sites, suggesting that they are likely to be pre-requisites for achieving increases in the uptake of home therapies. These included: clinicians being familiar with the evidence; the building blocks of the service being in place and working well; staff supporting the change; effective clinical leadership; staff being given the headroom to innovate; having sufficient staff capacity to deliver the change; and having a strong incentive to change (the CQUIN target). Sites achieving the greatest increases in uptake had focussed on both PD and home haemodialysis rather than just one of these therapies.

Success factors which were found in some but not all sites, mostly related to specific aspects of home therapies, such as initiatives designed to widen access, peer support, home therapy team structure and Trust support.

Suggestions from patients about what hospitals could do to achieve further increases in uptake rates, tended to highlight cultural issues, such as all staff being on message and the importance of good publicity in all clinical areas so that home therapies are portrayed as the norm rather than the exception. The research suggests that another useful marker of whether home therapies are part of the culture could be the degree to which in-centre haemodialysis units are involved in home therapies. The study identified a potential role in extending self-care opportunities as a stepping stone to going home; on-going patient education about treatment options; periodic reviews of treatment choice for in-centre haemodialysis patients and staff seeing it as part of their role to talk to patients about treatment options.

The report discusses whether the four sites were likely to continue to increase the uptake of home therapies, beyond the levels achieved in 2012. It certainly seems likely that if all the sites adopted all of the actions and strategies detailed in this study, uptake rates would continue to increase. However, as the proportion of patients on a home therapy increases, it may become more difficult to increase uptake rates amongst patients who have less initial interest in, or who face significant barriers to doing a home therapy.

For renal services wanting to increase the uptake of home therapies beyond the levels achieved in the study sites, a four-pronged approach is suggested: scaling up service initiatives designed to widen access; improving the quality of pre-dialysis education and develop it into pre-dialysis counselling; improving the training of SpRs and providing basic home therapy training to all staff; and providing emotional and psychological support to pre-dialysis and established dialysis patients.

Recommendations included: paying attention to how the wider culture of the service may encourage or discourage patients to consider home therapies; routine provision of self-care in haemodialysis units as a stepping stone to going home; and regular reviews of patient choice of treatment. The report also recommends that there should be no further expansion of in-centre haemodialysis units, with Trusts potentially considering reducing capacity in the medium-term, in order to improve patient incentives to opt for a home therapy.

Implications for commissioning

The report concludes by highlighting recommendations of particular relevance for commissioning. For specialised services commissioning, recommendations include: building the provision of low level emotional and psychological support into service specifications; setting standards for pre-dialysis education which takes an individualised approach and incorporates counselling; collecting data from Trusts about the clinical and patient outcomes achieved for home patients in order to build the evidence base for home therapies; developing an integrated service specification for CKD stage 5 which addresses lack of coordination between GP practices and hospital renal services; and noting that the study found positive evidence that CQUIN targets can incentivise accelerated uptake of home therapies, although careful negotiation and consultation is required when introducing such targets.

For Local Education and Training Boards and Councils, recommendations include; ensuring SpR training programmes cover home therapies early on and provide direct experience of patients being treated at home; and commissioning specialist counselling skills training for staff involved in pre-dialysis education.

2. INTRODUCTION AND BACKGROUND

For the past 15 years, NHS policy has stressed the importance of patient-centred care and patient choice, while also promoting the provision of care closer to home or in patients' own homes (DoH, 2007, 2009) and the expansion of self-care (DoH, 2001). For patients with kidney failure, the national service framework promotes informed patient choices about the preferred place, time and type of treatment (DoH, 2004). At the same time, a recent literature review has found consistent international evidence that home dialysis for people with kidney failure can result in increased life expectancy, a better quality of life, and cost savings compared with dialysis provided in satellite or hospital settings (Burke, 2011).

Patients with chronic kidney disease are grouped according to a number of stages, as set out in national guidance. At stage 5, patients are nearing end-stage renal failure and are offered a number of treatment options. The best option in terms of patient outcomes is transplantation. Patients who are unable to have a transplant or are waiting for a suitable donor are offered a number of other treatment choices: peritoneal dialysis, haemodialysis, or conservative care. Peritoneal dialysis (PD) is done by patients at home as continuous ambulatory PD during the day, or automated PD which involves treatment overnight. Haemodialysis can be done at home with patients responsible for setting up their machine, or in a hospital or satellite unit where care is provided by nurses.

Despite the evidence that home therapies deliver better patient outcomes, there is wide variation in the adoption of home therapies, both internationally and within the United Kingdom (Burke, 2011). In the West Midlands, the uptake of home therapies was in line with national averages, with 17.4% (range 9.9-27.4) of all dialysis patients managing their care at home at the end of 2009 (UK Renal Registry, 2011). In this context, the West Midlands Specialized Services Commissioning Team developed an ambitious plan to increase the uptake of home therapies over a 5-year period to 35% by April 2015. This provided a unique opportunity to evaluate how renal services approached this significant service change, as an example of a rapid shift of acute care to home settings, where professional-led care evolves into supported self-care. It was anticipated that this evaluation could also highlight lessons which have wider application, as NHS policy continues to promote out-of-hospital care and self-care for people with various long-term conditions.

Plans for a qualitative case study evaluation of four hospital renal dialysis services were developed during the first part of 2011, as part of a wider programme of work within the West Midlands Central Health Innovation and Education Cluster, based in the School of Health and Population Studies at the University of Birmingham and funded by the Department of Health. The aims of the evaluation were to:

- describe and track what renal teams do in order to increase the uptake of CKD home therapies
- assess the likely impact of this work on the uptake of home therapies
- identify lessons for the future.

This final report for the evaluation is presented in two sections. The main study reported in section 3 of the report is the qualitative evaluation undertaken in four hospitals, which also includes a quantitative analysis of changes in the uptake of home therapies over the study period. A smaller scale follow-on observational study in one site is then reported in section 4. Section 5 draws together the cross-cutting findings from both studies and discusses them in the context of the literature, concluding with a number of recommendations.

3. STUDY ONE : CASE STUDY EVALUATION

3.1 METHODOLOGY

3.1.1 Research design

The starting point for the evaluation was an assumption that each of the four case studies would be unique, with the home therapies goal being interpreted within different local contexts and being influenced by varying local factors. This is based on the 'realistic' approach to evaluation developed by Pawson and Tilley (1997). It recognises that what succeeds in one place may not succeed elsewhere, and assumes that interventions never work in the same way or in the same set of circumstances for everyone.

A rapid review of the literature was undertaken to identify evidence from systematic reviews of the literature for success factors for both health service change and shifts of care from hospital to home settings. An initial search identified two recent and relevant major systematic reviews, which were then used to develop an evaluation framework.

The first was a major systematic review of the literature on diffusion, dissemination and sustainability of innovation, published in 2004 (Greenhalgh et al). This review drew on 450 studies, mostly in the health sector, and identified success factors which were rated in terms of the strength of evidence. The first stage in developing our research framework was to identify success factors from this systematic review for which there was strong evidence from the health service studies only.

This was then added to from the second major systematic review of 613 studies, designed to identify best practice in shifting hospital care into the community, including time limited management of change issues (Singh, 2006). The success factors from these two systematic reviews were then mapped across to the four levels of Ferlie and Shortell's (2001) model for successful health system change. The second stage in developing our research framework was to apply these generic health service change success factors to renal dialysis services. This was done with reference to best practice guidance, using the Renal National Service Framework (DoH, 2004) and the recent haemodialysis toolkit (NHS Kidney Care, 2010). This resulted in a detailed research framework for likely service change success factors for renal dialysis home therapies, operating at four levels:

- Individual factors – related to staff, patients, carers and how services are provided to individuals
- Team factors – related to the renal team, how it is led, organised, trained, supported and resourced
- Organisational factors – related to the incentives, vision, strategy and culture of the organisation
- Wider system – related to national and regional policy and commissioning.

3.1.2 Site selection

All seven renal services in the West Midlands were offered the opportunity to express interest in taking part in the evaluation. Six sites expressed interest in taking part, and four were selected in order to achieve maximum geographical spread, a rural-urban mix, and variation in how dialysis services were organised. The demographic characteristics of the sites are summarised in Table 3.1. Each site agreed a clinical lead for the research, who worked with the research team to compile staff interview lists, agree the procedures for selecting and recruiting patients, and the information and research governance arrangements. An administrative lead was also agreed in each site, to undertake the compilation of patient sampling lists and other administrative work associated with recruiting patients.

Sites	No. dialysis patients *	No. Haemodialysis units	Catchment area	Geography	Population
1	1018	11	Very large	Inner city and urban with some smaller rural areas	Sizeable black and minority ethnic population
2	380	3	Medium	Urban with surrounding rural area	Small black and minority ethnic population
3	391	3	Medium	Inner city and urban	Sizeable black and minority ethnic population
4	223	2	Large	Rural with some small towns	Largely white population

* Figures for March 2011.

3.1.3 Research protocol and ethics

The research framework was used to generate initial questions for qualitative semi-structured interviews with staff and patients. These semi-structured interviews were designed to explore how each hospital was approaching the expansion of home dialysis, allowing local issues of importance to emerge, whilst also testing out the degree to which the success factors generated from the literature were being addressed, and how important these were proving to be for renal services. The questions were amended following initial discussions with renal consultant clinical leads about the evaluation and a small amount of observation of low clearance out-patient clinics in site 1.

The research protocol and topic guides for staff and patient interviews were approved ethically by Birmingham University in July 2011, with minor amendments approved in August 2012. The R&D offices of each Trust reviewed documentation and agreed to the research team undertaking the work (Appendix 7.1).

3.1.4 Staff recruitment

In each site, an interview list of staff job titles was agreed with the renal consultant clinical lead, based on including all staff groups which have contact with dialysis patients, plus renal and Trust senior managers. The majority of clinical staff were in senior or team leader roles. They were e-mailed by their renal clinical consultant lead, encouraging them to take part, and providing them with e-mail information from the research team, the Staff Information sheet and the consent form. Staff interviews were scheduled by the research team in site 1, and by the lead medical secretaries in sites 2, 3 and 4. Table 3.2 provides a breakdown of the roles of interviewees.

TABLE 3.2 : ROLES OF STAFF INTERVIEWED							
Staff Roles	Sites					Total	Total %
	1	2	3	4			
Renal consultant lead	1	1	1	1		4	
Renal consultant	8	6	3	2		19	
Clinical specialist	-	-	-	1		1	
Specialist registrar	2	2	1	-		5	
Sub-total doctors	11	9	5	4		29	30%
Acute ward nurse manager	2	1	1	1		5	
Dialysis unit nurse manager	3	3	4	3		13	
Lead renal nurse/renal matron	1	-	-	1		2	
Pre-dialysis nurse/sister	1	1	3	1		6	
PD nurse/sister	2	-	-	2		4	
Home therapy nurse	-	4	3	-		7	
Home haemodialysis nurse/sister	2	-	-	2		4	
Sub-total nurses	11	9	11	10		41	43%
Home therapy support worker	-	1	-	-		1	
Renal technician	1	1	1	1		4	
Psychologist	-	-	-	-		0	
Dietician	1	1	-	1		3	
Consultant vascular surgeon	-	1	1	-		2	
Renal social worker/assistant	1	-	-	1		2	
Renal business manager	1	-	1	1		3	
Sub-total other renal staff	4	4	3	4		15	16%
Trust general managers	2	1	-	1		4	
Trust clinical/medical director	1	2	1	1		5	
Trust finance manager	1	-	-	1		2	
Sub-total Trust managers	4	3	1	3		11	11%
TOTAL	30	25	20	21		96	
Kidney patients association chair	1	-	-	1		2	
No. interviews declined	3	0	7	0		10	

A total of 96 staff interviews were completed, with 9% of eligible staff refusing to take part. Staff had the option of withdrawing from the study for up to three weeks after their interview date, but there were no withdrawals at this stage. Ninety-four staff were interviewed between September 2011 and March 2012, with two additional interviews

completed in May and June 2012 for staff who had not been available for the site interview visits. The main staff groups who were interviewed were renal doctors (30%), renal nurses in a variety of roles (43%), other renal staff including allied health professionals, technicians and support workers (16%) and Trust senior business and clinical managers (11%).

3.1.5 Patient recruitment

The agreed inclusion criteria were as follows:

- aged 16 or over
- undertaking dialysis in a hospital, home or satellite clinic setting in the case study site area
- started on their current dialysis treatment within the last 24 months.

The majority of patients had gone onto dialysis for the first time within the last two years. A minority of had changed treatments, having been on other forms of dialysis previously and/or had a transplant. These patients had started their current dialysis treatment within the last 24 months.

Original plans to restrict participation to patients who had started their current dialysis treatment within the last 12 months, were amended in the light of the experience of sampling patients in site 1. The extension from 12 to 24 months represented a compromise between ensuring patients' experiences of the transition to dialysis were as recent as possible and ensuring that the patient pool was sufficiently large to secure variation in age, gender and ethnic group across the different types of dialysis treatments.

The exclusion criteria were:

- patients with limited intellectual or cognitive function which might affect their ability to consent
- patients expecting to have surgery or be transplanted within the next 2-3 months.

Each Trust provided the research team with an anonymised list of all the patients who had gone onto their current dialysis treatment within the last 24 months. The research team then selected a sample of 60-70 patients per site, based on achieving maximum variation in age, sex and ethnicity across different types of dialysis. This list was then checked by clinical staff in each site, in order to remove any patients who were having treatment/medical problems, or who were due to have surgery or be transplanted.

Patients were then sent a letter from the renal consultant clinical lead encouraging them to take part in the evaluation, and confirming that their participation would not affect their treatment. The Patient Information sheet and Consent form were included with this letter. This was followed about one week later by telephone calls from a renal medical secretary, to ask for patients' permission to have their name and telephone numbers passed to the University research team and to check if the patient needed to be interviewed in a language other than English. In three sites, the medical secretaries also timetabled some of the patient interviews during these initial telephone calls.

Patient contact details were then provided to the research team who contacted patients for telephone interviews. In three sites, patients' names and telephone numbers were provided on an encrypted memory stick which was collected in person by the researcher or couriered to the University. In the fourth site, patient details were only accessible on-site.

A total of 93 patients were interviewed between November 2011 and March 2012, with two additional interviews completed in August 2012 in Site 1 (in order to increase the number of interviewees on home haemodialysis). The number of interviews completed per site ranged from 21 to 25. Once saturation had been achieved, with as diverse a group of patients as possible, the interviews were deemed completed.

Three patients from site 3 asked to be interviewed in Panjabi, but subsequently declined to take part or were not contactable. A total of eight patients declined to be interviewed (data for refusals was collected in three out of four sites). Patients had the option of withdrawing from the study for up to three weeks after they had been interviewed. No patients withdrew from the study at this stage.

Overall, 15% of eligible patients across the four sites were interviewed (range 11-18%). The proportion of eligible patients within different treatment types who were interviewed was more variable: PD 22%; Home haemodialysis 64%; In-centre haemodialysis 9%. This reflects differences in the size of the eligible patient pool for different types of dialysis. Table 3.3 details the demographic characteristics of the patients in the study.

Appendix 7.2 provides details of the patient pool for sampling and a breakdown of the age, gender and ethnic group of the sampling pool and the patients included in the study.

TABLE 3.3 : CHARACERTISTICS OF THE STUDY PATIENTS						
Patient sampling	Sites				Total	
	1	2	3	4	No.	%
Eligible	205	152	129	132	618	-
Refusals	-	5	3	0	8	-
Interviewed	23	25	21	24	93	-
% eligible patients interviewed	11%	16%	16%	18%	-	15%
Treatment type						
PD	10	11	11	8	40	43%
Home haemodialysis	4	7	1	6	18	19%
In-centre haemodialysis	9	7	9	10	35	38%
Sex						
Male	14	18	12	11	55	59%
Female	9	7	9	13	38	41%
Age group						
18-39	5	5	3	5	18	19%
40-64	13	8	8	9	38	41%
65+	5	12	10	10	37	40%
Ethnic group						
White	13	25	15	23	76	82%
Indian	6	0	2	1	9	10%
Pakistani	2	0	0	0	2	2%
African Caribbean	2	0	4	0	6	6%
Other	0	0	0	0	0	0%
Acute/'crashlander' patients	4	2	6	6	18	19%

3.1.6 Data collection

3.1.6.1 Staff interviews

In each site, staff interviews were scheduled first, followed by the patient interviews (Table 3.4). This was designed to provide the research team with a good understanding of the service model and pathways prior to the patient interviews. Staff interviews took place between September 2011 and April 2012. Patient interviews took place between November 2011 and March 2012.

TABLE 3.4 : INTERVIEW TIMETABLE		
Sites	Staff interviews	Patient interviews
1	September - December 2011 1 additional interview May 2012	November 2011 – January 2012 2 additional interviews August 2012
2	October 2011	November 2011 – January 2012
3	December 2011 – March 2012	February – March 2012
4	March – April 2012 1 additional telephone interview June 2012	March 2012

One-to-one staff interviews took place on-site in a confidential office or room, away from clinical areas. At the start of the interview, participants were given verbal information about the study and any questions were answered prior to going through the consent procedure. Interviews lasted between 30 and 60 minutes, and were digitally recorded, with the permission of the interviewees. A small number of telephone interviews were undertaken with staff who had been unavailable on the scheduled interview days.

Each interview started by asking the staff member to talk briefly about their current role, including any involvement in home therapies. Interviews were semi-structured and therefore followed up issues raised by the participants as the interviews progressed. However, the following topics were covered with all interviewees:

- current role and involvement in home therapies
- the most recent 2 or 3 patients at CKD stage 5 who were choosing/had recently chosen their treatment, probing: reasons for treatment choice; role of the clinician; whether patients were typical; details of the pathway (not included for managers and Directors)
- why some patients go for a home therapy and others don't
- views about the push to increase the uptake of home therapies; approach being taken; factors that have helped or hindered
- support for home therapies from the Trust and its Senior Managers/Directors.

Each site also provided the research team with relevant documentation, which varied from site to site, but included:

- dialysis pathways and protocols
- patient information leaflets, DVDs and posters
- pre-dialysis information for patients
- PD and Home haemodialysis training handbooks for patients
- home therapy business/capacity plans.

3.1.6.2 Patient interviews

Patient telephone interviews took place in a private room at the University for patients from sites 2, 3 and 4. Patients from site 1 were interviewed by phone from a private office within the Trust.

At the start of each telephone call, patients were given a small amount of information about the study and the researcher checked the patient's current treatment and how long they had been on it. They were then asked if they wanted further information or to ask any questions. This was followed by the consent process which was recorded on the paper form

by the researcher and digitally recorded. Interviews were typically 20-30 minutes long, although some took up to 1 hour.

Each interview started by asking the patient to talk about how they had come to be on dialysis. This provided a springboard for following up details of their care and the pathway. Interviews were semi-structured and therefore followed up issues raised by the participants as the interviews progressed. However, the following topics were covered with all interviewees:

- patient journey – from first mention of needing dialysis to current treatment (teasing out sequence of events; treatment choices and reasons; sources of information and advice; training; on-going care and support)
- ideas about how to increase the number of patients being treated at home
- one message to the Trust's senior managers about your treatment
- one suggestion for improving the service.

As part of the research protocol, each site had an agreed arrangement with the research team for providing support or follow-up contact to any patients who became upset during the telephone interviews. This was required with one patient.

3.1.7 Data analysis

All interviews were transcribed verbatim. Different members of the research team analysed transcripts for: doctors; nurses and other renal staff; and Trust managers. Verbatim data was entered onto spread sheets with fields generated from the research framework. Additional fields were added to reflect new issues emerging from the interviews. A random selection of 10% of the staff transcripts and 10% of the patient transcripts were cross-checked by the whole team to ensure consistency in the selection of data for entry onto spread sheets.

A similar approach was taken to patient data analysis, which grouped patients on home therapies (with PD and home haemodialysis sub-groups) separately from patients on in-centre haemodialysis.

Spread sheet data was then analysed and discussed by the team, with individual case studies then being written up by a team member. Case studies 1 and 4 were written up by the Principle Investigator, Case study 2 by the Research Fellow and Case study 3 by the Research Assistant.

Each site was written up as a stand-alone case study report. This was a detailed confidential document, produced for that site. The draft report was sent to the clinical lead 7-10 days ahead of a 2-hour feedback meeting. These meetings were attended by 4-10 senior renal staff, and provided a forum for verifying and discussing findings. Following these meetings, sites were given the opportunity to provide further written comments and to request the

removal or anonymisation of any quotes which might be locally sensitive. A final revised report was then sent to each site. Findings from each site were then fed into this Final Report.

3.2 FINDINGS FROM THE FOUR SITES

This section presents a synthesis of findings from across the four sites. Following data collection and analysis, it was agreed within the team that the site-by-site findings were not sufficiently different to merit reporting each site separately. Any notable differences by site are highlighted where relevant in the findings which follow. Although the original research plan aimed to synthesise findings across both staff and patient interviews, considerable interest was shown in feedback meetings in the patient experience findings. This report therefore includes a lengthy appendix focussing just on patient experience. This has been written as a stand-alone appendix, which includes quotes designed to convey the variety and richness of the patients' experiences.

The findings are presented in four main sections based on the analytical framework, which aimed to identify factors at four levels:

Individual factors – related to staff, patients, carers, and how services are provided to individuals

Team factors – related to the renal teams and how they were led, organised, trained, supported and resourced

Organisational factors – related to the incentives, vision, strategy and culture of the organisation

Wider system – related to national and regional policy and commissioning.

The next section presents data to show how each site's home therapy uptake rates had changed, along with data from patient and staff interviews about ideas for increasing uptake rates in the future. The final section discusses the limitations of the study.

3.2.1 Individual factors : Dialysis pathways

The dialysis pathway in all four sites covered three phases of care for patients with chronic kidney disease stage 5. Pre-dialysis usually covers the 9-12 months prior to starting dialysis, when patients' kidney function is declining and nearing the point where dialysis will be needed. At this point, patients are offered pre-dialysis education over a period of time to help them consider their treatment options. Training is then provided for patients who opt for PD or Home haemodialysis, prior to them starting treatment. On-going care and support provided to patients on dialysis includes out-patient appointments and may include home visits to patients on a home therapy. All sites also had acute pathways for patients who

were admitted to hospital wards with end-stage renal failure and who needed urgent dialysis treatment.

3.2.1.1 Choosing a dialysis treatment

Pre-dialysis was the part of the CKD stage 5 pathway which varied the most across the four sites. It was also the part of the pathway which generated most debate with staff because of the complex issues bound up in implementing patient choice. These issues are explored in detail in this section of the report.

Choice models

The four sites took a variety of approaches to patient choice.

Site 1 : Although patient choice was articulated as a very important organising principle, there was no agreed choice model in operation, with different staff taking different approaches. Some staff were strongly committed to patients having fully open choices, whilst others appeared to operate more of a guided choice model (see below), with a small number of staff taking a proactive approach to promoting home therapies as preferred treatments whenever clinically appropriate. This site has subsequently re-designed its low clearance clinics and pre-dialysis education so that patient choice is approached consistently by staff.

Site 2 : Fully open patient choice was the agreed choice model in site 2, with staff presenting all options equally and neutrally. Within this model, staff encouraged patients to consider home therapies as positive and practical options, and took practical steps to overcome any barriers that patients faced.

Site 3 : PD was promoted as the first-line treatment, unless clinically inappropriate, with this site operating a guided choice model. Patient choice did not feature prominently in the staff interviews, with staff focussing more on their role in providing patients with information, education and support. The low key nature of patient choice in this site was also reflected in the patient interviews.

Site 4 : A very clear guided choice model was being used in this site. Patients were offered an overall choice of treatment either at home or in hospital, with home therapies being the preferred option. Within home therapies, PD was promoted as the first-line treatment, because it allowed vascular access to be preserved for patients who may have many years of treatment ahead of them. PD was followed by home haemodialysis with in-centre haemodialysis the last option. In-centre haemodialysis patients were encouraged to opt for self-care as a potential stepping stone at a later date to home haemodialysis. This hierarchy of treatment options was consistently described by all staff, and was also reflected in how patients described their experiences.

The role of staff in patient choice of dialysis treatment

Across the four sites, it was evident that there were dilemmas for staff in how they approached patient choice of treatment. Although there were no staff who were opposed to patients making choices, staff were concerned about their own role in supporting patient choices. In sites 1, 2 and 3, individual staff expressed concerns about staff having undue influence over patients' choices within a guided choice model. They talked about the fine line between encouraging patients to consider a home therapy, and inadvertently shifting towards 'doctor or nurse knows best'. In contrast, staff in site 4 did not see their role in promoting home therapies as potentially conflicting with patient choice, because home therapies deliver better outcomes and are therefore preferred treatments, whilst patients still retain the final decision about their treatment:

"[In the past we] all thought, well, if we influence them to make a decision that means we are biased so we shouldn't. The concept was that we should never influence people. We just have to tell about the treatments and it's up to them to choose.... As clinicians we should take a bit more responsibility in helping patients to choose. If you think this is the right form of treatment for this patient you shouldn't hesitate to express that.... And then again it's not forcing and still they have the choice. You tell them about all other forms of treatment as well so then it's up to the patient to make a choice." Renal consultant clinical lead, site 4.

Staff in site 4 consistently described their role as 'selling' or 'promoting' home therapies, which contrasted with more neutral descriptors used by staff in the other 3 sites.

A number of staff also highlighted the power of the first conversation about dialysis between doctors and patients, and that it can then be hard to get patients to consider different options:

"I do think patients do get swayed, particularly by consultants, because they think they know best. I think it's the initial conversation that they have, you know, which I can only presume will be a consultant initial conversation...but if they've had that underpinning by the consultant first, it's then very difficult [to influence them]." Renal ward sister, site 4.

Patients' decision-making

Overall, the majority of patients across the four sites reported either making their own treatment decision or having been guided by staff, and could articulate why they had chosen or ended up on their current treatment. A small minority could recall very little about this, possibly due to the effects of renal failure. There was also a handful of patients who said they had not been given all the options and described finding out about alternative treatment options only once they were on dialysis. These patients were evenly distributed across all treatment types and did not include a disproportionate number of acute starters where choices may have been restricted. This variety in patient experience was spread across the four sites, although site 4 had very high proportions of patients who clearly recalled their treatment choices, which contrasted with site 2 where numbers were the lowest.

A number of patients also described how they had made treatment decisions over a period of time. They talked about a gradual process of being introduced to treatment options well in advance and felt there were benefits in being able to make a treatment choice over a period of time. This reflects how all four sites operated, aiming to start preparing patients for dialysis 9-12 months in advance of needing to start treatment.

There were also some patients who, despite having known they would need dialysis for years in advance and having gone through pre-dialysis education, felt unable to make a treatment choice. These patients described how their strong emotional reactions to the transition to end-stage renal failure effectively left them unable to make proper treatment decisions or to consider home therapy options:

"I mean they were very, very nice but I was just too scared [to make a choice]." HD patient (female, indian, 40-64), site 2.

Some of these individuals then described how they only became open to home therapy options once they had become established on dialysis, suggesting that regular reviews of treatment choice may have positive results for home therapy uptake.

Both patient and staff interviews also highlighted the need for treatment choices to be reviewed in the light of changes in patients' circumstances and preferences. This appeared to be done in all sites in an informal way through out-patient appointments or contact with nursing staff. None of the sites undertook routine reviews of treatment choice or recorded information about informal reviews in patients' notes.

Pre-dialysis education

The majority of patients had been through pre-dialysis education. This was organised in different ways across the four sites, but all the sites provided patients with opportunities to talk in-depth on a one-to-one basis with specialist nursing staff either at home or in the hospital, and provided group information sessions which included short talks by patients already on dialysis. All sites also had a variety of written materials and DVDs about treatment options which patients could take home. Patients appeared to value these opportunities although they often recalled little detail of what was involved and how it had contributed to their decision-making.

Patients across all four sites saw health professionals as their main source of information about treatment options. They also talked about getting information from family or friends who had experience of dialysis, from other patients and from the internet. Most patients were happy with the information they had been given by health professionals. However, a few patients in each of the sites were critical and felt they had not been given a rounded picture of what life on dialysis would be like, with staff having created an overly positive view of treatment.

Staff and patients also appeared to have different perspectives on the role of information in patient decision-making. Staff tended to emphasise the importance of providing patients

with facts and detailed information about the different treatment options. They described a largely rational approach to decision-making with patients needing to weigh up this information in order to make a treatment decision. In contrast, patients appeared to be more focussed on using information to develop their understanding of what different treatments would mean for their everyday lives. For many patients this process of understanding what treatment means was also mixed up with and influenced by strong emotions and fears associated with the transition to end-stage renal failure (see 3.2.1.2).

During the interviews there were numerous examples of patients who had inaccurate information about other types of dialysis or who repeated common treatment myths. Given that all the patients were already on dialysis and had been through pre-dialysis education, this suggests some patients might benefit from on-going education, either as a way of encouraging them to re-consider home therapy options or to pave the way for potential future treatment changes.

Support from other patients

One of the patients' most commonly suggested improvements to the service was to have opportunities to talk to other patients at all stages in the clinical pathway, but particularly when making decisions about treatment. There were no patients who had been offered this opportunity within the pre-dialysis pathway, although it had recently been introduced in site 1 for patients interested in home haemodialysis, and site 2 would sometimes put pre-dialysis patients in touch with established patients in response to patient requests.

Patients described wanting to talk to other patients in order get a better idea about the experience of dialysis, to understand the pros and cons of different treatments from a patient's perspective, and to gain reassurance or support from talking to established dialysis patients who are in a similar situation to themselves:

"Speaking directly to someone who has had it [dialysis], so you're getting all the unfiltered information...it was useful to be able to speak to a person who had gone through that to give us, you know, warts and all what's going to happen, so that was good." PD patient (female, white, aged 18-39), site 4.

"I've been contacted by, informally, by one or two potential patients - to talk to them over the phone and two people have been here and actually, you know, looked at the machine and seen what's involved and had a chat and just talked through the problems....I mean, patients can be talked to by professionals, nurses or doctors and what have you, but I think they've got to -, you know, another patient, a fellow patient, just has that more credibility." Home haemodialysis patient (male, white, aged 65+), site 2.

However, by no means all patients wanted these opportunities, and there was a distinct minority of patients who described actively avoiding talking to other patients, because it would be unhelpful or because other patients' views might be one-sided. Some clinical staff also expressed these fears, although others thought that patients can also have a powerful positive influence on other patients:

“...they’ll see [someone] who was next to them going off to home haemo. and he comes to visit, dialysing 6 times a week, playing football, feeling great, they might think actually I could do that.” Consultant, site 1.

In the absence of peer support schemes, a number of patients across all four sites had found their own ways of seeking out and talking to patients on established treatments, often informally during hospital visits:

“Patients tend to chat to each other as well about you know, and there were people there [dialysis unit] who’d been through almost every kind of dialysis known to man and could tell me a blow by blow account you know what they thought was good about it and what they thought was terrible about it. So that was all quite helpful.” Home haemodialysis patient (male, white, aged 40-64), site 4.

Patients’ reasons for choosing their treatment

For those patients who described making a choice about their treatment, the commonest factors they considered were convenience, time and flexibility.

Convenience This was the commonest reason given in several sites, and was cited as the deciding factor by many home and in-centre patients.

Time and flexibility The impact of treatment on how patients spend their time was also a common reason for choosing a treatment, cited by both home and in-centre patients. Some PD and HHD patients perceived their treatment to take less time, or to be more flexible than in-centre HD. This resulted in them in having more time to do what was important to them - work, family and holidays were common examples. In contrast, some in-centre HD patients described liking the predictable routine of treatment three times a week, which gave them regular free time to pursue interests.

In site 4, convenience and time were particularly important factors which appeared to be working in favour of home therapies. A number of patients said they would have opted for in-centre haemodialysis if they had lived nearer one of the two hospitals, but cited high fuel costs, parking charges, lengthy travel times and poor public transport as the spur to choosing a home therapy.

In all four sites, it was striking that patients on PD or HHD tended to talk very positively about their treatment and their reasons for choosing it. In addition to the factors listed above, they highlighted as important: being independent and in control; having as normal a life as possible; keeping treatment as part of family life; and saving on travel costs.

“Well, you feel as if I’m the patient sort of thing, whereas if you do everything at home you don’t feel like a patient, you just feel like a normal human being that just happens to have to do something [dialysis].” PD patient (female, white, aged 40-64) site 2.

With the benefit of hindsight, some of the home therapy patients reported feeling better and subsequently being able to do more and have a better quality of life, compared with earlier experiences of being on in-centre haemodialysis.

This contrasted with many of the in-centre HD patients who described their treatment choice as a way of avoiding fears and concerns about other treatment options, to do with: fear of self-needling; ease of treatment; coping at home if something goes wrong; wanting rapid access to health professionals; lacking self confidence to self-treat; wanting to be looked after or lacking support at home; not wanting to disrupt family life; and fear of isolation. Interestingly very few patients raised practical barriers to home therapies, such as housing or space. This suggests that many of the barriers to home therapies are attitudinal and psychological rather than practical.

Psychological barriers were also mentioned by a few home therapy patients, who had fears or dislikes related to a specific treatment, such as: not wanting to see your own blood going through a machine (haemodialysis); not wanting to have your body invaded (CAPD); and fears about the risk of infections (PD).

3.2.1.2 Patient experience of the transition to end-stage renal failure

Just over one-third (37%) of the patients interviewed talked in detail about their transition to dialysis as a highly emotional and difficult experience. The majority of these patients had established chronic kidney disease and had known they would need dialysis years in advance of starting treatment. A smaller number (n=7) were acute patients who were previously unknown to the service. Despite the fact that most of these patients had known they would need dialysis, they described feelings of shock, trauma and being scared when it became clear they would need dialysis soon:

“The actual going onto dialysis and actually accepting it [was the hardest part] - knowing for over twenty years that the likelihood of it as happening is one thing, but the actual reality of it...” Home haemodialysis patient (female, white, aged 40-64), site 4.

“...they were explaining to me but it just didn't go through me head that I was going to get ill, like. I mean they were very, very nice but I was just too scared.” In-centre haemodialysis patient (female, indian, 40-64), site 2.

Patients talked at length about being scared, depressed and feeling isolated, often repeatedly making this point in different parts of their interviews, with great strength of feeling being expressed. In contrast, during the staff interviews there were only three nurses who talked about the emotional impact of needing dialysis:

“So quite often people are shocked, you know, they just kind of don't know what to think really about anything and even when they, even if they've had all the information, they start with us, they still need a lot of support, to kind of make the right choices really... I kind of equate it to like the grieving really they've kind of lost their kidneys and it's almost like a death for them, you know, they're not working and so therefore they kind of go through all those emotions that come with bereavement really.” Dialysis unit nurse manager, site 4.

Although they highlighted the emotional impact of needing dialysis on patients, these staff did not talk about how patients are supported through this transition, and how the pre-dialysis pathway or training processes are adapted to take account of patients' distress.

There were also patients who described on-going psychological issues which continued even when they were well established on dialysis:

“It’s again it’s that freedom...oh I can’t do this tomorrow I got to be on dialysis. And that’s what the problem I’m dealing with because the machine is doing what it’s supposed to do, it’s keeping me alive so I should be grateful for that, I can’t complain. But it’s good to complain, have a moan. It is, you’re like your life being taken away from you, but you’ve been given life really. I’ve never felt better so.” In-centre haemodialysis patient (female, white, 40-64), site 2.

“So they focus totally on the practical side of things. Have they done it? Why haven’t they done it? You’re going to die if you don’t do it. It’s all very black and white, all very aggressive and you know perhaps that works for some people, it certainly doesn’t work for me. No disrespect, but sometime you don’t want to tell them you’ve got a problem... perhaps they’ve got caring fatigue as it were. [There’s] a huge mental side to it, well I don’t know what you’d call it, a psychological element they probably don’t quite press.” PD patient (male, white, 40-64), site 2.

Finally, there was one patient who spoke eloquently and at length about his experience of the transition to dialysis and what might help patients cope and adapt:

“People go through terrible periods of depression and anxiety and of course you know because they’re feeling so sick often their whole kind of relationships start to get a bit funny you know and they have a lot of anger. And there’s also the kind of you know effect on people’s kind of love life and all sorts of things you know from what I’ve gathered from others and my own experience. You know I went through a period towards the end of my preparations for dialysis where I had to go to the doctor with depression because I was just so unhappy because I felt sick every day and my whole life just kind of crumbled around me really. And you know you’ve lost your career, you’ve lost everything.

If somebody had spoken to me earlier on and said you might go through these things, this is going to be a very hard few years for you as you make this transition and we’re here to help and you know, if this kind of thing happens well then don’t worry about it, it’s what to expect.” Home haemodialysis patient (male, white, aged 40-64), site 4.

The same patient highlighted the different perspectives that patients and staff may have, with patients needing much more than the medical management of their kidney disease:

“I had the feeling sometimes that if I had been able to put my kidneys on a plate and send them into the hospital it probably would have worked as well really. He [the consultant] didn’t seem to be particularly kind of interested to talk to me about the kind of wider implications of dialysis and kidney failure. And although that was kind of helped out a little bit by the renal nurse you know, I’ve said to them since that it might be worth, at that early stage, actually each person having a session with somebody who was trained in psychology because I think that the transition to that kind of life is extremely traumatic.” Home haemodialysis patient (male, white, aged 40-64), site 4.

3.2.1.3 Training for Home Therapies

Both staff and patients from across all four sites thought that the training provided to patients worked very well. This applied equally to training for PD and training for home haemodialysis, although the programmes differ in their content and length. Patients were able to recall their training in considerable detail and provided very specific feedback about what they liked and what could be improved. They particularly valued three aspects of their training:

Flexibility Training programmes allowed patients to learn at their own pace without feeling any pressure to complete the training. The PD programmes were highlighted as being extremely flexible, with patients able to train for lengths of time that suited their own circumstances, and their particular capacity and speed of learning.

Thoroughness The training programmes cover the right amount of detail to enable patients to feel confident but not overwhelmed. The written materials were also seen as valuable back-up materials which patients could take home and refer to again once they were on a home therapy.

Staff continuity Lots of patients were full of praise for the nurse who had trained them. They valued having the same nurse training them because this allowed the nurse to gear the information to patients' own home circumstances.

In each site, there were just two or three criticisms or suggestions for improvement, but these were all made in the context of patients being satisfied that the training had prepared them well for home therapies. The four commonest criticism and suggestions for improvement were:

Peer support during training Some patients would have liked to talk to established patients and see them undergoing treatment. This was partly about learning style, with patients preferring to learn by seeing, and partly about making the treatment 'real' and providing reassurance.

Home-based training Several patients expressed a preference for being trained at home, in order to simulate what it would be like for them. They expressed surprise at how noisy the dialysis machines were at home, because this had not been obvious to them when training in the hospital.

Balanced information Several patients felt that, in retrospect, the training had not fully prepared them for what life on dialysis would be like. They thought the training had been overly positive and should include the more negative aspects of treatment. Staff, however, showed an awareness of the tightrope between being honest with patients and potentially scaring them off.

Information formats Although the written materials rated well, some patients thought staff had not been well informed about web-based information which they tended to source without any guidance from staff. In site 1, some patients requested written materials that

were adapted for people with low literacy levels and translated materials for non-English speakers.

Delays and slow pace A few patients in sites 1 and 4 were critical of the slow pace of the home haemodialysis training, feeling talked down to, and wondering if training had been delayed due to staff shortages. In both these sites, there were waiting lists for patients wanting to train for home haemodialysis.

In site 4, there was one further criticism from patients who thought that the home haemodialysis training should not be done during the twilight shift because many dialysis patients are less alert and able to learn in the evening. Some staff were similarly critical of this arrangement and thought there should be a dedicated training area. Patients were being trained at one end of the dialysis unit in a busy and noisy environment. However, this arrangement does seem to have encouraged some in-centre patients to switch to home haemodialysis (see 3.2.1.5).

Overall, there was no evidence that the training needed to improve in any very significant ways. Of the patients interviewed, there were no reports of anyone having to switch treatments because the training had not fully prepared them for self-caring at home.

3.2.1.4 On-going Care and Support

A number of issues were raised about on-going care and support. Treatment specific comments are summarised first, followed by more generic issues which were raised by patients irrespective of their treatment type.

Transitional support for home therapy patients

All the sites provided graduated support for home therapy patients in the first few weeks of treatment, with nursing staff visiting patients at home during treatment. Patients were positive about this temporary extra level of support which had helped them to manage the transition to home therapy. Solo home haemodialysis patients in site 4 had a further enhanced level of support, with additional home visits and telephone calls in the first few weeks of being at home.

Peritoneal dialysis

On-going care was seen almost unanimously by patients in all sites as very good. The 24-hour telephone support provided by the PD machine manufacturers was highly praised, providing rapid advice and effective technical support when needed. The only comments related to very occasional problems in getting out-of-hours advice, which was usually about suspected infection. All four sites provided out-of-hours advice via staff working on the acute wards, which underlines the importance of these staff being well trained about PD.

“So ward x then, the support is top notch. They’re at the end of the phone if you’re worried about anything and I have used that a couple of times and it’s good.” PD patient, site 2 (female, white, aged 40-64)

Home haemodialysis

Patients were again very positive and valued having on-going contact with home haemodialysis staff by phone and through home visits. There were a few patients who talked about feeling isolated at home, despite being well supported by staff. Several suggested that occasional opportunities to meet up informally with other patients on home haemodialysis might help reduce isolation. Site 1 was in the process of introducing a buddy system so that a new home patient could be supported by an established patient in the first few months of being at home.

In-centre haemodialysis

The large majority of in-centre patients were similarly positive about their on-going care. Many of them highlighted how well supported they are, because of the regular direct contact with nursing staff. Quite a number also talked very positively about the camaraderie which develops with patients on the same treatment shift, which was frequently likened to an extended family. For quite a number of in-centre patients there was a clear perception that in-centre patients are well supported whilst home therapy patients have little if any contact with staff and tend to be quite isolated. Given the level of support provided to home patients and that there was very little evidence of isolation amongst patients in this study, this misperception is a potential barrier to home therapies for in-centre haemodialysis patients.

Criticisms raised by in-centre patients tended to be about transport and treatment delays rather than about the treatment. Some frustrations were expressed by the patients who used hospital transport who often had to endure very lengthy journeys before and after treatment, making treatment days very long days indeed. A few patients also commented on treatment delays on arrival at the haemodialysis centre, with some waiting areas being cramped and uncomfortable. One younger patient was critical of being treated alongside mostly older people, and commented that she felt out of place. In site 1, some patients were critical of staff, who they saw as machine-focussed and hard-pressed, whilst others had found them unable to answer questions about other types of dialysis treatment.

Overall, staff raised very few issues about on-going care and support. Although the very large majority of staff thought it worked very well, a few staff expressed some concerns that the nursing staff in the home therapy, PD and home haemodialysis teams could easily become over-stretched as the number of home therapy patients increases (see 3.2.2.3).

Moving on to the issues raised by patients across all treatment types, comments were made on three themes: lack of coordination with GP practices; out-patient continuity of care; and reviews of treatment choice.

Co-ordination with GP practices

This issue was raised by patients in sites 2 and 4. Considerable frustration was expressed by a number of patients in each site who had experienced a lack of coordination between

hospitals and GPs. The most frequent issue was about GPs prescribing medication for minor ailments unrelated to kidney disease. Patients recounted being told by GPs to go back to the hospital, whilst the hospitals saw this as the responsibility of GPs:

“Even my GP, when I asked questions [about] what antihistamine to take because of having hay fever... she said well I don’t really understand exactly all they do in dialysis, and if you have a problem it’s best to ring up the hospital anyway. But I thought well yes but there’s so many things that cross over between the hospital and the GP, you know, and even she doesn’t seem to know exactly what happens.” PD patient, site 4 (female, white, aged 65+)

“.... you get tossed between your doctor and the hospital. The doctor won’t see you or treat you – they might see you, but they won’t treat you because you’re a renal patient and you’re not treated at the doctors [GP]. The doctor at the hospital won’t see you because you’ve not seen your GP....But now I’ve been on renal for so long I think he [GP] realises not everything is going to be renal and I’m not that delicate” Home therapies patient, site 2.

This lack of clarity about the relative responsibilities of GPs and hospitals also surfaced over counselling, particularly in site 2 where there is no specialist renal psychology service:

“My patients, if they say they are struggling I will ask their GPs to refer them for counselling but I have no control as to whether or not they get it.” Consultant, site 2.

Out-patient appointments

This issue was raised in site 4 only, where a fairly new system of review appointments has been introduced, with most appointments being nurse-led and patients seeing their consultant only once or twice a year. Although only a few patients raised this issue, strong feelings were expressed about the importance of continuity of contact with ‘their consultant’. Although some staff also thought that in-centre haemodialysis patients should be reviewed more frequently, the system for getting patients a rapid clinic appointment when needed, appeared to work well.

Reviews of treatment choice

Very few patients could recall having their choice of treatment reviewed. This is particularly significant for in-centre haemodialysis patients, some of whom reported becoming more open to home therapy options only once they had got used to being on dialysis (see 3.2.1.1).

3.2.1.5 Approaches to Increasing the Uptake of Home Therapies

Assisted APD

All four sites have introduced assisted APD programmes, where care assistants visit twice daily to assist people with their PD machines. This service has been used in all the sites to extend the provision of APD to patients who would not normally be seen as suitable for PD, such as people living alone or frail older people with little or no carer support. In some instances, assisted APD was being used as a temporary measure to provide additional support and training at home before patients move on to full self-care. Although the numbers taking up this service were very small in all four sites, it has the potential to extend APD to new groups of patients, particularly following the introduction of a tariff for assisted

APD in April 2012. It may also be a very significant way of increasing the uptake of PD, as the dialysis population becomes increasingly old and frail.

Acute PD pathway

Sites 1, 2 and 4 have been developing new acute PD pathways which are designed to increase the proportion of patients on acute wards taking up PD. Historically, the large majority of patients on acute wards who need to start dialysis for the first time, have gone onto in-centre haemodialysis. Staff have historically seen in-centre haemodialysis as the automatic treatment for acutely ill patients. The approaches across the three sites varied a little, but generally included:

- improving links between the acute wards and the PD/home therapy team, either through named liaison leads (site 1) or by PD/home therapy staff having a regular presence on the wards (sites 2 and 4);
- pre-dialysis counselling slots which are reserved for patients on the wards (site 4), or pre-dialysis counselling staff having the flexibility to respond quickly to requests from the wards (site 2);
- additional surgical capacity to enable rapid PD catheter insertion (sites 1 and 4), and training a renal consultant to undertake catheter insertions (site 4);
- PD training for ward nursing staff, designed to help them to talk in an informed and positive way with patients about PD as a viable treatment option (site 2).

A small number of the patient interviews were with patients who had been on acute wards as 'crashlanders' prior to starting dialysis. Site 4 had successfully started some of these patients on PD whilst they were acutely ill, and the patients were very positive about the information and support they had received from staff to enable this to happen.

Dialysis treatment reviews

Staff in all four sites recognised that some patients need time to adjust to the prospect of being on dialysis, and may become open to home therapy options only once they have successfully started treatment. Despite this recognition, none of the sites had built choice of treatment reviews into their dialysis pathways and were unsure how often dialysis choices were covered in routine out-patient review appointments. In addition, none of the sites had ways of flagging the discussion of dialysis choices with established patients on their patient information systems. There were some examples of nursing staff believing that treatment choice was covered by doctors in out-patient reviews, whilst doctors believed it was being done informally by in-centre haemodialysis nurses.

Switching from in-centre to home haemodialysis

Throughout the interviews in all four sites, staff repeatedly said that the biggest challenge in increasing the uptake of home therapies was tackling the legacy of large in-centre

haemodialysis programmes where the majority of dialysis patients have historically had treatment. All four sites were focussing their efforts on their new dialysis patients rather than attempting to persuade established in-centre haemodialysis patients to switch to a home therapy. The latter was seen as a rather challenging task, where considerable effort would probably deliver few, if any, patients willing to switch.

Staff saw established in-centre haemodialysis patients as benefitting from and liking contact with both nursing staff and other patients, and therefore unlikely to cope well with self-care at home. The interviews with in-centre patients confirmed this view with the patients saying they gained a lot from regular contact with staff and other patients and feeling they lacked the confidence to self-care at home (see 3.2.1.4).

Site 3 had had some success in switching some in-centre haemodialysis patients to home haemodialysis, although the numbers had been far fewer than expected. This had been achieved through home therapy link nurses talking to patients in the three haemodialysis units. This site had also tried to introduce self-care into its haemodialysis units, but had found that there was little interest in it from established patients.

Site 4 was the only site where significant numbers of in-centre haemodialysis patients had switched to home haemodialysis. This site had deliberately recruited home haemodialysis patients from its two hospital haemodialysis units, when it started building up its home haemodialysis programme three years ago. The majority of its current home haemodialysis patients were former in-centre patients. In discussing this with staff, there appear to have been three key factors which supported this unusual success.

Firstly, this site presented self-care as the norm for in-centre haemodialysis patients and promoted it strongly with patients. For those patients who take up self-care, it can be a practical stepping-stone to home haemodialysis, as patients gain the skills and confidence which would be required to treat themselves at home, in a safe environment. Switching to home haemodialysis can then become a natural progression. The organisation of the units also appeared to incentivise self-care, because self-care patients could arrive and start self-care ahead of the fixed treatment slots for the rest of the patients. Because all the haemodialysis patients shared the same treatment space, this created a very visible incentive for patients to take up self-care. Although some staff thought this sharing of space was not ideal and would have preferred a separate self-care unit or treatment area, the opportunity to see other patients doing self-care does appear to have acted as a catalyst for self-care for some patients.

Secondly, a less than ideal arrangement for training home haemodialysis patients appeared to have resulted in more patients being persuaded to switch treatment. In the absence of a dedicated training area for home haemodialysis patients, the training usually took place on the twilight shift, with patients sharing the treatment space with in-centre patients. Both staff and patients provided examples of where this has resulted in in-centre patients asking to be trained themselves, because they have seen first-hand what is involved and have been able to chat to the patients being trained. This provides another practical example of how

first-hand experience of a home therapy and talking to other patients can be powerful ways of promoting home therapies with patients.

Thirdly, the introduction of the NxStage haemodialysis machine had opened up home haemodialysis to patients who live alone, who had limited space or who needed a portable machine. At least half of the patients who had switched from in-centre to home haemodialysis had the NxStage machine. Interviews with six of these patients were very positive, with patients reporting feeling much better than on in-centre dialysis, because of the more frequent and gentler episodes of treatment. The NxStage machine had also allowed home haemodialysis to be provided to patients who lived alone.

Overall, site 4 had considerable success in switching a significant number of in-centre haemodialysis patients to home haemodialysis. This seems to have been down to a combination of factors rather than a single initiative, including: promoting self-care as the norm; incentivising self-care; using self-care to develop patients' skills and confidence as a stepping stone to going home; opportunities for in-centre patients to talk to and see patients in-training for home, in shared treatment spaces; using the NxStage machine to extend home haemodialysis to patients who might otherwise not be able to do home haemodialysis.

3.2.1.6 Suggestions about how to continue increasing the uptake of home therapies

Looking to the future, both staff and patients had a range of ideas about how sites could continue to increase the uptake of home therapies.

Patients' suggestions

In all four sites, the most frequent suggestion from patients was to have more visible information and publicity about home therapies, and for this to be provided to all patients in all treatment areas. Some patients commented that they would not have known that home therapies were available when looking at the posters and leaflets available in out-patients, the wards, haemodialysis units and waiting areas:

"I suppose more having it [home therapies] more visible... more patient information in the outpatient areas and stuff like that... In outpatients here because they've not that long moved over ... there was nothing that screamed out at me as if to say oh have you thought of a home therapy?" In-centre haemodialysis patient, (female, white, aged 40-64), site 1.

Other patients suggested that home therapies should be promoted or marketed more deliberately by staff, with the commonest suggestion being that staff should spell out the benefits of home therapies much more clearly:

"Yeah I think if they just encourage people and if they got people to go and explain. If they just said to them listen are you interested and they said yeah well we'll get somebody to come in and have a chat with you first and just explain to you, you know, the benefits and what have you. And just see that it's possible as well. I guess it's hidden away at home isn't it, people don't see it?" Home haemodialysis patient, (male, white, aged 40-64) site 2.

Some patients suggested targeting those patients who might be most likely to opt for a home therapy, because they work or who would otherwise have a long journey to make to a haemodialysis unit.

Patients also suggested improving existing information about home therapies, so that more prominence is given to three issues of concern to many patients:

- how patients are supported at home, including details of what happens when they first go home, out-of-hours arrangements and how often they will have contact with nursing staff
- how problems are dealt with for home patients, including telephone/technical support if there are machine problems, and infections or problems with fistulas and catheters
- practical issues, such as how much space is required for equipment.

Comments from in-centre patients suggest that they lack information about home therapies, but also have significant fears about home therapies – implying they might benefit from information designed to allay fears and provide practical information and reassurance about how home therapies work in practice.

Staff suggestions

In several sites staff suggested that home therapy staff could run drop-in clinics in haemodialysis units, so that current in-centre patients could talk to staff as a way of becoming better informed about home therapies. Staff were also keen to find ways of building patients' confidence to self-care, and thought that opportunities to talk to existing home therapy patients might help. For other staff, self-care opportunities in haemodialysis centres were seen as a practical way of building patients' confidence in their own abilities. Some staff suggested having self-care as an option in all haemodialysis units.

In a similar vein, an expansion of APD was seen as a practical way of building up patients' abilities to self-care and extending PD to groups of patients who would otherwise be seen as unsuitable. Staff in sites 2 and 4, were particularly keen on APD because of the travel distances involved for some of their patients, however they were also aware of the potential costs involved. Several staff also suggested extending the idea of assisted PD to home haemodialysis, with paid carers assisting patients at home so that home haemodialysis could be made available to patients who live alone or do not have a supportive carer to help them. Some consultants were keen to see whether some haemodialysis patients could be trained for home immediately, rather than risk getting them used to in-centre treatment first. A more formal review process was also suggested, so that established patients have the opportunity to review their choice of treatment

Further awareness training for staff and opportunities for all staff groups to get direct experience of home therapies were also seen as effective ways of skilling up all staff groups

to support the home therapies goal through their day-to-day interactions with patients. Likewise, staff thought there should be better feedback loops for clinicians to show the clinical and quality of life outcomes achieved for patients on home therapies. The ability to demonstrate positive clinical outcomes and patient satisfaction was seen as a powerful way of incentivising all clinical staff to continue promoting home therapies with patients.

3.2.2 Team factors : Staff knowledge, experience, training, capacity and support for home therapies

A striking feature of the research was the enormous amount of gratitude and praise given to the staff by the patients. When asked to give one main message to the hospital, around a half of patients in all the sites had very positive things to say about staff, typified by these comments:

“They do seem to have a very happy team, a very respectful team, you know, and including the consultants who on occasions are quite happy to phone you and talk to you which I think is quite exceptional these days.... We’ve been so impressed that in fact it caused me to get rid of my private health policy.” PD patient, (male, white, aged 65+), site 4.

“I could honestly say that I am very happy with my treatment. You know they’re bright, they’re cheerful, they’re helpful, someone never comes into the ward even from the ward next door without saying ‘good morning, hello how are you?’” In-centre patient, (female, white, aged 65+) site 2.

“I mean the staff are great, always there for you if you want them.” Home haemodialysis patient, (female, white, aged 65+) site 1.

Nurses and consultants were frequently highlighted for being exceptional, hard-working and going beyond their job requirements to provide the best patient care. Most patients commented on the personalities and attitudes of staff, how easy they are to communicate with and the environment they create, rather than focusing on clinical or other aspects of the services. The small number of patients who did voice criticisms tended to do so within this context of overall gratitude and praise for the services.

Staff tended to be more insightful into a set of staffing issues which influence service delivery, and it is these issues which are explored in detail in this section.

3.2.2.1 Staff views about home therapies

In all four sites, the large majority of staff expressed positive views about home therapies. They were aware of the drive to increase the uptake of home therapies and were generally supportive of this direction of travel. This included staff working on the renal wards and in the haemodialysis units just as much as staff whose day-to-day role involved them with home therapy patients:

"I'm liking the way now it's [home therapy] coming back in to the fore again. Because I think it is so much better for the patients than having to get on transport, taken all round the area before they come here and then waiting for transport again. They can get on with their lives really". Satellite unit nurse manager, site 2.

Overall, the nursing staff working in PD, home haemodialysis and pre-dialysis counselling and the consultants demonstrated the strongest support for home therapies, with particularly positive views being expressed about outcomes for patients:

"If they are medically stable then there is no reason why, from a medical perspective, you can't consider dialysing at home. Home dialysis can be more frequent dialysis, you dialyse better. You live longer and do better. Studies show that nocturnal haemodialysis is equivalent in life expectancy to a functioning renal transplant." Consultant, site2.

A small minority of staff in all sites except site 4, expressed some doubts about some aspects of the home therapies agenda. Site 4 was notable for *all* staff expressing strong and positive views about the drive to increase the uptake of home therapies. In the other sites, although a few staff had doubts that home therapies do deliver better outcomes, most doubts tended to be about the local CQUIN targets which had been set by the commissioners. Some staff objected to a financial penalty being associated with specific treatments which they felt patients should chose freely and that this could distort clinical practice. Others were opposed to the target on principle:

"I'm slightly wary of targets, that to achieve a target we could be pushing it to people who aren't happy with it." Consultant, site 1.

"...it's upsetting that this target's had to come and it's upsetting that some people seem to have changed their practice consequent to it. I mean, why should [we] have to have a target to do what we're meant to do anyway?" Consultant, site 3.

In contrast, some of the more senior clinical nursing and medical leads, and Trust senior managers, thought that the CQUIN targets had provided some useful impetus for change. This issue is explored in more detail in section 3.2.4.1. However, this renal consultant clinical lead expressed eloquently the fine balance that exists between patient choice, clinically appropriate treatments and achieving externally-set targets:

"We are glad we've achieved the CQUIN targets for this year and hopefully the way we are going very soon we will reach the target for next year as well, very well in advance. But I still don't want to set a figure [target]. We will still work with the concept of right patient choosing the right treatment rather than PD or haemo. or in-centre. I think we will try towards home therapy if possible, but still we feel right patient choosing the right treatment. In the process if we can get the numbers up significantly, that's a bonus." Renal consultant clinical lead, site 4.

A number of staff also talked about how their views about home therapies had changed over time. Some staff talked about particular patients whose persistence in wanting home haemodialysis had challenged staff views about manageable risk by making an against-the-odds success of home treatment:

“The first patient that we highlighted for going home [for home haemo.], a lot of the unit staff disagreed with that decision. They didn’t feel the patient was right. They didn’t feel the patient would be compliant. They felt loads of different things. And I think a lot of it was a very difficult patient, very strong-minded, not overly complaint to treatment in the hospital, upset a lot of staff, said what they thought. And we put this patient home and they’ve blossomed again. And everyone who raised questions was like “Fair play” you know “We got that wrong”.” Renal matron, site 4.

Staff provided examples of how practice has become more inclusive and less risk averse:

“At one time, they couldn't go home if they'd got a line in, they couldn't go home unless they lived with somebody - there's no barriers really to it [now]. I don't see any anyway unless you were, lacked capacity I suppose but even then if your partner was willing to be, if they'd got the capacity and they were willing to do it, we would look at it and we wouldn't sometimes do it in council houses if you rented, but now we do, we try and have no barriers.” Senior nurse, site 2.

“I think it's easy to make an opinion about somebody that comes in to clinic and think oh he's old, we'll put him on haemo. You need to see the bigger picture, you know, if he's got lots of support at home, you know, people to help and actually he's pretty fit and you know mentally he's all there, there shouldn't be any reason why you couldn't put them on PD.” Consultant, site 4.

Optimism about patients was seen as going hand-in-hand with problem solving skills which may be required to make home treatment possible:

“It's always about solving problems and thinking, looking at the bigger picture. You have to be quite optimistic as well, because you just know that you've got somebody that's on their knees because they need dialysis, that they're actually going to be a different person in 3 months' time once they've had some dialysis.” PD sister, site 4.

3.2.2.2 Staff knowledge, experience and confidence in home therapies

Within the context of broad staff support for home therapies, a number of issues were raised about how staff are trained and gain experience of home therapies and how team structures and roles impact on staff confidence in home therapies. These issues are explored in detail in this section.

Patients' perspectives

From the patient interviews, it was clear that staff working in home therapies were seen as highly skilled and patients did not raise any questions about roles or clinical competence. They did however comment on the ability of staff across the service to answer informal questions about home therapies and to signpost patients to appropriate sources of information and advice. In all four sites, a number of patients described their long-term relationships with the service, and how they used their informal encounters with a wide range of staff to find out more about their condition and their treatment:

“...it was actually one of the health care assistants, I was asking her about something to do with the [haemodialysis] machine and she said “Oh I don't know what you're bothered about asking for, you're not going home, you wouldn't be going home on one of these machines anyway” and I was completely if you like shot down in flames over it. And I'm like I'm asking

questions because I'm interested..... I mean for some people they'd just go "OK I won't bother asking then"." Home haemodialysis patient, (female, white, aged 40-64) site 4.

"I've asked some of the nurses about it [home haemodialysis] you know since [starting treatment] and they said, well it does disrupt your home life a bit."

In-centre haemodialysis patient, (male, white, aged 65+) site 1.

These examples highlight the importance of *all* staff, not just home therapy staff, being well informed about dialysis options so that they can answer these casual questions, and to do so in ways which present home therapy options accurately and in a positive light.

The staff and patient interviews in all four sites drew attention to three staff groups whose understanding of home therapies and ability to answer patients' questions may need to be improved : ward staff, haemodialysis unit staff and Specialist Registrars. The next section explores how induction, education and training have been used to up-skill ward and haemodialysis unit staff. This is followed by exploring the role of experience in increasing staff confidence about home therapies, and how team structures and flexible roles impact on this need for this experience. The final section uses the example of Specialist Registrars to illustrate the interplay of experience and training in equipping staff to be confident about home therapies.

Induction, education and training

Ward staff All four sites have put some effort into educating ward staff about home therapies, and particularly about PD, because of the role of ward staff in providing out of hours telephone advice to PD patients. It was also recognised that patients may chat to ward nursing staff and ask questions about home therapies, or that ward staff may have opportunities to educate patients about home therapies:

"It's not something our nurses, my nurses [acute ward] talk about, you know and say 'well 'have you thought about going on home dialysis?' I think that nurses don't know what the set-up is like at home - it isn't something we advertise very well and it's not something we educate the patients, you know we could do it better, we could do it a lot more."

Hospital dialysis unit sister, site 1.

Sites 1, 2 and 3 had all recently undertaken informal education about PD with ward staff, largely through having a presence on the ward and talking with staff about particular patients. Some of the staff involved in this work expressed frustration that this informal approach to education may not be very effective, as ward staff tended to see it as low priority:

"We've tried recently especially with the ward staff because they cover us (PD) when we're shut..... we were trying desperately to do more [staff] education on the ward and I ring fenced an afternoon a week where I would go up there and whoever was free I'd take off into a side room and do some education... but there's still a real unwillingness to run with it."

Nurse, site 3.

Site 4 had moved to a more formal approach, with newly appointed ward staff spending three weeks training with the PD team as part of their six-month preceptorship programme.

Haemodialysis unit staff In a similar vein, all four sites also recognised the need to educate haemodialysis unit staff about both PD and home haemodialysis:

“I think a lot of effective patient education is delivered through everyday conversation and chat. You know somebody might ask a question. And for the haemodialysis patients, they’re chattering away as they’re going on three times a week to the staff in the unit. So they may ask a few questions. Well if that group of staff haven’t got any knowledge of peritoneal dialysis or how you would manage an APD machine at home then the conversation isn’t going to go any further.” Pre-dialysis nurse, site 4.

Informal approaches to staff education were also being used with these in-centre staff in a couple of sites, with home haemodialysis nurses spending time in the units, in order to provide both staff and patients with information about home therapy options.

Site 4 had again taken a more structured approach and developed an initial rotation for new dialysis unit staff which provided them with an overview of all treatment types:

“We normally try and spare a month for all new [dialysis unit] staff to do a rotation, and they would spend a week with the PD team, a week with the home [haemodialysis] team, a week with pre-dialysis and a week with a renal unit. So and they get a sort of general all-rounder and that’s part of their educational development. So it’s just a little taster really in each area to see what everyone does.” Dialysis unit nurse manager, site 4.

In three of the sites, staff education was complicated by the fact that some or all of the haemodialysis units were being run by independent companies. To date, staff in these units had not been included in formal education sessions, because the NHS was not seen as being responsible for their education. However, in several sites staff had been included in the more informal unit-based educational contact with the home haemodialysis nurses.

Finally, it is worth noting that all four sites had organised periodic education sessions or study days about home therapies, as a way of ensuring that all staff were aware of the drive to increase the uptake of home therapies.

Appraisals, personal development plans and unit training plans

There were no examples of any of the sites including the home therapies targets in staff appraisals and personal development plans. None of the sites had defined the competencies that all staff might be expected to have for home therapies, irrespective of their role (such as, an outline knowledge of all treatment options, being able to answer patients’ questions, signposting patients to appropriate sources of information and advice). There were also no examples of home therapies being included in renal service annual training plans.

This conspicuous absence of home therapies in the routine training and development mechanisms which Trusts use to develop and support their staff, suggests that all four sites were still in the early stages of the change management cycle for home therapies (see 5.6).

The importance of experience of home therapies to staff

A common theme from staff in all four sites was the importance they attach to getting direct experience of home therapies. Although education and training were seen as important, the opportunity to gain first-hand experience of patients on PD or home haemodialysis was of equal if not greater importance to many staff. They were keen to see patients at home having their treatment, to talk to them about how they managed the treatment and hear what they thought of it. These experiences were seen as ways of making home therapies 'real' to staff, so that they in turn could talk in an informed way about home therapies to other patients.

Whilst induction arrangements in some sites provided some of this experience for new staff, there was a bigger group of existing staff who were seen as likely to benefit from these opportunities. Some nurse managers suggested that the tendency towards specialisation has meant that there are groups of staff who have little if any experience of renal services outside of their specialism, particularly if staff do not rotate across different services:

"They've tended to be employed and they've stuck where they are... so when you get newly qualifieds just going straight into haemo. and not even done any ward work, they can't see the whole picture then and can't advise patients on what it's like to go on PD because they've not seen it." Senior nurse, site 2.

Site 2 was therefore starting to design a rotation system to widen the experience of staff:

"the staff are rotating or will be starting to rotate...the benefit is that you end up with a renal nurse who knows all about everything, so they're not got the haemo. blinkers on, they haven't just got PD blinkers on, they haven't just got the ward blinkers on or the transplant blinkers on, that you've got what was always designed as a true renal nurse who even if they decided to work in haemo. permanently eventually, can at least talk to the patient 'well this is what PD is about and this is what transplantation's about'." Home therapies nurse, site 2.

Site 3 was also trying to develop rotation opportunities, with members of the home therapy team swapping roles with ward staff in order to give them experience of home therapies. This had not yet met with much success due to work pressures for the ward staff.

The importance of experience was also highlighted in site 4 where flexible staff roles have developed to enable a relatively small service to provide cover for absent staff and flex capacity when needed. A positive spin-off from these flexible roles has been that staff have gained experience of other parts of the service, which in turn has increased their confidence in talking to patients about all treatment options.

A second example of the importance of experience also comes from site 4, where dialysis unit staff had taken on the role of providing on-going support to patients who had switched from in-centre to home haemodialysis. This had led in turn to in-centre staff being unusually knowledgeable about home haemodialysis, and able to talk positively with in-centre patients about the option of home haemodialysis.

Team structures were also seen by staff as significant in either restricting or widening experience of home therapies. For example, in site 1 there were separate teams for PD,

Home haemodialysis, hospital haemodialysis and 11 In-centre haemodialysis teams in units run by an independent provider. These teams not only ran as separate teams but were geographically separated from one another. Here, a number of staff talked about the impact of this separation, with services and teams described as often operating in silos. Although individual staff put effort into liaising across teams, it meant that staff in general found it hard to keep up to date with what was happening in another part of the service. This meant that some staff described feeling under confident about talking with patients about therapies provided by other teams, including home therapies.

Site 4 provided an example of how the barriers which can arise with separate teams can be minimised through flexible staffing arrangements. In this site, a culture of very flexible working meant that most staff had experience of working in most clinical areas through covering for staff absences. This appeared to have resulted in staff in all teams being particularly knowledgeable and confident about home therapies. A notable example was when In-centre haemodialysis staff had supported patients switching to home haemodialysis because the home haemodialysis team was at full capacity, thereby gaining first-hand experience of home haemodialysis.

In contrast to sites 1 and 4 where there were separate PD and home haemodialysis teams, sites 2 and 3 had integrated their staff into single home therapy teams. In site 2, staff tended to specialise in either PD or home haemodialysis but were being trained to cover both types of dialysis so that all staff could deal with patient queries and undertake home visits for both types of treatment. In site 3, a single nurse manager for home therapies had been recently appointed to bring together existing PD and home haemodialysis teams. Staff working in these teams could see one of the benefits of working in an integrated home therapy team would be the opportunity to gain wider experience of another home therapy.

The role of Specialist Registrars

This final section considers the role of Specialist Registrars (SpRs) in relation to home therapies. Five SpRs were interviewed across the four sites and were at different stages in the training programme. However, their role was discussed more widely through the staff interviews and a number of issues were raised which merit detailed consideration.

In all four sites, the SpRs had similar roles, working on the wards, in low clearance clinics and out-patient clinics. In all these settings, they had had some experience of discussing dialysis treatment options with patients and answering questions about home therapies. However, they had had little if any training about home therapies and felt ill-equipped to discuss home therapies with patients, particularly home haemodialysis.

“None [time spent on training about home therapies]. I very rarely get involved with PD peritonitis but that’s about it, nothing else and nothing on home haemodialysis.” Specialist registrar, site 3.

None of the five SpRs had ever seen a patient undergoing home haemodialysis and thought that they therefore struggled to portray this as a positive option to patients and could not

always answer patients' questions fully. They were also unaware of how well home haemodialysis patients do, because they had not been involved in out-patient clinics for these patients:

"If you're far removed from what's going onthen you don't really know what's going on, unless you actually are going to these clinics where [home haemodialysis] patients are attending and you get the chance to see how they're getting on." Specialist registrar, site 1.

Although they thought that their knowledge and confidence about PD was better, again none had seen PD patients having treatment in their own homes. They also thought their views about PD might be skewed negatively because they tended to have most contact with PD patients on the wards who had infections or other problems.

As already noted, the regional training programme had given relatively little time to PD and home haemodialysis, and several of the SpRs thought this should be expanded and introduced early in the programme. In the absence of more formal training, the home therapies team in site 2 had been approached by their SpRs to provide them with experience of PD and home haemodialysis clinics and home visits. The SpRs who had taken up this opportunity had found that just half a day spent in clinic or on home visits to be particularly valuable, underlining the educational role that direct experience can have.

Finally, none of the four hospitals provided new SpRs with any induction about how they were approaching treatment choices, and how and when patients were referred for pre-dialysis counselling. Given that SpRs were involved in out-patient clinics where treatment choices were discussed with patients, this seems like an important oversight and a missed opportunity to ensure SpRs were well versed in each hospital's approach.

In conclusion, SpRs appear to be a neglected staff group whose role in home therapies has been under-estimated. They receive little if any formal or informal training and have few if any opportunities to learn from experience about home therapies. They do however have regular pre and post-dialysis contact with patients, and as doctors are in a position of particular influence with patients, which could be harnessed very positively for home therapies.

3.2.2.3 Staffing and capacity issues

In all four sites, most staff thought that the staffing levels for home therapies were about right. In three sites, new home therapy nursing posts had been agreed within the last 12-24 months, along with additional surgical capacity. In two sites, new consultant posts had been funded on the back of the CQUIN targets and in one site a new technician's post had been funded.

There was experience of two different approaches to staff capacity issues and planning. In site 1, there was a well developed detailed business plan setting out the additional staff capacity required to enable the home haemodialysis service to deliver its CQUIN targets. This had resulted in new posts being funded by the Trust. In contrast, site 4 had had to demonstrate success in increasing the uptake of home haemodialysis before funding for

additional posts had been agreed. This had resulted in significant workload pressures for the staff involved.

Interestingly, none of the sites had business or capacity plans which included both PD and home haemodialysis and which covered the remaining three years of the CQUIN target. Sites 2 and 3 had no formal business plans in place at all.

For staff, the funding of new posts was seen very positively as evidence of Trust support for home therapies. However, some staff were concerned about the sustainability of both PD and home haemodialysis if numbers continue to increase, suggesting that future capacity plans are needed:

“Well staffing, you always need to have plenty of staff to either deliver the education, deliver the training, support them at home.... a big barrier has got to be staffing... if you haven’t got the staff to train and then support the patient at home it’s the same reasons, you’ll get them dropping off and coming back in to centre.... it’s all very well growing it, you’ve got to sustain it [too].” PD sister, site 4.

Sustainability was also raised as a concern in relation to both the medical and nursing clinical leads for home therapies. Staff in several sites questioned the wisdom of depending on a small number of clinical champions for home therapies and suggested that home therapies should become owned more widely and embedded within the service.

Looking to the future, there were some staff who were concerned that a continuing increase in the number of patients on home therapies could impact negatively on the need for in-centre haemodialysis staff:

“...if there’s a massive influx [onto home therapies] that might then have an adverse impact on our in-hospital dialysis and satellite dialysis because there may be spare capacity and maybe an impact on our nursing contingent.” Consultant, site 3.

“You know, if everybody goes home it’s going to take all our patients. But I suppose in reality that never happens, but it is a little niggle isn’t it?” Dialysis unit nurse manager, site 4.

However, other staff thought that this would be more than offset by increases in dialysis numbers as the population ages. At a managerial level there was awareness of the potential impact on staff roles, with hospital or unit staff possibly needing to change roles if the proportion of home patients continues to rise significantly:

“It means changing the role of healthcare professionals we already have and I think, yes, it is a different skill and it’s a different working [pattern] and I think, you know, that does present challenges... if we do get to a position where we say well, we’re not requiring as many dialysis stations in the hospital, however, we are requiring more support for patients in the community, we need to change the role of some of our staff and I think people understand that.” Centre clinical lead, medicine, site 4.

3.2.2.4 Clinical leadership and champions for home therapies

A combination of strong clinical leaders, individuals who act as champions for home therapies, and enthusiastic home therapy nursing teams were frequently identified as the

key to successfully increasing the uptake of home therapies. In all the sites, a strong team approach was seen as one of the pre-requisites for successful change:

“...it’s been successful partly because there’s been an overall will amongst the whole of the multi-disciplinary team to do it. There’s been no one who has been against it or outspoken about it.” Consultant, site 1.

“It’s not something we’ve thrown lots of resource at, it’s just that I think we’re fortunate to have staff who want to do this it’s been driven by enthusiastic staff wanting to provide, you know, better care for their patients.” Centre clinical lead, medicine, site 4.

In all four sites, there were highly visible clinical nursing and medical leaders for home therapies, who were widely praised for being highly committed, enthusiastic and effective. Some of these staff were in formal leadership positions, whilst others were not. In all four sites, the renal clinical consultant leads were all very supportive of the home therapies agenda and had helped to create a climate within which change could take place. Site 2 had benefitted from having a leading expert in PD which had generated both staff and patient confidence in PD as an effective home therapy.

In site 1, staff thought that their clinical leaders had built a strong and visible profile for the service with the Trust and externally, which had helped them to secure new resources for home therapies. This was borne out in the interviews with senior Trust managers and by this site being the only one to have a formal Trust-level business plan for home haemodialysis.

In addition to identifiable leaders, staff also thought that their success with home therapies, and with home haemodialysis in particular, owed a lot to individuals at all levels who were comfortable with challenging existing practice and designing new ways of working. Staff described some of the inevitable tensions that arise when services change:

“it’s a bit scary for everybody, but I think I’m one of these strange people that like a change – I like things to – challenges and things to be done differently and let’s see how it works. We’ve had to iron things out and calm things down and identify problems and then find solutions to them and there’s been a lot of – there is a lot of angst but we’re getting there and we’re just plodding a way through and we will get there to provide a perfect service then – that’s what I want.” Home therapies nurse, site 2.

This description of trying out change and then ironing out problems as they arise, typifies the culture of the clinical team in site 2. Here new ideas are generated at all levels in the service and decisions are made jointly between nurses and doctors at the senior renal team meetings. There is a deliberate approach of not over-analyzing service changes at the outset, but letting the vision and enthusiasm of staff on the ground drive the detail of the change.

A similar approach was being taken in site 4, where there is a very strong and cohesive renal senior team which has sustained a focus on home therapy service change for a number of years, without experiencing the potential disruption of personnel changes. Nursing staff have led most of the service changes, which have been delivered simultaneously in quite a number of areas, as described earlier in this section.

In sites 1 and 3, there appeared to be somewhat less cohesive approaches being taken across the service. Instead, site 1 has focussed attention on home haemodialysis and site 3 on PD, with the relevant consultant and nursing staff championing change in these spheres very effectively.

In several of the sites, staff talked about the time being right for widening the ownership of home therapies to a wider group of staff. They acknowledged the strength of leading service change in the early days through a small group of committed staff, but felt that future success would depend on more staff 'owning' the home therapies agenda. In a similar vein, some staff in site 4 were keen to see the active involvement of more junior nursing staff in home therapies. In all four sites, home therapies tended to be discussed regularly at senior clinical multi-disciplinary team meetings, which had provided an important forum for discussing issues and monitoring progress. However, there were fewer opportunities for more junior staff to participate in debate and keep up to date with developments.

3.2.3 Organisational factors

Most staff in all four sites thought their Trusts were supportive of the expansion of home therapies. Individual staff had different perspectives about what this support meant. For many, support was evidenced in new staff posts and home haemodialysis machines being funded. Other staff drew attention to particular senior managers in the Trust who had taken an interest in home therapies and were well informed about what was being achieved. Site 3 in particular had benefitted from support from their Trust Medical Director who was also a renal physician.

For some staff, Trust-level support was evidenced in the service being given the freedom to design and implement home therapy services without interference, whilst in site 4, the home haemodialysis nurse had won a Trust prize for innovation, which many staff saw as symbolic of Trust support.

Interviews with Trust senior managers and clinical leaders in sites 1 and 4 revealed a strong level of support and a good understanding of the challenges involved in increasing the uptake of home therapies:

"I think the blocks that will stop it happening is probably our ability to keep up with the training and the supporting these patients at home and that's a little bit about how do you move or change some of the resource and it might be nurses, it might be renal technicians, who previously worked in here [hospital] and now are going to have to work out there [in the community]." Divisional operating officer, site 1.

"Well, I think we're doing very well, if we look at our relative percentage of patients who do have, who are dialysed by peritoneal dialysis, it's extremely high and rising and if we look at the proportion of patients who are on home haemodialysis that's also much higher than the national average so I think it's a real area of success for us and something, you know, I think we're very proud of." Centre clinical lead, medicine, site 4.

In both these sites, senior managers also talked about the push for home-based treatments being well aligned with Trust strategy, and something that they should be doing, irrespective of targets:

“It costs less, the outcomes are good if not better than for in-centre dialysis, and it fits with the move to out of hospital care. It’s a win-win, provided patients also support it... it fits with the Trust’s strategy, and the move to the new hospital and having more services in the community and in patients’ homes.” Divisional medical director, site 2.

Finally it is worth noting that several sites had experienced practical bureaucratic problems in the purchase and supply of home haemodialysis machines, which had led to significant delays in getting patients home. Although these delays were not interpreted by staff as evidence of a lack of Trust support, they did lead to considerable frustration for both staff and patients, and took considerable time and effort to overcome. These experiences suggest that Trusts may need to find more flexible procurement methods which are more responsive to fluctuations in demand for machines.

3.2.4 Wider system factors

Relatively little was said by staff, including Trust senior managers, about if and how the wider system supported the hospitals’ efforts to increase the uptake of home therapies. Two issues were raised: the tariff for dialysis and the CQUIN target.

In two sites, some frustration had been experienced by virtue of the national tariff system for payments to Trusts, because it had taken some time for tariffs to be introduced for newer dialysis services such as Assisted APD and solo home haemodialysis. Without these tariffs, there was a disincentive for hospitals to introduce these services because, although they were more expensive to run, Trusts were only remunerated for standard APD and Home haemodialysis. Tariffs for these two services have since been introduced.

3.2.4.1 The CQUIN target

In April 2010, the regional specialised services commissioner introduced a home therapies target for each Trust which was also included in the annual CQUIN financial incentive scheme. Year-by-year targets for increasing the uptake of home therapies were set out for a 5-year period, with all Trusts required to reach 35% of their patients on a home therapy by April 2015.

Staff raised a number of points about this target during interviews. Many staff talked about initial negative reactions to the target, because there was a perception that it had been imposed without sufficient consultation. Staff were quick to see that a financial penalty would be imposed if targets were not met, rather than a financial reward for achievement of targets. Some staff saw a potential conflict between achieving the target and patient choice, whilst others expressed anger that they had been given a target for something that they should already be doing:

“...it’s upsetting that this target’s had to come and it’s upsetting that some people seem to have changed their practice consequent to it. I mean, why should [we] have to have a target to do what we’re meant to do anyway?” Consultant, site 3.

There were also concerns that the scheme failed to take full account of the inter-relationships between different parts of the service. For example, although transplantation is seen as the ideal treatment, Trusts achieving high transplantation rates could find themselves penalised for not achieving home therapy targets, because PD and home haemodialysis patients were successfully transplanted leading to a diminished pool of more healthy patients who would be ideal for a home therapy. All sites also queried whether they could in fact achieve the 35% target, which was seen as arbitrary and not evidence-based.

Despite these concerns and criticisms, many staff acknowledged, somewhat reluctantly, that the CQUIN had played a positive role in enabling them to expand their home therapy programmes. Clinical leads and consultants were quick to acknowledge that it had provided a useful lever for securing additional resources from their Trusts:

“There’s money issues for them [the Trust] if people aren’t on home dialysis. For me money issues aren’t important, although they are in the big picture. And actually it [CQUIN target] has helped to, I don’t know, kind of highlight the importance of home therapy and I think it’s helped us get assisted [PD]. So in fact it has helped get another treatment option.” Consultant, site 2.

“But also the commissioners, by having a bit of a stick as well as a carrot for us to achieve higher home therapy rates, [it] has been very helpful in our negotiations with our Trust to say ‘look, we’ll lose this X amount of money if we don’t invest to achieve it’.” Consultant, site 4.

For some staff this reinforced a cynical view that Trusts were only supportive of home therapies because of the possibility of financial penalties:

“I haven’t got a clue what the Trust thinks. I mean it’s you know it’s the new government directive isn’t it? So I’m sure they’re pulling out all the stops that they can possibly pull out now, aren’t they, to get you know our 35% of patients on, because they’re going to lose money if they don’t.” Nurse, site 4.

For others, there was an acknowledgement that the target had created a useful positive profile for home therapies within their Trusts, particularly with Executive teams and Boards, which might not otherwise have been achieved. Trust senior managers also acknowledged that the CQUIN target had helped to stimulate change:

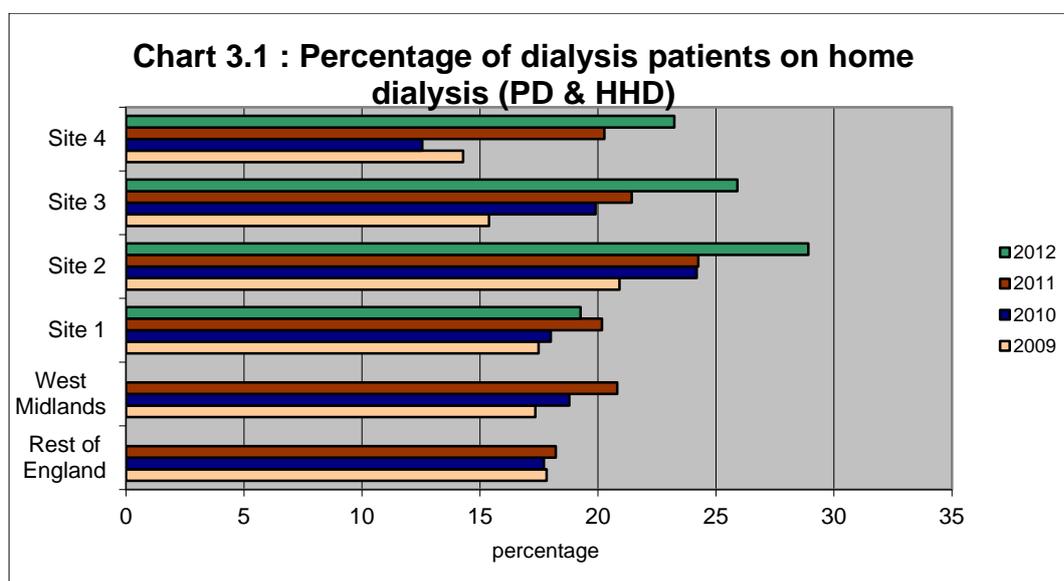
“We have for a very long time I think, not provided the level of home therapies that we should have.... I think we would all accept that and there’s probably many different reasons for that.... and the CQUIN’s probably given us the initiative to do that.” Divisional operating officer, site 1.

Overall, senior renal and managerial staff tended to conclude that the CQUIN target had had a positive effect, enabling improvements to the uptake of home therapies to be made at a speed which would probably not have been otherwise achieved.

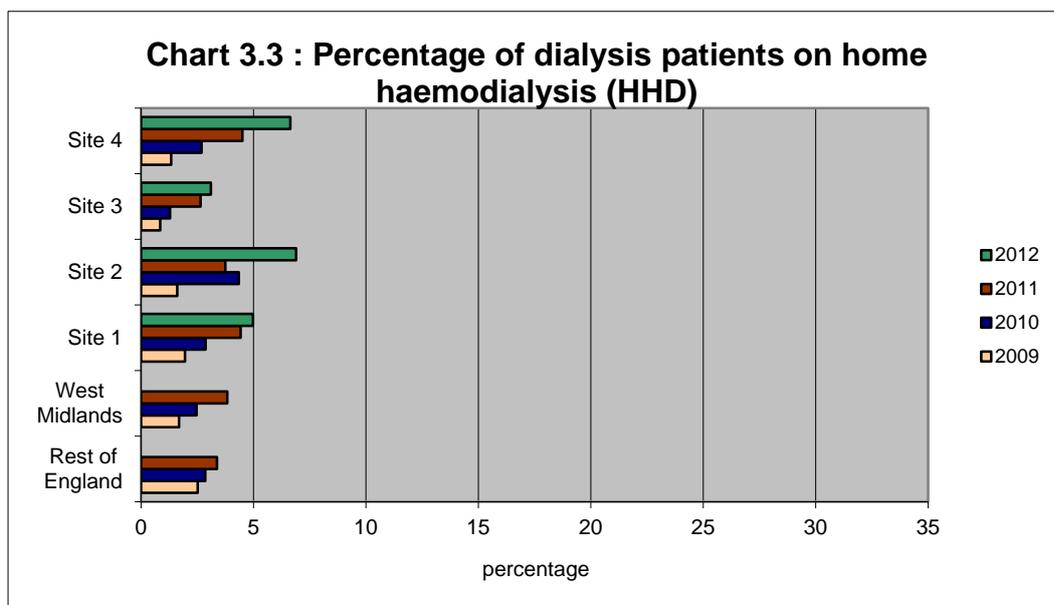
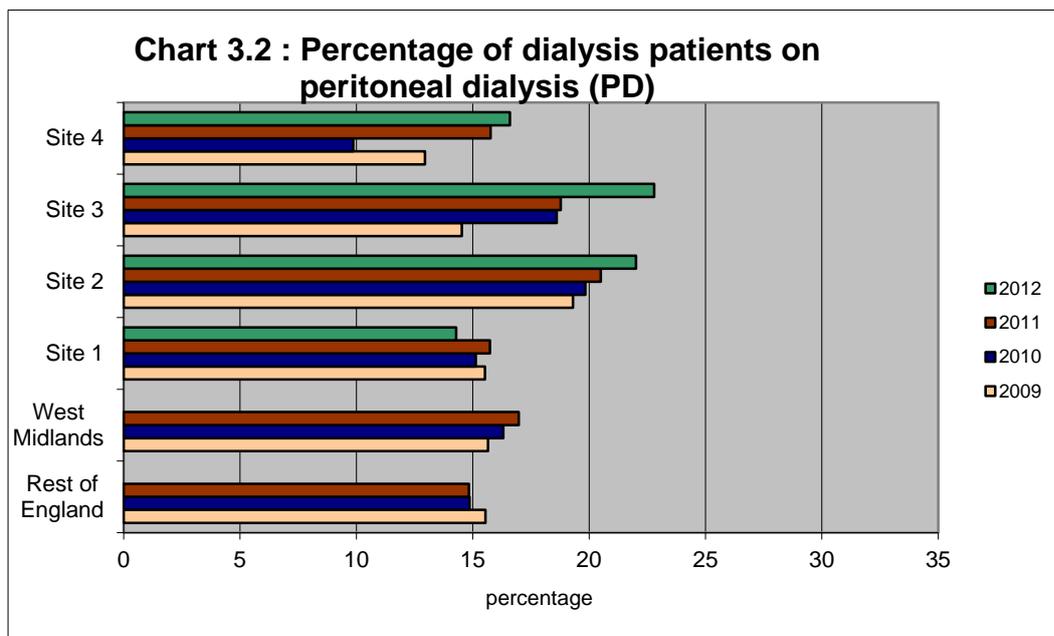
3.2.5 Changes in the uptake of home therapies

This section presents quantitative data showing changes in the uptake of home therapies from 2009 to 2012. The data is derived from Renal Registry reports for England, based on a spot survey of patient treatment modalities on 31st December for the years 2009, 2010 and 2011. Data for 2012 was provided by the four sites based on their return to the UK Renal Registry (this meant that the data had not yet been through the Renal Registry’s processes for data checking or cleansing). Numerical data is detailed in Appendix 7.3. Figures for 2009 act as a baseline year, pre-dating the introduction of the regional commissioner’s CQUIN targets for increasing the uptake of home therapies which came into operation in April 2010. Data for all England hospitals and the seven hospital trusts in the West Midlands providing dialysis services (inclusive of sites 1-4) is also included, for comparison purposes for the years 2009-11. Data for 2012 for England and the West Midlands is not available from the Renal Registry until 2014 and cannot therefore be included. England data for home haemodialysis may be under-reported due to coding issues at a minority of hospitals (Renal Registry, 2012).

Chart 3.1 shows how the proportion of dialysis patients on a home therapy (PD and Home haemodialysis combined) has increased over time. In 2009, West Midlands hospitals were marginally (0.5%) below the England average of 17.8% of dialysis patients on home treatments. For the study sites, two were below, one was above and one was in line with the West Midlands and England averages. Two years later, at the end of 2011, two of the study sites were at the West Midlands average and two were above. The West Midlands average which had increased by 3 percentage points, whilst the England average remained static. The four study sites achieved increases on their 2009 baseline of 2.7 – 6 percentage points by the end of 2011 and 1.8 - 10.5 by the end of 2012. Although the actual number of patients on home treatments in any one site was relatively small, and therefore subject to natural variation year on year, it is notable that over the two years, all four sites increased their proportion of home treatment patients, whilst the England figures were static.



Charts 3.2 and 3.3 show how sites differed in their separate uptake rates for PD and Home haemodialysis. Site 1 achieved all of its increase in home treatment uptake through home haemodialysis, with PD uptake rates dropping very slightly. In contrast, sites 2, 3 and 4 increased the uptake rates of both types of treatment. Site 3 achieved the greatest increase in PD uptake across the four sites, whilst sites 2 and 4 achieved the greatest increases in home haemodialysis uptake. These differences between the sites are in line with how all four sites described their approaches to increasing the uptake of home treatments (see 3.2.1.5).



Another approach to analysing the changes in uptake of home therapies is to compare each site's ranking in 2009 and 2011 with the 52 Hospital Trusts in England which provide dialysis services. Table 3.5 shows that in 2009 none of the study sites were in the top quartile (25%) for PD, Home haemodialysis, or Home therapies (PD and Home haemodialysis combined). By 2011, site 2 was in the top quartile for PD and Home therapies, and site 3 was in the top quartile for PD.

In 2011 all four sites were in the top 50% of Trusts for PD, Home haemodialysis and Home therapies. This compared with 2009 when the top 50% only included site 1 for Home haemodialysis and site 2 for PD and Home therapies.

	PD		Home haemodialysis (HHD)		Home therapies (PD and HHD)	
	2009	2011	2009	2011	2009	2011
Site 1	31	24	22	14	31	20
Site 2	14	9	27	20	17	11
Site 3	36	12	33	26	38	17
Site 4	41	23	29	13	40	19

Top quartile
 Top 50%

Table 3.6 shows the year-by-year changes made by the four sites in their uptake of home therapies. It shows that sites 2, 3 and 4 achieved similar percentage increases, whilst site 1 achieved a relatively small increase which was well below that of the other sites.

3.2.5.1 Statistical analysis

Given the observed changes in home therapy uptake rates, statistical analysis was undertaken, in order to assess whether the observed changes could be accounted for by:

- taking part in the study (study effect)
- changes in the population characteristics of the study sites.

The analysis of changes in population characteristics was determined partly by the availability of national data from the Renal Registry and partly by the factors known to have some effect on the uptake of home therapies. It was undertaken for the proportion of renal replacement therapy patients who were:

- aged over 65
- from black and minority ethnic (BME) groups
- successfully transplanted.

TABLE 3.6 : PERCENTAGE OF DIALYSIS PATIENTS ON HOME DIALYSIS						
Site	2009	2010	2011	2012	% point change 2009- 2011	% point change 2009-2012
1	17.5	18	20.2	19.3	2.7	1.8
2	20.9	24.2	24.3	28.9	3.4	8
3	15.4	19.9	21.4	25.9	7	10.5
4	14.3	12.6	20.3	23.2	6	8.9
Sub-total study sites	17.4	18.9	21.2	22.7	3.8	5.3
5	20.3	19.5	23	-	2.8	*
6	27.4	29.1	28.6	-	1.2	*
7	9.9	12.8	14	-	4.1	*
Sub-total, non-study sites	17.2	18.6	20.1	-	2.9	*
West Midlands (sites 1-7)	17.3	18.8	20.8	-	3.5	*
Rest of England	17.8	17.7	18.2	-	0.4	*

*Data not available for 2012 for non-study sites, West Midlands and Rest of England.

Previous research has suggested that uptake rates for home therapies are often lower amongst (BME) communities in this country, and can be lower for older patients, particularly for PD (Renal Registry, 2012). If transplantation rates rise, this can impact on the uptake of home therapies, particularly PD, as transplant patients are often the younger fitter patients who would also be more likely to opt for a home therapy.

Changes in these characteristics of the RRT population were analysed between 2009 and 2011, as changes had the potential to influence home therapy uptake rates. In addition, the analysis looked at changes in the total size of the RRT population over the same time period. It could be argued that if the RRT population increased more during the study period, compared with the rest of England, this could account for some of the increases in home therapy uptake, as these would be new dialysis patients who would be targeted for home therapies by the study sites.

Differences in patient case mix could potentially account for some of the differences between study sites or between the study sites and the rest of England. This may have been relevant in site 1 which is a specialist centre taking referrals from a very wide catchment area (including some of the study sites) for particularly complex patients. However, this could not be analysed in the absence of appropriate Renal Registry data.

The data were analysed using a Poisson regression model for the total numbers of renal replacement therapy (RRT) patients, and logistic regression models for the numbers on

Home therapies and for other characteristics of the population. The models incorporated fixed effects for sites and linear time effects within three groups of sites: the four study hospitals; the three other West Midlands hospitals providing renal services; all other English hospitals providing renal services (45 hospitals). Data for the all the hospitals included in this analysis were taken from the Renal Registry reports for 2009 and 2011. Overlap between eligible patient groups in consecutive years can be expected to generate temporal correlations within individual sites. Allowance for this effect was made through autoregressive models fitted using generalised estimating equations within the STATA 12 package.

Changes in the uptake of home therapies

Table 3.6 on the previous page shows how the percentage of dialysis patients on a home therapy changed between 2009 and 2011 for the study sites, the West Midlands and the rest of England. Table 3.7 summarises the results of statistical analysis which shows that the West Midlands average year-on-year increase was significantly ($P < 0.001$) different from the remaining 45 English hospitals for which there was little year-on-year change. Within the West Midlands the changes were similar in the study sites to the non-study sites ($P = 0.723$) suggesting that there was no identifiable study effect which could explain the observed changes in the uptake of home therapies.

TABLE 3.7 : STATISTICAL ANALYSIS OF THE CHANGES IN THE PROPORTION OF PATIENTS ON A HOME THERAPY, 2009-2011		
	Proportion of dialysis patients on home therapies	
	Odds ratio	P
Study sites (n=4)	1.13 (1.07, 1.20)	†0.723
Non-study sites (n=3)	1.11 (1.02, 1.20)	
West Midlands (n=7)	1.12 (1.07, 1.18)	††<0.001
Rest of England (n=45)	0.98 (0.96, 1.0)	

† Study sites vs. Non-study sites with the West Midlands; †† West Midlands vs. Rest of England.

Population changes

Table 3.8 shows how the renal replacement therapy population changed between 2009 and 2011 in the study sites compared with the rest of England for: the proportion transplanted; the proportion aged under 65; and the proportion of BME patients. The only significant difference between any of the study sites and the rest of England was for site 1 where there was a significant ($P < 0.001$) increase in the proportion of patients aged under 65.

TABLE 3.8 : CHANGES IN THE RENAL REPLACEMENT THERAPY POPULATION, 2009-2011															
	Patient population			Percentage transplanted				Percentage aged under 65				Percentage black and minority ethnic patients			
Site	2009	2011	% change	2009	2011	% change	P-value	2009	2011	% change	P-value	2009	2011	% change	P-value
1	1821	1923	5.6	43.8	44.8	2.4	0.417	53.7	68.0	26.6	<0.001	33.6	35.9	6.8	0.128
2	640	695	8.6	41.7	42.4	1.7	0.502	64.1	60.3	-5.9	0.064	6.5	6.6	1.5	0.280
3	477	516	8.2	26.4	26.7	1.2	0.519	57.9	57.0	-1.5	0.575	26.1	27.1	3.6	0.077
4	337	342	1.5	33.5	35.1	4.6	0.948	59.3	55.6	-6.4	0.189	3.9	5.0	27.7	0.360
5	794	886	11.6	46.0	49.0	6.6	0.456	63.6	65.5	2.9	0.571	16.1	17.7	9.9	0.565
6	292	287	-1.7	27.4	30.7	11.9	0.458	60.3	56.4	-6.4	0.220	12.8	13.6	6.1	0.887
7	622	666	7.1	25.2	26.1	3.5	0.707	53.9	54.2	0.6	0.879	37.4	37.7	1.0	0.903
Rest of England	35979	39350	9.1	48.7	50.6	3.9		64.2	64.9	1.1		19.8	22.2	11.8	

P-values compare change within study sites to the Rest of England.

When study sites are compared with the non study sites in the West Midlands and the West Midlands is compared with the Rest of England, there are no significant differences in population changes between 2009 and 2011 (Table 3.9). It should however be remembered that with relatively small sample sizes, there would need to be a very large difference in order to achieve a significant P value.

TABLE 3.9 : STATISTICAL ANALYSIS OF THE CHANGES IN THE RRT POPULATION, 2009-2011

	All RRT patients		Age < 65		BME		Transplants	
	% change in number	p	% change in odds	p	% change in odds	p	% change in odds	p
Study sites (n = 4)	3.0 (1.0,5.1)	†0.681	15.0 (10.1,20.2)	†0.001	4.7 (-0.6,10.4)	†0.340	1.02(0.99,1.05)	†0.232
Non-study sites (n = 3)	3.8 (1.0,6.6)		0.8 (-5.1,7.0)		3.0 (0.0,5.9)		1.05 (1.01,1.10)	
Rest of England (n = 45)	4.6 (4.0,5.2)	‡0.153	1.4 (0.1,2.8)	‡<0.001	7.2 (5.4,9.0)	‡0.003	1.04 (1.03,1.05)	‡0.660

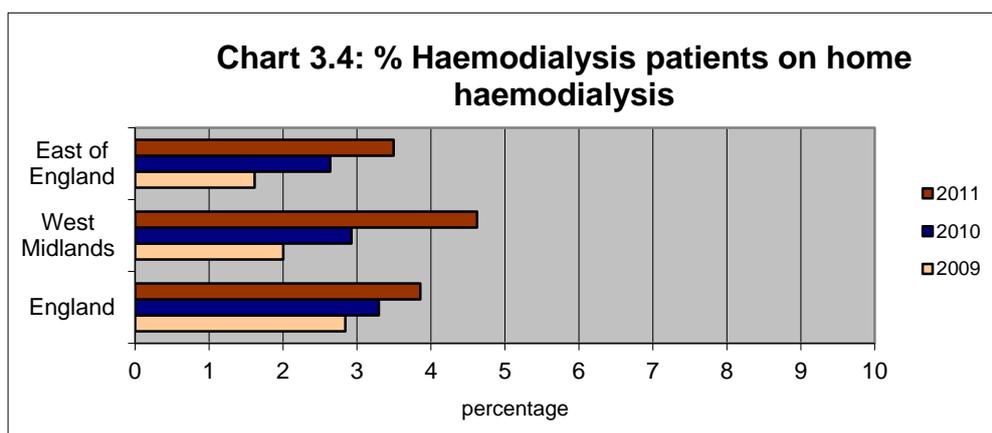
†Study sites vs. non-study sites within the West Midlands; ‡West Midlands vs. Rest of England.

The conclusion of this analysis is that although there were some changes in the population characteristics of the study sites during the study period, these were not significantly different from changes in the non-study sites in the West Midlands or the rest of England, and are therefore unlikely to explain the observed significant increases in the uptake of home therapies.

Home therapy targets in other parts of the country

Online searches identified two other parts of the country where specialised services commissioners had negotiated CQUIN targets for home therapy. It is important to note that NHS structural changes implemented in 2011 and 2013 led to the closure of some of the websites for specialised services commissioning groups, and this may not therefore provide a full picture of commissioner-led targets related to home therapies.

In the East of England, commissioners introduced a five-year target in April 2010, for the six renal service providers to increase the proportion of haemodialysis patients treated at home to 10% by 2015 (East of England Specialised Commissioning Group, 2009). This differed from the West Midlands target of 35% of all dialysis patients to be treated at home (peritoneal dialysis or home haemodialysis) by 2015. Comparative data from the Renal Registry is provided in Appendix 7.3, with Chart 3.4 showing that providers in the East of England achieved increases above those for England in the first two years of the CQUIN target (December 2009- December 2011), although the East of England remained below the England average. This provides limited additional evidence of the incentivising effect of CQUIN targets.



% point change 2009-2011: England: 1%; West Midlands: 2.6%; East of England: 1.9%

More recently, the North-East Specialised Commissioning Group introduced individualised CQUIN targets for hospitals to increase the absolute number of *new* patients on home therapies, for 2011-2012 (Newcastle-upon-Tyne NHS Trust, 2012). In addition, the national Specialist Services CQUIN menu included for the first time in April 2012, a target for local agreement for increasing the number of patients receiving dialysis at home. Data is not yet available to enable any further analysis of the effect of these CQUIN targets on home therapy uptake.

3.2.6 Summary of the findings from each site

This section provides a summary of the main findings from each of the four sites. It highlights how services were organised, the approach each site was taking to increase the uptake of home therapies and actions they had taken to support the achievement of the April 2015 CQUIN target. The following findings applied to all four sites and are not therefore repeated in the summaries which follow:

- very positive feedback from patients about staff and the quality of the services
- well developed and effective systems for training patients for their chosen home therapy, and providing on-going care and support once patients were on their treatment
- high levels of support from most staff for increasing the uptake of home therapies, but mixed views about the value of the home therapies CQUIN target
- effective clinical leadership from both consultants and nurses for increasing the uptake of home therapies.

3.2.6.1 Site 1

Site 1 was a large teaching hospital providing dialysis services to a large and diverse population drawn from inner-city, urban and rural areas. Whilst patient choice of treatment was a strong underpinning principle, clinical staff described a variety of approaches to

patient choice of dialysis treatment, which was mirrored in the experience of the patients interviewed. Pre-dialysis education was considered to be under resourced and had been affected by staff changes. The service had pioneered a peer support programme for patients interested in home haemodialysis, and was involved in training staff in other hospitals to introduce peer support. This programme was being extended into a buddy system which would provide on-going support to patients once they start home haemodialysis.

On-going care in the haemodialysis units was criticised by a vocal minority of patients who criticised transport arrangements, delays in being treated and staff attitudes. In addition, a number of the south Asian patients who were interviewed expressed dissatisfaction with the service, which was mostly about staff attitudes and lack of access to interpreters.

There were well established separate teams for PD and home haemodialysis and 11 different in-centre nursing teams operated by an independent provider. Nursing staff tended to express confidence in their own area of expertise but felt less confident in their knowledge of other treatments, including home therapies. This was seen as being largely due to lack of experience of other treatments arising from separate teams which were described by some staff as operating in silos. However, this had been recognised as an issue and home therapies had recently been introduced into the induction programme for all new staff. There were also plans to extend rotations for new staff as a way of skilling them up about home therapies.

The service had focussed primarily on increasing the uptake of home haemodialysis and in two years had developed one of the biggest programmes in the country. Staff interviews reflected this, with staff tending to equate home therapies with home haemodialysis, often to the exclusion of PD. Recent developments in PD included an assisted peritoneal dialysis service for frail older people and an acute pathway designed to increase PD uptake for acutely ill patients. The service had been successful at securing additional funding for home haemodialysis. It was the only site with a forward looking capacity plan designed to support the April 2015 CQUIN target. There was positive and visible support among Trust senior managers for increasing the uptake of home therapies, with the clinical leads having particularly strong profiles within the wider Trust. There was also good alignment between the home therapies plan and the Trust's business plan.

In 2011, this site had the greatest proportion of patients on home haemodialysis compared with the other three sites, in excess of the regional and national averages. However, by 2012, two other sites had expanded their programmes beyond the level in site 1. Unlike the other three sites, site 1 did not expand the proportion of patients on PD, which fell slightly, and resulted in a slower overall increase in the uptake of home therapies than the other sites.

3.2.6.2 Site 2

Site 2 was a medium sized hospital providing services to a largely white population drawn from urban areas with high levels of disadvantage and a wide rural catchment area. There was a very clear dialysis choice model, described as 'fully open choice' for patients, with no guidance from staff (except for clinical reasons). Patients were offered tightly structured pre-dialysis education which included several home visits from pre-dialysis specialist nurses. Peer support was seen as important and was offered on an ad hoc basis in response to patients' requests.

In addition to a clear choice model which all staff signed up to, the site was distinctive in its culture and how it organised its services for home therapies. There was a clear model of leadership which involved joint problem-solving by the senior team (comprising consultants and senior nurses) and a culture of allowing nursing teams to devise appropriate ways of implementing in-principle decisions made by the senior team. This was reflected in the approach to home therapies, where staff described a 'can-do' attitude to finding ways of supporting patients to go home, if that was their choice.

The site had reorganised its nursing teams with separate teams for PD and Home haemodialysis having been replaced by an integrated team dealing with both types of home therapy. A single integrated approach to home therapies through the home therapy team was seen by staff as a useful way of widening the skills of staff and had allowed staff to work more closely with the wards and haemodialysis units in order to identify patients who might be suitable for a home therapy. Rotation had been used to increase the knowledge and experience of newly appointed/qualified staff about home therapies. There were however still some staff groups, such as haemodialysis unit staff and registrars, who thought they needed to increase their knowledge and understanding of home therapies.

This site had focussed on increasing the uptake of home therapies rather than PD or Home haemodialysis as individual treatments. They had recently introduced an assisted PD service for frail older people and an acute PD pathway. Uptake levels for PD were historically high, with this site being well above regional and national averages for PD in all four years between 2009 and 2012. Home haemodialysis uptake rates had increased between 2009 and 2012 at the same rate as site 4 and at almost double the rate of sites 1 and 3. Overall, this site had the highest uptake rates for home therapies across the four sites for each of the four years, 2009-2012.

3.2.6.3 Site 3

Site 3 was a medium sized hospital providing services to a largely urban disadvantaged, multiracial population. Patient choice of dialysis treatment was relatively low key here, with staff using a 'guided choice' model to encourage patients to consider home therapies first, and within home therapies to consider PD first. In-centre haemodialysis was viewed by staff as the treatment of last resort. There was also a strong emphasis on identifying early those patients likely to need dialysis, with the pre-dialysis team providing lifestyle advice well

before dialysis options were discussed. This early intervention was reported to have slowed the decline in many patients' kidney function and delayed the need for dialysis.

Clinical teams had been reorganised very recently from separate teams for PD and Home haemodialysis into a single integrated team for home therapy. This was seen by staff as a positive move that was contributing to a culture change in which home therapies were becoming more of a norm. In recognition of the need for all staff to be well informed about treatment options, rotation and informal education had recently been tried, but with mixed success due to competing work pressures for staff. An integrated approach to home therapies was also supported by the tradition of all consultants working with patients on all treatment modalities rather than specialising in PD or haemodialysis.

Staff consistently highlighted strong clinical leadership from both doctors and nurses as one of the main reasons why home therapy numbers had increased. Although staff thought there was support from Trust senior managers, this was the only site where Trust senior managers were hard to engage or declined to take part in the research in significant numbers. However, some support was evident from the additional resources agreed by the Trust to support the achievement of the CQUIN targets.

This site had focussed on increasing the uptake of home therapies, and particularly PD. It had started below the regional and national averages for the percentage of patients on a home therapy in 2009, but by 2012 had seen a 10.5% increase in uptake rates, achieving the greatest percentage point increase across the four sites. Increases in the uptake of PD were greatest compared with the other three sites. These increases were however achieved against a backdrop of changes in its dialysis population (an increase in its RRT population and reductions in transplant rates) which were not mirrored in the other sites and which may have favoured home therapy uptake.

3.2.6.4 Site 4

Site 4 was a small-medium sized hospital serving a large, rural catchment area, with a predominantly white population. It provides an example of a service working on multiple changes to its delivery in a fairly intense way over a relatively short period of time.

In a similar vein to site 3, this site used a 'guided choice' model, but with a greater emphasis on patient choice, and offered patients a primary choice between treatment at home and hospital. This site was unique in having unanimous support amongst interviewed staff for its approach to patient choice, and consistency of staff opinion about how to promote home therapies with patients. This was the only site where the large majority of staff talked comfortably about a proactive approach to 'promoting' and 'selling' home therapies, albeit with patients retaining the final say about treatment.

The service had separate teams for PD, Home haemodialysis and In-centre haemodialysis, but had a strong ethos of working flexibly across teams, as and when needed to cover staff absences. This had resulted in staff gaining experience of the full range of treatment options, outside of their areas of specialist expertise, including In-centre haemodialysis staff,

who were unusually knowledgeable about and supportive of home therapies. This was the only site where all staff, irrespective of where they worked, expressed confidence in answering patients' ad hoc questions about home therapies, a finding which was corroborated by patient feedback.

There were well developed induction and rotation arrangements which provided newly qualified staff with hands-on experience of both PD and Home haemodialysis. Regular team study days were used to keep staff up to date with changes in how home therapies were being delivered. There was unanimous support for increasing the uptake of home therapies, with all senior staff seeing themselves as having a part to play, supported by strong clinical leaders for home therapy.

Staff capacity for home therapies had been increased, with support from the Trust, but only in retrospect once uptake had increased. This had led to home therapy staff working at or beyond full capacity, sometimes working well beyond their contracted hours in order to support patients. At the time of the interviews, there was thought to be sufficient staff capacity for home therapies, although there were concerns about how increasing numbers of patients could be sustained longer-term. Trust support for home therapies was evident amongst senior managers who were well informed and saw home therapies aligning with the Trust's business plan.

The service had started with a low baseline for home therapies in 2009 and 2010 which was below regional and national averages. Sizeable increases in home therapy uptake rates followed in 2011 and 2012, as a range of new services bedded in. Developments in PD included assisted PD, fast access to PD for acute patients who would otherwise have gone onto In-centre haemodialysis and switching In-centre patients to PD. The home haemodialysis programme had been grown by recruiting In-centre patients, using self-care as a stepping stone to going home. Access had also been extended by introducing a solo home haemodialysis service and the portable NxStage machine, both of which were popular with patients. There was some evidence from patients that lengthy travel time, distance and costs to get to the limited number of Haemodialysis units had acted as a significant incentive for some patients to opt for home therapies.

Table 3.10 summarises what the four sites had done to increase the uptake of home therapies.

TABLE 3.10 : SUMMARY OF ACTIONS TAKEN BY SITES TO INCREASE THE UPTAKE OF HOME DIALYSIS

	Sites			
	1	2	3	4
Individual level : staff and patients				
Assisted APD introduced to widen access to more frail patients or those living alone	√	√	√	√
Rapid/direct access to PD for acute patients, to prevent acute patients automatically going onto in-centre haemodialysis	√	√	√	√
Rapid PD catheter insertion	√			√
Solo home haemodialysis introduced, so patients do not need to have a carer involved				√
Portable home haemodialysis machine introduced (NxStage machine)				√
Self-care/minimal care routinely available in In-centre haemodialysis units as a possible stepping stone to home haemodialysis				√
One-off reviews of In-centre haemodialysis patients' treatment options		√	√	√
In-centre haemodialysis patients successfully switched to home dialysis				√
Peer support scheme for patients interested in home haemodialysis	√			
Informal peer support available for patients interested in home dialysis		√		
Team level : the renal team				
Additional specialist home dialysis staff recruited	√	√	√	√
Awareness training/updates on home dialysis provided for all staff				√
Home dialysis included in the induction of all new staff	√			√
Staff rotation used to increase staff knowledge of home dialysis		√		√
Focus on increasing both home haemodialysis and PD uptake		√	√	√
Organisational level : the Trust				
Significant additional resources secured from the Trust for staff and home dialysis machines	√	√	√	√
Forward-looking resource and capacity plan developed for achieving the 2015 target for home haemodialysis	√			
Visible support secured from Trust senior management	√			√
Home dialysis targets deliberately aligned with the Trust's strategic plan	√	√		√

3.3 LIMITATIONS OF THE STUDY

Study one had a number of limitations which need to be borne in mind when considering the findings. Firstly, the four case study sites were not selected to be representative of renal services across the country or the region, and findings might not therefore be generalisable. In selecting the sites, there was a balance between finding sites that were sufficiently different to provide variation in service models, geography and patient populations, and the interest and capacity of sites to be involved in a study of short duration due to funding and time constraints. Some of the findings may therefore be context specific to individual sites, particularly in site 4 which was the only rural area. Having said this, there was a considerable degree of similarity in the findings across the sites, which suggests that the study does provide insights that other areas may find useful.

Secondly, the snapshot nature of the data, collected at a single point in time, may provide less insight into the service change process than studying sites over a period of time through multiple data collection time points. This is relevant, given the 5-year timeframe for service change embodied in the CQUIN home therapy target. It therefore needs to be remembered that the findings on service change processes reflect experiences of the first 15-24 months of a potential 5-year process of change, and rely heavily on staff reflections about what has happened, rather than observation of changes over time.

Thirdly, there are limitations arising from the selection of participants. Frontline staff at entry level clinical grades were not included in the study, which focussed on interviewing staff in middle to senior clinical or managerial roles. This means that the study was not able to triangulate reported practice by more senior staff with frontline staff. Given that many studies report differences between what senior staff say happens and what actually happens in practice, this may mean that the study findings are overly positive. However, this is partially offset by the triangulation of findings between staff and patients, which is arguably one of the study's strengths. This triangulation did not find many significant disparities between staff and patient perceptions of how the services operated.

There may also be limitations arising from how patients were selected for the study. The original intention was to include one-third of patients on each of the main dialysis treatment types – PD, home haemodialysis and in-centre haemodialysis - and to select within these treatment types for variation in age, sex and ethnic group. In practice, the small numbers of patients on home haemodialysis in all four sites meant that some of the age and ethnic groups categories could not be filled. This was also the case, to a lesser extent, for PD and in-centre haemodialysis patients where younger patients and some ethnic groups were under-represented. This was exacerbated by excluding patients whose current treatment had started more than 2 years previously, although this was also a strength which ensured that patient experiences were about recent and current practice.

Finally, there are limitations in the usefulness of the research to the sites taking part, due to the time lag between data collection and completion of the final report. During this period, which varied between 14 and 20 months for the 4 sites, services have inevitably continued to change, which potentially makes the findings less relevant. To some degree this was offset by providing written and verbal feedback to each site within 6 months of data collection, although this feedback was restricted to the findings for each individual site, and did not include cross-site findings. Although this time lag could reduce the usefulness of the research to the four sites involved, this does not apply nationally. Arguably the research is more relevant nationally given that the majority of hospitals are further behind the four sites participating in this research, in increasing the uptake of home therapies.

4. STUDY TWO : OBSERVATIONAL STUDY

4.1 INTRODUCTION

The observational study was a small scale piece of research undertaken in one of the case study sites. Following the feedback of findings from case study 1, staff in site 2 expressed interest in exploring how they could improve the pre-dialysis pathway. They were keen to get a more detailed understanding of patients' concerns and perceived barriers to home therapies, and how well clinicians tackled these issues and answered patients' questions. It was agreed that the study would:

- 1) analyse the range of strategies staff use to identify, explore and overcome possible barriers to home therapies;
- 2) observe staff and patient perspectives on home therapies, the concerns and questions that patients raise, and how these are addressed by staff;
- 3) analyse the range of communication styles and strategies which staff use.

Following discussion with the renal team, it was agreed that these aims would be achieved most appropriately by observing pre-dialysis home visits and clinic appointments (out-patient appointments taking place either before or after home visits), with patients at CKD stages 4 and 5. The inclusion of patients at CKD stage 4 was designed to capture very early conversations about treatment options taking place well before patients might need dialysis.

4.1.1 Organisation of pre-dialysis

Site 2 had a clear rationale for its pre-dialysis pathway. When patients were thought to be 9-12 months away from needing dialysis, consultants would have a brief initial discussion about treatment options and refer them to the pre-dialysis nursing team. Consultants were clear that clinic appointments were not conducive to lengthy discussion of options, and that the pre-dialysis nurses had the prime role in educating patients and supporting them to make decisions. Following referral, patients would then have several pre-dialysis home visits, plus an optional group session at the hospital. The first home visit usually focussed on presenting dialysis options in a standardised way, using a commercial teaching aid. The second visit focussed on discussing patients' treatment preferences. Carers were encouraged to be present during home visits.

4.2 METHODOLOGY

The observational study was included in the original case study evaluation research protocol, the ethical submission approved by Birmingham University in July 2011, and the R&D approval from the Trust (see Appendix 7.1) . The inclusion and exclusion criteria were as follows:

Inclusion:

- pre-dialysis patients at CKD stages 4 and 5
- patients switching from one form of end-stage renal treatment to another.

Exclusion:

- patients unable to give consent
- acute patients on hospital wards.

4.2.1 Out-patient clinics

A pilot was run in mid-June with five patients who were observed in a general nephrology clinic. The pilot highlighted that only a small proportion of appointments were likely to include discussion of treatment options. This led to an increase in the number of planned observations in order to generate sufficient data for the study. Observations were planned for a 3-week period in July 2012, with at least one clinic being observed for each of the 11 doctors working in the unit.

Medical and nursing staff were sent Information sheets and Consent forms inviting them to take part in the study. Medical staff reviewed clinic lists in order to confirm that there were patients listed who met the inclusion criteria. Letters were then sent to all the eligible patients 7-10 days prior to the clinic. A short covering letter from the renal consultant clinical lead encouraged patients to take part and emphasised that their participation would not affect their treatment. The Patient Information sheet about the research and the Consent form were included with the letter.

Patient consent was taken in a private room by one of the research team, once patients had arrived in clinic. Patients then saw the doctor and the consultation was recorded by a second researcher sitting in a corner of the room, using a small digital audio recorder. The researcher had no involvement in the consultation and made every effort not to interact with patients.

A total of 8 clinics in 3 hospitals were observed. Plans to observe a 9th clinic were abandoned because there were no eligible patients. Three of the clinics were CKD clinics, 4 were general nephrology clinics and one was a mixed CKD/general nephrology clinic. A total of 7 consultants and 3 registrars took part, with one consultant excluded due to time constraints and annual leave.

A total of 123 patients in the 8 clinics were eligible to take part in the study. Six patients refused and one was unable to consent, resulting in 116 patients taking part in the study. Treatment options including dialysis were discussed with 35 patients (30% of the observed consultations). Recordings were transcribed for these 35 appointments. Table 4.1 summarises the characteristics of the patients taking part, who were mostly white, male and aged 65+.

TABLE 4.1 : PATIENT CHARACTERISTICS, OUT-PATIENT CLINICS		
PATIENT SAMPLING	Total	
	No.	%
Eligible patients	123	-
Refusals	6	5%
Patients unable to consent	1	1%
Sample size	116	-
Observed but not relevant	81	70%
Observed and included in study	35	30%
PATIENTS INCLUDED IN THE STUDY (n=35)		
Hospital location		
Main hospital	21	60%
2 nd hospital	9	26%
3 rd hospital	5	14%
Sex		
Male	24	69%
Female	11	31%
Age group		
18-39	3	9%
40-64	4	11%
65+	28	80%
Ethnic group		
White	34	97%
Indian	1	3%

4.2.2 Home Visits

Observation of home visits had originally been planned to take place during 2011 as a separate piece of work at site 2. However, this work had been delayed due to staff workloads, absences and leave. As only one observation had been completed, it was decided to incorporate this work into this observational study. Patients were identified for possible inclusion in the study by pre-dialysis nursing staff, as referrals came through from consultants. The observations were undertaken with all patients scheduled for a home visit during July 2012.

Patients were sent a short covering letter from the renal consultant clinical lead one week in advance of their home visit. This letter encouraged patients to take part and emphasised that their participation would not affect their treatment. The Patient Information sheet

about the research and the Consent form were included with the letter. On arrival at the patient's house, the pre-dialysis nurse introduced the researcher, who reminded the patient about the purpose of the research and gave them an opportunity to ask questions before completing the Consent form. The researcher then sat apart from the nurse and the patient and recorded the consultation using a small digital audio recorder. There were no refusals to take part. Most of the home visits lasted about 1 hour, and covered dialysis options in-depth along with discussion about which options might be most appropriate for the patient.

A total of 7 visits were observed, one in September 2011 and six in July 2012. Six of the visits were first visits, and one was a second visit. Carers were present at all of the visits. Two pre-dialysis nurses took part. Five of the patients were female, two were male, and all were ethnically white. Their ages were not recorded. These observations were all undertaken by one member of the research team.

4.2.3 Data analysis

All recordings were transcribed verbatim. Four researchers coded the data using the qualitative data-input programme NVivo. Home visits transcripts were coded from start to finish. Clinic appointments were coded in detail only for the parts of the consultation where treatment options, including dialysis, were discussed. The remaining parts of the consultation were coded at a high level based on the three main themes. A small number of transcripts were coded initially in order to identify possible themes. These were then discussed and refined by the team. Table 4.2 shows the three content themes and sub-themes which were then agreed and used in the initial coding of the transcripts:

Themes	Sub-themes
Medical issues	management of the condition symptoms medications tests and test results patients' feelings about their condition
Decision-making	how patients made decisions about dialysis barriers to dialysis how patients felt about dialysis
Dialysis options	how dialysis works how patients learnt about dialysis how staff educated patients identification of potential problems

Following the first stage of coding, the research team identified areas for detailed analysis, based on the three research aims. This was undertaken by individual members of the team, with results discussed and amended by the whole team. The findings and recommendations were presented to the renal team in December 2012, followed by a written report in January 2013.

4.3 FINDINGS

The findings are presented in three sections, based on the aims of the study:

- 1) barriers to home therapy
- 2) staff and patient perspectives
- 3) communication styles and strategies.

Findings apply to both home visits and the clinic appointments, unless otherwise stated.

4.3.1 Barriers to home therapy

Barriers were identified and discussed in 17 of the 35 clinic appointments. The most common barriers were medical or practical issues:

Space Not having enough space at home for home therapy equipment or consumable items;

Treatment lead-in times How long it would take to prepare for dialysis, especially the lead-in times for inserting fistulas and catheters;

Impact on patients' lives Concerns about how a particular treatment might affect a patient's life, most commonly the impact on work, finances and holidays.

Barriers to in-centre haemodialysis were also raised by some patients who were concerned about travel time and transport arrangements. It is notable that some of the more common barriers that were identified by patients and staff in the case study interviews (pages 29-30) were not raised in this study - isolation at home; lack of self-confidence to self-care at home; and fears about being away from medical support.

The more obvious practical issues e.g. space at home or travel, tended to be brought up by the health professional, particularly during home visits. Patients tended to follow the clinician's lead, rather than instigate these discussions, although a small number of patients did raise issues they were particularly concerned about. Staff dealt with barriers very directly and made concerted efforts to resolve them through problem-solving. For example, there was lengthy discussion about how to get re-housed for one patient living in a council-owned property with insufficient space to do home haemodialysis.

Some patients were observed to have considerable difficulty in understanding some of the information or issues being discussed, despite being given simple and repeated explanations by staff. Clinicians were observed to generally accept patients' views about barriers at face value. There was little probing to try and uncover any underlying issues which might be presenting as practical barriers, or which might explain why some patients had difficulties in understanding some of the treatment options.

4.3.2 Staff and patient perspectives

Staff consistently provided patients with information about the full range of treatment options. Patients were encouraged to think about all available options, which were presented positively, with no biases observed. On the occasions when staff did recommend one treatment over another, clear explanations were given about why this option may suit the patient best. Typically, staff recommended PD to patients as the first-line treatment.

Although there were no observable biases in how staff talked with patients about treatment options, the use of a flipchart teaching aid during home visits presented options in a set order. This meant that in-centre haemodialysis was presented first and in considerable detail, even if patients had already expressed interest in a home therapy.

Eighteen patients (42%) were observed to display emotional reactions when discussing dialysis. Although staff tended not to discuss patients' emotional reactions head-on, there was usually tactile reassurance or strong non-verbal communication indicating empathy and understanding. Staff tended to deal with patients' emotional reactions by problem-solving and coming up with practical solutions. For example, one patient was particularly concerned and upset that going onto dialysis would result in a loss of earnings. The clinician suggested that the patient apply for state help through the Citizen's Advice Bureau, thereby providing a practical solution to an emotional issue.

Staff rarely explored with patients the reasons behind their choice of treatment, particularly during home visits. On the few occasions when this did occur, the discussion tended to be about why a particular choice was *not* possible, rather than reasons *for* a particular choice. During feedback to staff at the site, it became apparent that this issue is usually covered in second home visits, which were under-represented in this study.

4.3.2.1 Patients' questions and concerns

Patients asked questions in three categories:

- when dialysis will be needed
- practical issues
- general treatment queries.

When dialysis will be needed

This type of question was very common in the clinic appointments and often took up a lot of consultation time. Patients tended to ask multiple questions of the kind detailed in Table 4.3. Time and timing came across as very important to patients, who appeared to be trying to understand what the future holds and how life will change when they start dialysis.

TABLE 4.3 : COMMON PATIENT QUESTIONS
When will dialysis be needed?

<p>Am I at the stage of needing dialysis yet? Am I some way off needing dialysis? How long will it be (before I need dialysis)? How fast is the decline now? Are my kidneys holding their own? At what eGFR will I need dialysis? How do you know my GFR will go to x when it's at x now? How will I know when I need dialysis? What does the future mean? (in response to clinician saying they might need dialysis in the future)</p>

Clinicians answered these questions clearly, emphasising that there was no definitive way to predict when patients would need dialysis but that a rough estimate could be made by looking at a patient's eGFR in combination with how a patient felt overall. They often answered these questions initially in non-specific terms, saying that dialysis would be needed sometime in the future or near future. This usually resulted in patients asking further questions, often about their rate of eGFR decline and how it may change in the future. Although not directly related to dialysis choices, these questions were observed to be particularly important to patients. The ways in which these questions were answered by clinicians therefore provided a backdrop to future discussions about dialysis choices.

Practical issues

The practical issues set out in Table 4.4 show that patients were concerned about understanding what starting dialysis would mean for their everyday life.

TABLE 4.4 : COMMON PATIENT QUESTIONS
Practical issues related to dialysis

<p>Does the PD fluid freeze, if stored outside? Can I go to the bathroom at night if I go for CAPD at night? Does doing PD cut down on the risk of infections (compared with using needles for haemodialysis)? Can you carry the APD machine in the car? How much stuff is there? Do you need a special room? Do you have to have a big machine? Do you have to have your floor tested? How will I be able to starve for the anaesthetic when I'm a diabetic? What's the waiting time (for fistula/catheter insertion)? How do I get to the hospital for x? And how many times do I have to go there?</p>
--

General treatment queries

The more general treatment queries patients raised, again seemed to involve patients in trying to understand their options and how their life would change when they start dialysis. Common queries were about: the flexibility of the treatment; whether they could change treatment at some point if the one they chose did not suit them; and when was the right time to start thinking about dialysis options. Clinicians answered all these questions clearly and concisely.

Finally, it is worth noting that the clinic appointments included a small number of patients who had already had pre-dialysis home visits. None of these patients appeared to have unanswered questions, suggesting that the home visits were working well in providing patients with information about dialysis.

4.3.3 Communication styles and strategies

4.3.3.1 Clinic appointments

Patients' treatment decisions

A number of elements of decision-making were routinely covered in most of the clinic appointments, including: why forward planning is important; emphasising that choices could be changed at any time; and providing reassurance about what will happen in the future. These routine elements of decision-making tended to have a practical focus, but also provided patients with information and reassurance. Clinicians dealt with these aspects of decision-making in clear, concise and consistent ways.

It was noticeable that clinicians also tended to use clinic appointments to confirm or re-confirm patients' decisions, using prompts such as: "So you've decided to do PD...?" or "Are you still thinking you want to have in-centre haemodialysis?" This style of questioning tended to elicit confirmation of treatment choices. As noted earlier, staff tended not explore *why* patients had made a particular choice.

Structure, format and style of consultations

Clinic appointments were fairly homogenous in their structure and format and were usually clinician-led. They tended to start with a general discussion of medical issues including how the patient was feeling, symptom management, eGFR and other test results, and a check on medication. This first part of the consultation was very clearly clinician-led and involved clinicians asking lots of questions, many of which had yes/no answers. Whilst these topics are core functions of clinic appointments and inevitably involve a relatively passive role for patients, by covering these issues first, it appears to set the tone for the rest of the consultation. Most patients were therefore observed to continue in a passive role throughout the rest of the appointment, even when clinicians subsequently tried to engage patients in a two-way discussion about dialysis or other treatment options. This format for

clinic appointments, which begins with clinician-led medical issues, appears to result in a climate which is not very conducive to exploring and discussing patients' choices.

In terms of questioning, clinicians were observed to ask patients lots of questions. These questions tended to be closed questions about medical issues, checking for symptoms of worsening kidney problems, checking medication or where patients were on the pathway. Although most clinicians also asked more open-ended questions about the patient's well-being, these were asked most often whilst the clinician was busy doing something else, such as writing notes or printing out prescriptions/clinical test requests. For some patients, this could be a useful non-direct way of getting them to open up. However, other patients could interpret such questions from a doctor who is busy doing something else, as not proper questions or important questions which need a response. It was also noticeable that some clinicians asked patients open-ended questions towards the end of the appointment, when there was little time left to respond in any detail to concerns that patients raised.

When patients did ask questions, clinicians tended to answer these questions at face value rather than exploring what might lie behind the questions and concerns. Some clinicians commented that they do this in order to manage appointment length, as there was perceived to be insufficient time to explore issues in-depth with patients.

Overall, the observation confirmed the views expressed by staff from this site in the case study evaluation, that out-patient appointments are not particularly conducive to patient-led discussion of treatment choices and options, particularly compared with lengthier and more informal home visits.

4.3.3.2 Home visits

All the home visits lasted between 45 and 60 minutes. They were relaxed in style, with obvious warmth and rapport between the nurses and the patients, and their carer/spouse. This rapport helped the nurses to explain the breadth and detail of treatment options and fostered positive interactions with patients.

The first home visits started with general conversation between the nurse and patients and checking how well they were and symptoms of kidney failure. This was followed by the nurse giving information about kidney failure and then going through treatment options. This was done in a set order prescribed by a set of detailed flipcharts, which were used as an educational visual aid (Table 4.5).

TABLE 4.5 : ORDER OF TOPICS COVERED BY THE VISUAL AID
Kidney function and chronic kidney disease Signs and symptoms of chronic kidney disease In-centre haemodialysis Home haemodialysis Peritoneal dialysis Transplantation Conservative care

This site had decided some time previously to adopt the use of these commercially produced flipcharts in order to ensure that pre-dialysis patients received sufficient information about all treatment options. This was part of quality assuring the pre-dialysis home visits. However, in practice, the flipcharts were observed to be a mixed blessing. On the positive side, they did appear to provide reassurance to both the nurse and patient that all information had been covered and ensured that the patients had as much information as they wanted about treatment options. On the other hand, the flipcharts tended to be centre-stage with the nurses seeming reticent to veer too far away from the path laid out by the flipchart. This meant that patients were given information about treatment options in a pre-defined order, irrespective of their expressed interest in any particular treatment.

For home therapies, this is significant because patients who expressed an initial interest or asked at the start of the visit about home therapies, had to defer their interest or their question until some of the other treatments had been gone through using the flipchart. The order in which the therapies were considered is also possibly sub-optimal for encouraging patients to consider opting for home therapies. The primacy-recency effect means that many patients will tend to remember most about the first and last treatments covered – in this case, in-centre haemodialysis and conservative care. An alternative approach would be to ensure home therapies are presented first and then summarised at the end in order to encourage as many patients as possible to seriously consider home therapies.

Analysis of airtime

A useful way of analysing clinician-patient interactions is to look at how much time is taken up by each person talking. On average, in the home visits, staff talked for two-thirds of the appointment time, with the rest of the time split equally between the patient and carer (Table 4.6). In terms of the academic literature in this field, this is about standard, with healthcare professionals tending to talk more than patients due to the technical and explanatory nature of medical appointments. What may be slightly different here is that previous studies have been based on only two people being present in appointments - a healthcare professional and a patient. The presence of the carer here means that patients

effectively had half the time to talk. This may not be problematic, as in many cases the carer will be helping the patient to understand the issues at hand.

TABLE 4.6 : ANALYSIS OF AIRTIME FOR PATIENTS, CARERS AND HEALTHCARE PROFESSIONALS								
Speaker	Patient number							Average for all patients
	1	2	3	4	5	6	7	
Healthcare Professional	68%	58%	85%	64%	72%	61%	64%	67%
Patient	8%	16%	3%	20%	13%	12%	22%	13%
Patient's carer/spouse	12%	15%	5%	15%	8%	15%	12%	12%

Analysing shared decision-making

The OPTION Scale (Observing Patient Involvement in Decision Making) was selected as the most relevant validated tool to analyse decision-making during the home visits. This is a tool developed in the USA and adapted for General Practice in the United Kingdom, to assess physician skill in developing shared decision-making (Elwyn et al, 2012). It identifies twelve behaviours that clinicians can use to promote active participation in decision-making by patients (Table 4.7).

TABLE 4.7 : THE OPTION SCALE	
<ol style="list-style-type: none"> 1. Identifies a problem needing a decision-making process 2. States that there is more than one way to deal with the problem 3. Checks the patient's preferred information format (visual/words/numbers) 4. Lists options, including the choice of no action, if feasible 5. Explains the pros and cons of options to the patient 6. Explores the patient's expectations (or ideas) about how the problem is to be managed 	<ol style="list-style-type: none"> 7. Explores the patient's concerns (fears) about how the problem is to be managed 8. Checks that the patient has understood the information 9. Provides opportunities for the patient to ask questions 10. Asks for the patient's preferred level of involvement in decision-making 11. Provides an opportunity to defer a decision 12. Indicates that patients can their change mind after a decision has been made*
<p>*This item was adapted from the original for the purposes of this analysis. The original item was: indicates the need to review the decision (or deferment).</p>	

Home visit transcripts were coded for these 12 behaviours, and analysed for the frequency with which they were observed. The results are presented in Table 4.8, along with examples of each type of behaviour.

TABLE 4.8 : FREQUENCY AND EXAMPLES OF OBSERVED BEHAVIOURS FROM THE OPTION SCALE IN THE PRE-DIALYSIS HOME VISITS	
Observed in 6 or more home visits	Examples
Identifies a problem needing a decision-making process	<i>"The idea is to be able to give you enough information so that in the future you can decide what you're doing...it's your life, it's your decision."</i>
States that there is more than one way to deal with an identified problem	<i>"So you were examined for both [treatments]... so you can choose whichever one you want."</i>
Lists options, including the choice of no action if feasible	<i>"We've got dialysis, we've got transplantation and then we've got conservative treatment...You can dialyse at home and for at home we've got haemodialysis or peritoneal dialysis. In hospital we've got haemodialysis."</i>
Explains the pros and cons of options to the patient	<i>"Benefits, well there's someone doing it for you. So you feel secure don' you, that you're being cared for by a trained professional...No equipment needed at home...You've got regular contact with people in the same situation. Points to consider: the travel, fixed time...Two needles to be put in every time."</i>
Provides opportunities for the patient to ask questions	<i>"Are there any questions that you've got kind of in your head before I start?"</i>
Observed in 3-5 home visits	Examples
Explores the patients' expectations or ideas about how the problem is to be managed	<i>"You still supply things to do swimming, don't you?" "Yes we do. And sometimes you can get them from your GP. It's a watertight sterile dressing...You put over before you go swimming."</i>
Explores the patients' concerns (fears) about how the problem is to be managed	<i>"It's trying to sort out your dialysis times to suit you. For those who go to hospital and they're working in the day, they go on the evening shift."</i>
Indicates that patients can change their mind after a decision has been made	<i>"By the time you get to 15% they'd like a decision, 'cos if you want the haemodialysis that's when they'd be putting something in your arm."</i>
Provides an opportunity to defer a decision	<i>"If it is that you decide on a treatment and it wasn't particularly what you thought it would be...you can move to other forms of treatment in the future."</i>
Not observed	
Checks the patients preferred information format (visual/words/numbers)	
Checks that the patient has understood the information	
Asks for the patient's preferred level of involvement in decision-making	

4.4 DISCUSSION

It is worth noting that the observational study highlighted that staff were dealing with very wide variations in how patients interacted with the service, in particular: how interested they were in making their own treatment decisions; their ability and capacity to engage with complex information about different treatments; and if/how they used information to inform treatment decisions. Quite a number of patients appeared to find treatment decision-making quite difficult, with some patients needing to repeatedly go over the same ground without making any tangible progress in their decision-making. This makes for a challenging mix for the pre-dialysis nurses, who demonstrated a high level of rapport with the patients and great skill in helping them through a difficult decision-making process.

The observation and analysis have highlighted a number of ways in which pre-dialysis education might be adapted to encourage more patients to opt for a home therapy.

Firstly, both the outpatient appointments and the pre-dialysis home visits were observed to have fairly fixed formats and styles. These seemed geared to information-giving to patients rather than information-gathering or a more two-way exploration of patients' views and treatment options. Similarly, staff consultation styles were geared to information-giving, but may need adapting to encourage shared decision-making, by incorporating a more exploratory, active-listening style of consultation. The pre-dialysis home visits in particular were long enough to allow nurses to use more of the exploratory, shared decision-making behaviours suggested by the OPTION scale.

Secondly, there appeared to be a strong reliance on written and verbal information, which may not suit the learning styles of all patients. There is scope to widen the range of information formats and to gear the selected format to each patient's preferred learning styles. This would require staff to ask a few questions about preferred learning styles.

Thirdly, the information-giving approach to pre-dialysis clearly worked well for some patients, possibly those who are already interested in home therapies, but it may be less effective at encouraging others who have less initial interest. Information can go some way to allaying patients' fears and uncertainties about treatment, but discussion about feelings and emotions may also be needed to encourage more reticent or reluctant patients to consider home therapies and overcome fears.

Fourthly, the dominant information-giving style means that clinicians are missing out on opportunities to learn from patients about why and how they make their treatment choices. This is valuable intelligence which should ideally be sought to help shape services in the future.

Recommendations arising from this study are incorporated into overall study recommendations in section 5.

4.5 LIMITATIONS OF THE STUDY

In considering the results, a number of limitations should be borne in mind. Firstly, the most significant limitation is that the study took place in one site only and the findings are therefore not generalisable. In the absence of comparison across multiple sites, it is not possible to know whether this site was typical or unusual in how it was approaching pre-dialysis education.

Secondly, it was only possible to include a small number of home visits due to the relatively small number of visits scheduled during the data collection period, and there was an imbalance with six of the seven visits being first visits. Ideally, a larger number of home visits with an equal split between first and second visits would have been included. The skew towards first home visits could mean that some of the issues identified through the observation would be different in the light of data from more second visits.

Thirdly, it is difficult to establish whether the presence of an observer during consultations affected the interaction between patients and staff. Although every effort was made to be unobtrusive and remain in the background, there were a few occasions when either a patient or a member of staff interacted with the observer, thereby changing the otherwise naturalistic design.

5. DISCUSSION AND RECOMMENDATIONS

This chapter draws together the findings from the two studies. Key themes are identified and discussed in relation to the original aims of the research and the literature.

5.1 THE DIALYSIS PATHWAY

Pre-dialysis was the part of the pathway which varied the most across the four sites. It was also the part of the pathway which attracted most comments from both staff and patients. There appeared to be differences in the perspectives of staff and patients. Staff tended to focus their comments on patient choice of treatment, highlighting a range of philosophical and practical issues related to choice. They were also concerned about how best to support patients in making their treatment choice. In contrast, many patients described the months running up to starting dialysis as a time of huge emotional and psychological upheaval in which they had to face up to the implications of going onto dialysis, and what this might mean for everyday life. Within this context, although choice of treatment was important, for many patients it appeared to be dwarfed somewhat by the overall impact of this transition to end-stage renal failure. This issue is covered in more detail in section 5.4.

Overall, staff were very aware that pre-dialysis was probably the most significant part of the pathway for influencing home therapy uptake rates. It was also seen as the most challenging part of the pathway where practice was not static and new approaches were still being developed both nationally and locally.

In contrast to pre-dialysis, the training and on-going support parts of the pathway for home therapies were seen by both patients and staff as well established and working very well. Although minor improvements to training were suggested, the feedback from patients was overwhelmingly positive, and there was no evidence that patients felt unprepared for going home. On-going support was also viewed favourably by patients, particularly the support provided by renal teams. However, two wider issues impacted negatively on a minority of patients. Although these issues were not particularly related to home therapies, they are highlighted here because they caused these patients considerable frustration and wasted time. Firstly, patients found themselves bounced back and forth between hospitals and GP practices, often over medication and the treatment of ailments unrelated to their renal failure. Secondly, some patients found they could not access psychological support or counselling through GP practices, because they were seen as needing a specialist service, whilst this service was not available to them via any of the hospitals, unless they were seriously clinically depressed.

Recommendation

Renal services should find ways of improving the coordination of care for dialysis patients between hospitals and primary care, in order to improve prescribing procedures and clarify access to psychological support and counselling.

5.2 PATIENT BARRIERS TO HOME THERAPIES

Very small numbers of patients faced practical barriers in being able to take up a home therapy. These were patients whose housing or plumbing was unsuitable, or who lacked space, and there were good examples of staff supporting patients to overcome these practical barriers in both studies.

The main barriers which came through from both the staff and patient interviews were psychological, to do with: patient motivation; myths, misunderstandings and fears about home dialysis, including lack of support, which were not dispelled through education; specific fears related to individual treatments, such as the fear of self needling; a lack of confidence in self-care; difficulties in understanding complex information and making decisions; a reluctance to make treatment choices, preferring instead to follow clinician guidance; and distressing psychological and emotional reactions to the transition to end-stage renal failure.

This finding is similar to a number of recent studies, such as Morton et al (2011) who studied barriers to home treatment in two Australian renal units where home dialysis was encouraged and McLaughlin et al (2003) who looked at barriers to home treatment amongst in-centre haemodialysis patients in Canada. Both studies found patients were concerned about dialysing without medical supervision, and the Australian study found patients were concerned about support overnight and at weekends. The Canadian study also found that lack of understanding of home treatments and low confidence in self-care were significant barriers to home treatment. Our conclusion that most barriers were to do with psychological issues is similar to a more recent Canadian study (Zhang et al, 2010) which concluded that a range of psychosocial factors were of equal importance in determining patient preferences to clinical or treatment factors.

A wider perspective on barriers is included in section 5.7 in the discussion of success factors for increasing the uptake of home therapies. This includes how care is organised, how individual staff and teams influence outcomes and wider organisational and system issues.

Recommendation

Psychological barriers Hospitals could benefit from working more closely with psychological services to draw on a range of skills and techniques which could be used to help overcome some of the psychological barriers to home therapies. Some of these approaches could be incorporated into pre-dialysis education, given its crucial role in supporting patients to actively consider home therapies (see next section).

5.3 PRE-DIALYSIS EDUCATION

As noted earlier, pre-dialysis was the one part of the dialysis pathway which staff and patients commented on the most. This included pre-dialysis education where practice was still evolving. Patient interview data from study 1 and the observations from study 2 suggest that pre-dialysis was not working optimally and could improve in a number of ways. Table 5.1 summarises the main findings from the two studies. It is important to remember that some of these points were made by a relatively small number of patients, but they were points which were mostly raised across all four sites.

Teaching and learning methods

Both studies found that many patients appeared to find the choice of dialysis treatment very difficult. The reasons for this are probably quite complex, but feedback from patients does suggest that there are some fairly simple changes to teaching and learning methods and the use of information which could help more patients to engage with the process. The strong reliance on verbal and written information clearly did not suit some patients, who were keen to use more active learning methods, such as talking to other patients, seeing treatments in progress and handling dialysis equipment.

There is a very large literature on teaching and learning styles which is somewhat contentious in terms of whether it affects outcomes or not. However, there is a reasonable consensus that teaching methods and materials should be selected to cater for a range of learning styles, as this improves learner satisfaction. Appendix 7.4 provides some suggestions about how pre-dialysis education could be adapted to cater for patients' different learning styles. This includes ensuring that patients' preferred learning style is assessed so that the best teaching methods are used for each patient.

Interestingly, research by McLaughlin et al (2008) in Canada found that active learning, which involved problem-solving in small group sessions, was key to changing dialysis modality selection in favour of self-care (home therapies). This contrasted with more passive techniques involving learning in a multidisciplinary clinic, reading or watching audio-visual materials, which were not as effective in encouraging patients to opt for self-care.

Information about treatment options

One of the challenges for pre-dialysis education is the sheer volume and complexity of information which patients need to have in order to make a treatment choice. Patients in this study suggested that the quality of information needs to improve. This is in line with recent research suggesting that there is considerable scope for improving the written information provided to renal patients in this country (Bekker et al, 2009; Winterbottom et al, 2007).

TABLE 5.1 : SUMMARY OF FINDINGS ABOUT PRE-DIALYSIS EDUCATION

Teaching and learning methods

- more variety in learning methods was requested, to include talking to other patients, seeing patients being treated and seeing dialysis machines in operation
- some patients wanted a wider range of information materials to be used, including computer-based materials, signposting to websites and simpler information for people with learning impairments e.g. dyslexia
- study 2 found large amounts of information were routinely given to patients, without taking account of what they already knew or had said they wanted to know about
- some patients described wanting pre-dialysis education to be made more 'real' so they could apply it to their own lives, and thought this could be achieved best by having more opportunities to talk to and watch patients on different types of dialysis
- some patients suspected that health professionals were being overly positive about dialysis or home dialysis – these patients were keen to talk to other patients in order to get a more balanced view of what life is like on dialysis

Information

- some patients described having information overload and not understanding the complexity of what was presented to them
- study 2 found that one-to-one pre-dialysis sessions were information heavy, with patients being given lots of detailed information and very little time given to helping them apply it to their own lives
- treatment myths and misunderstandings were common among in-centre haemodialysis patients despite them having gone through pre-dialysis education

Choice and Decision-making

- many patients reported finding treatment choices very difficult and some who reported making choices were unclear as to how and why they had made that choice
- some patients reported not being able to make a decision because of the scary and traumatic nature of the transition to end-stage renal failure, and that they only became open to home therapies once they were established on dialysis
- study 2 found that opportunities were missed to get feedback from patients about how and why they had made their treatment choice, leaving staff unclear about how patients made decisions and how the pre-dialysis pathway could improve.

Patients also described having 'information overload', a finding which is similar to non-renal studies which have tended to show how little information many patients retain. For example, research suggests that 40-80% of medical information is forgotten immediately by patients (Kessels, 2003), almost half of information is remembered incorrectly (Anderson et al, 1979) and that as more information is given, more is forgotten (McGuire, 1996).

Research also suggests that patients who are in heightened states of distress or physically ill, have a reduced capacity to absorb information. This applies to patients nearing end-stage renal failure and makes the provision of essential information about treatment options to pre-dialysis patients even more challenging.

Previous research has found that renal patients benefit from being given information over a period of time, and some research has suggested this should start at CKD stage 4 (see Morton et al's (2008) systematic review). All four hospitals had designed their pre-dialysis pathways so that patients had a number of opportunities to think about treatment choices over quite a number of months. Study 2 also highlighted that staff in site 2 had considerable strengths in providing patients with information. However, it also highlighted that pre-dialysis education in this site was very focussed on information-giving to the exclusion of much time spent helping patients apply that information to their own lives. Study 2 highlighted that staff could spend more time with patients on a two-way exploration of treatment options, which enables patients to apply information to their own circumstances and explores how emotional or psychological barriers to home therapies could be overcome. This has implications for staff skills, which were observed in this site to be very well developed for information-giving, but would need adapting to encourage a more exploratory approach with patients.

If the focus for pre-dialysis one-to-one sessions is shifted away from information-giving towards helping patients apply information about treatment options to their own lives, it would mean that detailed information about treatment options needs to be provided ahead of these sessions. This might suit some patients who would be willing and able to look at detailed information at home, whilst others might need more direct input from staff or opportunities to go over information they have been given previously. We would argue that the use of senior specialist nursing time is best used, not in providing information, but in supporting patients to use that information to make treatment decisions.

Study 1 also highlighted potential differences of view between staff and patients about the role of information in patient decision-making. It was notable that staff tended to talk about providing patients with information so that they could weigh up all the options in order to make a decision. This seemed to be a fairly rational and fact-based approach to decision-making, and one which is reflected in some of the currently available decision-aids and tools for dialysis treatment (see for example the Yorkshire Dialysis Decision Aid (Bekker, 2013), which is currently being trialled in the UK). However, this contrasted with the ways in which many patients talked about their treatment decisions. Only a handful of patients talked about weighing all the options in a similar fashion to that described by staff. Instead, most patients described thinking about their own lives and often gave one main and highly individual reason for choosing a particular treatment. This chimes with the findings of a systematic review of patient pre-dialysis decision-making in CKD patients, which found that the priorities guiding most patient decision-making were related to minimising the intrusiveness of dialysis on daily life and selecting a modality which accorded with their

values and identity (Harwood and Clark, 2012). Although information about treatments was a pre-requisite, this was insufficient for patients to make a choice.

Individualised approach to pre-dialysis education

Given the wide variation in patients' motivation and interest in making a treatment choice and the earlier discussion about the role of information, our research suggests that a much more individualised approach to pre-dialysis education is needed. This would involve using specialist staff to help patients apply information about treatment options to their own lives, using methods which suit each patient's learning style, exploring what treatments would mean in practice in patients' living circumstances, and thinking about how psychosocial barriers might be reduced. This is much more akin to counselling than education and would demand a high level of staff skill.

This is similar to the conclusions drawn in two recent systematic reviews, the most recent of which suggested that patient treatment decision-making is not primarily driven by the principle of choice, but is "very individual and contextually driven" (p. 10, Harwood and Clark, 2012). Similarly, Hutchinson and Courthold (2011) also argue for education that goes beyond the relaying of facts which patients then use to make a choice. They highlight that before patients can begin to engage in discussion about dialysis they must have reached a point of acceptance that dialysis is necessary. They argue that the role of physicians is to empathetically engage patients in contemplating this change to their life, having individualised conversations with them about what is important to them, what they value and hindrances to self-care. This is also where peer support may also have some value, in helping patients to interpret the facts about therapy options and to get a better sense of what life on dialysis is really like. In this context, it is notable that one of the most commonly suggested improvements to the service suggested by patients was to be offered chances to talk with established dialysis patients.

Some might query whether the NHS can deliver this kind of individualised approach to choice of therapy for patients with chronic kidney disease. Although it might require upfront investment in staff skill development, this is likely to be more than offset by savings because patients choose the right treatment the first time and avoid the need for additional services arising from unsuitable choices.

Patient choice

Finally, it is worth noting three findings which relate to patient choice of treatment. Firstly, study 2 found that staff rarely asked patients about their reasons for their choice of treatment, accepting their choice at face value. This meant that staff tended to miss out on useful information about patients choices which could potentially help them to improve the service. Secondly, the study found that some patients only became open to home therapies once they had started on dialysis, but that few of them had had their treatment choice reviewed. It may therefore be helpful to ensure that there are structured, periodic reviews of treatment choice within the dialysis pathway. Secondly, study 2 highlighted that many

patients with chronic kidney disease may feel unprepared for making a decision about their treatment. Up to this point, patients have not usually been engaged in making decisions, and are used to a relatively passive role during their out-patient appointments. A separate literature review undertaken on decision-making for renal replacement therapy options (Brown, 2012) highlights that the ways in which patients are used to interacting with the health service will influence how they engage with treatment decision-making. It may therefore help to prepare patients for the very significant decision about renal replacement therapy by actively engaging them in making lower level, smaller decisions about their treatment in the earlier stages of their kidney disease.

Recommendations

Teaching methods and learning materials Patient engagement in pre-dialysis education would be improved by using a wider variety of teaching materials and methods, which cater for the full range of learning styles. Staff should assess patients preferred learning styles and get feedback on the suitability of their teaching methods and materials.

Information about therapy options The amount of time spent on information giving in one-to-one pre-dialysis sessions should be reduced in order to release time for supporting patients to apply this information. This could be done for many but not all patients, by providing them with information ahead of one-to-one sessions and using appointment time to check understanding, clarify misunderstandings and fill gaps.

Individualised approach to pre-dialysis education A more individualised approach is required to support patients in applying information to their own lives and staff will need to enhance their skills so that they are confident to engage in a two-way exploration of treatment options with patients. This should include exploring the emotional impact of end-stage renal failure (in order to help reduce fears or concerns which might restrict patients' choices).

Counselling skills Pre-dialysis nursing staff should be trained in counselling skills, to support the move to a more individualised approach to pre-dialysis education, enabling them to explore issues with patients and help them apply treatment information to their own lives.

Peer support All patients should be offered opportunities to talk to patients who are already on dialysis as part of the pre-dialysis education pathway. These opportunities would also be valuable for some patients during training for PD or home haemodialysis and once patients have started dialysis.

Patients' reasons for their choice of therapy Pre-dialysis nurses should ensure they explore the reasons behind patients' choice, lack of choice or reluctance to make a choice, including possible psychological barriers to home therapy such as fears about isolation or lack of self confidence to self-care. This would also be a useful source of intelligence about how and why patients make their therapy choice, which should be used to help shape future services.

Reviews of treatment choice Patient choice of treatment should be reviewed periodically with dialysis patients, as preferences can change over time and some patients may only become more open to home therapies once they have started on dialysis. Reviews of treatment choice would ideally be undertaken at least annually and recorded in the patient's notes.

Patient decision-making Patients should be encouraged to make low level decisions about aspects of their treatment earlier on in the CKD pathway in order to help prepare them for the more complex choice of renal replacement therapy.

5.4 PATIENTS' UNMET PSYCHOLOGICAL AND EMOTIONAL NEEDS

This study found that there are considerable unmet needs amongst dialysis patients related to their emotional and psychological adjustment during the transition to dialysis and in the early months on dialysis. This was not something we set out to explore in the study, but it arose from the open-ended nature of the patient interviews. This reflects accounts in the current literature especially for renal patients experiencing mild to moderate distress (Bass et al, 1999; Weisbord et al, 2007; Schell et al, 2012). Most of the patients who talked about their reactions to the transition to end-stage renal failure described it as a traumatic and scary experience, with just over one-third of all patients describing it in these terms. Although a few patients were phlegmatic, accepting and reported adjusting quickly to their life on dialysis, this was not the usual experience. In contrast, only a handful of staff acknowledged these emotional and psychological issues for patients, and only two staff talked about how this transition can impact on patients and their ability to make treatment decisions. Although three of the four sites could refer to psychiatry, referral was only possible for the extremely distressed or seriously clinically depressed patients. Access to psychology was also quite restricted in all sites, and often only available to patients with treatment related problems, such as needle phobia or poor adherence to treatment or diet. A number of other studies have similarly found that only a minority of renal patients receive adequate support and treatment for these needs (BRS, 2002; Watnick et al, 2003; Hedayati et al, 2008).

During discussion of this issue in site feedback sessions, staff suggested that this is a well known background factor which they automatically take into account. However, if this was the case, it is likely that the issue would have been acknowledged more often during staff interviews. Some of the patients were quite critical of staff failing to engage with these issues, and felt that as patients, they might have adjusted more quickly to dialysis if there had been better support and real interest shown by staff in the wider implications of dialysis, such as the impact on family relationships, roles and feelings of self worth.

Whilst this level of unmet need is an important issue in its own right, there was also some evidence from patients that emotional and psychological distress can impact negatively on the uptake of home therapies. For some patients, high distress levels had meant that they

were unable to engage properly with pre-dialysis education. They suggested in retrospect, that they had not been able to make a considered treatment choice. Home therapies, which might at first appear daunting, had only become real options once they had been on dialysis for some months (section 3.2.1.1).

This suggestion that emotional distress can impact on patients' ability to engage with treatment decision-making, is supported by the generic literature on patient decision-making, and by studies with patients with other long-term conditions (see Brown, 2012). The literature suggests that patients' ability to absorb and think about complex treatment information is affected by the stress of their illness (Cassell et al, 2001). For renal patients, this may be exacerbated by their deteriorating health and uremic condition in the run-up to dialysis, which can also impact adversely on cognitive functioning. Research with cancer patients has found that emotional distress can affect patient understanding (Anderson et al, 2008; Ryan et al, 2005) and that difficulty in accepting diagnosis can limit people's ability to be actively involved in decision-making (Beaver et al, 2007).

There appear to be no direct studies on the impact of psychological distress on renal patients' decision-making. However, a number of recent studies do highlight patients' emotional reactions to reaching end-stage renal failure. For instance, a recent systematic review of 18 qualitative studies of decision-making and choice for renal patients (Morton et al, 2010) identified four major themes to be central to treatment choices for renal patients approaching end-stage renal failure. One of these was about patients confronting their own mortality, with some patients reported to be startled by the realisation that they could die from their disease, even though many had had chronic kidney disease for some time. A recent small-scale study in the USA (Schell et al, 2012) also found that renal patients experienced strong emotions not only on diagnosis but throughout the course of their disease, whilst an Australian study (Tong et al, 2009) found that most patients initially experienced despair and disbelief following diagnosis and described the experience as traumatic, shocking and overwhelming. The uncertainty of not knowing when they would need treatment was also reported as making patients feel even more fearful and anxious. There is also one recent study which found that high pre-dialysis stressor levels were a significant predictor of patients selecting in-centre haemodialysis, whilst home therapies were associated with lower pre-dialysis stressor levels (Harwood et al, 2012).

Overall, the findings from our study support the literature and suggest that there are large numbers of patients who would benefit from some form of psychological support during the transition to end-stage renal failure. This would be valuable in its own right for patients, as well as helping to reduce any impact on patients' ability to process information and make decisions about treatment options. Given that there are probably large numbers of patients who might benefit from getting psychological and emotional support, the most feasible interventions are probably low level interventions which can be incorporated into everyday practice and which are relatively easy and cheap to implement. Further research might be helpful here in reviewing the effectiveness of low level interventions and assessing the appropriateness of different interventions for renal patients.

One option could be for staff to regularly check on all patients' emotional well-being as a part of routine appointments, although findings from study 2 suggest that these approaches might be hard to implement. Here skilled, compassionate and highly experienced staff did not appear to engage fully with patients about feelings and emotions, even when patients expressed distress quite openly. Their observed tendency to tackle emotional issues in a practical manner through problem-solving, suggests that clinical staff need a wider range of communication skills in order to deal effectively with these issues with patients.

Recommendations

Support for all patients Hospitals could benefit from considering how to incorporate emotional and psychological support into everyday practice for patients nearing end-stage renal failure. This could include building this kind of support into pre-dialysis education as these sessions provide considerably more time for exploration of views and feelings than routine hospital appointments. An alternative would be to consider front-loading emotional and psychological support into the early pre-dialysis period, ahead of pre-dialysis education, in order to reduce any potential impact on patient decision-making .

Low level interventions Further research into the effectiveness of low level interventions with renal patients might be helpful in identifying which interventions are the most effective and easy to implement. This research could include work with patients to investigate which interventions are the most acceptable to which groups of patients.

Impact on decision-making Further research into the impact of emotional and psychological distress on renal treatment decision-making could be helpful particularly if there is a continued push to increase the uptake of home therapies. This could include finding ways of presenting home therapy options which minimise further fear and anxiety.

5.5 STAFFING ISSUES

The role of all staff

Support for the goal of increasing the uptake of home therapies was evident in all four sites from all renal staff and not surprisingly, was particularly strong amongst staff working in pre-dialysis education, PD and home haemodialysis. However, staff working on the wards and in the haemodialysis units were keen to increase their knowledge and experience of home therapies, because they were aware that they had opportunities to talk to and influence patients. This was a point that was reinforced by the patient interviews. Patients recounted examples where ward and haemodialysis unit staff could not answer patients' casual questions about home therapies, or where a somewhat negative message about home therapies was given to patients by the way their questions were answered. For a small number of patients already on dialysis, this appeared to have dampened an interest in home therapies. This finding highlights the importance of all staff being 'on message', and is

a reminder that positive work undertaken by staff involved in an initiative can be undermined inadvertently by patients' interactions with the service as a whole.

Induction and training

Given the important role that all staff can play in relation to home therapies, it is significant that none of the sites had included home therapies in their unit training plans or in the appraisals and staff development plans of all staff. At a minimum, it might be expected that all renal staff, wherever they work, would be equipped to answer patients' casual questions about home therapies and to know how and when to signpost patients to specialist home therapy staff. One site did however have a structured approach to the induction of new staff, most of whom were due to work on the wards or the haemodialysis unit, and who spent time during their induction with the PD and home haemodialysis teams.

Another aspect of this issue is that many staff stressed the importance of gaining first-hand experience of home therapies, in addition to knowing more about how home therapies work. Direct experience was seen as crucial, because this allowed staff to talk with patients in an informed way. This issue is highlighted in some of the UK literature, with Hutchinson and Courthold (2011) emphasising three linked points: that for staff to be able to talk with confidence about home therapies they require direct experience of home therapies; that visiting patients at home is an essential part of training for both medical and nursing staff; and that *all* members of staff with whom the patient comes into contact must be equally capable of talking about the benefits of home therapies. Specialist registrars (SpRs) provide an interesting example of how renal units may under-estimate the influence that the wider group of renal staff, beyond home therapy staff, can have on patients and their openness to home therapies. Without exception, the SpRs in our study expressed a positive attitude towards and interest in home therapies but said they lacked the confidence, knowledge and direct experience when it came to discussing treatment options with patients. This was despite the fact that in all four sites, SpRs were having conversations with patients about treatment options during out-patient appointments. The significance of their role in relation to home therapies appeared not to be acknowledged, particularly by their consultant colleagues, who tended to see patient treatment decisions as being the preserve of consultants and home therapy nursing staff.

SpRs pointed out that they lacked direct experience of home haemodialysis and that their only contact with PD patients was with patients having problems, who they saw out of hours on the wards. Relatively little training time was given to home therapies and this tended to be scheduled late on in their training programme. None of the four hospitals had provided any induction for new SpRs about how patient treatment choice was approached locally and how and when patients were referred for pre-dialysis counselling. Taken together, this could potentially result in SpRs having an unintended bias against home therapies, simply because they lacked the knowledge, experience and training about home therapy options.

Home therapy team structures

Another issue which emerged from the research was about how teams were structured and how this might impact on home therapy uptake. The crucial issue was whether there should be separate PD and Home haemodialysis teams or an integrated team covering both home therapies. In all four sites, staff tended to advocate for the effectiveness of their own team structure. Where there were separate teams, this allowed specialisation and a single focus on a therapy. Where there were integrated teams, staff saw this as allowing them to gain broader experience of another home therapy which could help them when caring for patients, and also provided for more flexibility in staffing the service. Whilst both team structures appeared to work well where they were found, our conclusion is that team structure appeared to matter less than an overall culture of staff being flexible so that they gained experience of both home therapies. For example, in site 4 a culture of flexible staff roles provided staff with experience outside their separate specialist teams for PD and home haemodialysis. This contrasted with site 1 where there were also separate teams, but these were seen by many staff as operating in silos. Staff rarely if ever worked outside their role and expressed a need to broaden their experience of the other home therapy.

Staff capacity

Finally, all four sites had been successful at leveraging in additional resources for home therapies so that additional home therapy staff could be recruited, in support of achieving the CQUIN target. However, only one site had a capacity plan which covered the full 5 years of the CQUIN target, and this was only for Home haemodialysis and not PD. At the time of the interviews, all the sites thought their home therapies staff capacity was about right. This is unlikely to be the case if the sites are to meet their CQUIN targets for April 2015, which would require a further 10% or greater increase in home therapies uptake, with sites needing to repeat a similar level of increases in two years as that achieved in the first three years of the target (and significantly greater in site 1).

Recommendations

The role of all staff As a minimum, all clinical renal staff should have some basic training in home therapies which includes equipping them to answer patients' casual questions about home therapies and knowing how and when to signpost patients to specialist staff.

Formalising home therapies within induction and training arrangements If hospitals want to continue to increase the uptake of home therapies, it will be important to include home therapies in formal arrangements for induction, training, staff appraisals, personal development plans and unit training plans. This will help to ensure that all staff are appropriately equipped, whatever their role.

Specialist registrars Regional training programmes should ensure that that SpRs get adequate training about home therapies early on in their training programme, along with opportunities to gain first-hand experience of both PD and home haemodialysis in the home setting. Hospitals should include home therapies in the induction programme for new spRs

on rotation, so that they understand the local approach taken to renal replacement therapy choices and pre-dialysis education.

Home therapy team structures Hospitals wanting to increase the uptake of home therapies should ensure that their team structure provides specialist home therapy staff with opportunities to gain experience of both PD and Home haemodialysis, so that they can talk credibly with patients about both types of therapy. This appears to be more important than whether there are separate PD and Home haemodialysis teams or an integrated home therapy team, and could have the added advantage of providing flexible staff capacity when there are relatively small numbers of specialist staff.

Staff capacity Further increases in home therapy staff capacity will be needed if hospitals are to achieve further increases in home therapy uptake in line with their 2015 CQUIN target, and renal units should therefore develop workforce capacity plans.

5.6 HOME THERAPIES AS AN EXAMPLE OF SERVICE CHANGE

The research design used evidence from two relevant systematic reviews and applied it to an existing model for successful health system change, in order to develop a renal-relevant framework for analysing the staff and patient interviews. This approach enabled the research to build on the evidence base, to look for issues which might otherwise have been overlooked and provided an analytical framework which set individual issues into the context of an overall model of health service change. Renal home therapies and the approaches being taken by the case study sites to increase their uptake, therefore provide an interesting example of service change.

The Ferlie and Shortell (2001) model for successful health service change proposes that sustained change requires action at each of four distinct levels: at the individual level, which in this case was patients and staff; at the team level, which in this case was the renal team; at the organisational level, which in this case was the hospital Trust; and at the level of the wider system, which in this case was regional commissioning and national policies. The study data demonstrated that actions to support an increase in the uptake of home therapies were indeed being made at all four of these levels in all four sites. At the same time, all four sites made increases in the uptake of home therapies over a two year period, sustaining increases which were above the England average change in uptake rates. These increases were extended in the third year.

Some of the research findings suggest that all four sites were still in the early stages of the service change. This is often characterized by a small number of enthusiastic and highly committed staff driving forward a service change within their own sphere of control. Staff may go above and beyond the requirements of the job to champion this change, which is often seen by staff as belonging to individual champions. This was certainly the case in three of the sites, where there were clearly identifiable champions for home therapies who

were given credit by their colleagues for driving the change. This approach compares with later stages in the cycle of change when service changes become more embedded, relying less on individual leaders and being seen by others as part of the service as a whole rather than being aligned with specific individuals. The complete absence of home therapies in staff personal development plans and appraisals, and unit training plans also suggests that the changes were not yet embedded in the four sites.

5.7 SUCCESS FACTORS FOR INCREASING THE UPTAKE OF HOME THERAPIES

Drawing together the findings from the two studies, this section discusses which factors appear to have been most significant for increasing the uptake of home therapies. A research design with multiple case studies is helpful with this, particularly if there are significant variations in performance between sites, notable differences in service delivery or different approaches to managing service change. Unfortunately, this was not the case in this study, as three of the four sites achieved similar increases in the uptake of home therapies during the study period. Although the four sites were also not markedly different in how they had approached increasing the uptake of home therapies, there were sufficient differences between them to merit a discussion of factors likely to have had some influence on home therapy uptake. Study 1 also generated data from both staff and patients about factors which they thought were important in influencing the uptake of home therapies, but which none of the four sites had yet put into place - gaps which are potentially useful pointers about changes which sites might need to make if they wish to see further increases in the uptake of home therapies. However, this is less good evidence, as it simply reports opinions about what might be useful, rather than what has been tried.

Success factors found in some but not all sites

Peer support for pre-dialysis patients was seen by both staff and patients as a valuable way of encouraging patients to consider home therapies, and was the most frequent suggestion for improvement from patients. Although all sites provided some peer support, it was rather limited except in site 1, which was the only site to have an established programme with sufficient capacity to offer peer support to all patients interested in home haemodialysis. Routine access to peer support for patients interested in either PD or home haemodialysis would improve patient experience and could encourage some patients to opt for a home therapy, particularly those patients who reported wanting treatment options to be made more 'real' for them.

Initiatives designed to widen access to home haemodialysis had been used successfully in just one site, but with notable results, with a considerable proportion of current home haemodialysis patients being patients who had previously been on in-centre haemodialysis or solo dialysers and/or users of the NxStage machine. There was also evidence from just

one site that self-care can be an important stepping stone to home therapy for some patients, and that staff in these units can play an important role in talking to patients about all types of treatment. Interestingly, lengthy travel distances and times to the limited number of in-centre haemodialysis units appeared to have been a significant deciding factor for some patients in this site in opting for a home therapy. This suggests that a further expansion of in-centre haemodialysis units would not be advisable, and that more patients would take up home therapies if in-centre haemodialysis was made somewhat less accessible. This latter option is likely to be politically difficult given the current climate of patient choice. It could also impact negatively, and possibly unfairly, on those patients for whom in-centre haemodialysis is the only clinically appropriate option. Despite these points, it is worth bearing in mind that travel distance and ease of travel appear to operate as significant incentives or disincentives for patients when making decisions about dialysis treatment options.

The patient choice model was discussed at length in staff interviews and staff in each site tended to attach a lot of importance to the model being used locally. However, the research found that there were various choice models being used and no one model stood out as being more effective than the others. What seemed to be more important was that all staff were clear about the choice model and were using it consistently.

Although team structure was a concern for staff, particularly whether there were separate or integrated teams for PD and home haemodialysis, this appeared to be less important than whether staff could gain experience of both types of home therapy (in order to then be able to talk credibly with patients about home therapies). Several sites thought it was important that all staff in the wider renal service had direct experience of and a working knowledge of home therapies which enabled them to answer patients' informal questions. However, there was only one site that achieved this, with ward and in-centre haemodialysis staff demonstrating a strong understanding of and commitment to home therapies.

At the organisational level, three of the four sites had visible support from Trust senior management, outside of the renal service, and alignment between the home therapies goal and the Trust's strategy. Although this was not present in one site, it did not seem to have constrained progress, as this site had achieved the greatest increase in the uptake of home therapies during the study period. This suggests that organisational support can help but that it may not be a necessary condition for increasing the uptake of home therapies.

Gaps

The research identified a number of gaps in the service, which are discussed in detail elsewhere in the report. These were gaps which were identified from staff and/or patient interviews and from the observational study. Providing routine emotional and psychological support to distressed patients as they go through the transition to end-stage renal failure has already been discussed in detail, and has the potential to open up home therapies to some patients who might otherwise be too distressed to consider these treatment options. The fact that some patients reported only becoming open to home therapies once they

were established on dialysis, suggests that on-going education would be helpful. It also suggests that a more formalised system of reviewing patient choices of treatment for established patients could pick up some patients who could be supported to switch to home therapies. Many patients noted that publicity materials about home therapies could be improved and that they are not available in all clinical areas.

For staff, the study identified that the wider group of renal staff had not had basic training about home therapies in order to equip them to answer patients' casual questions. Home therapies also did not feature in unit training plans or personal development plans. Equipping Specialist Registrars to talk with patients about home therapies was highlighted as a gap, as was the need for pre-dialysis nurses to develop counselling skills.

There were no sites which were routinely analysing patient outcomes separately for their home therapy patients and feeding this back to staff. Some staff thought this would be helpful and would also contribute to improving the profile of home therapies amongst staff, and ensuring all staff knew about their effectiveness.

A number of the gaps identified above are worth addressing in their own right, but they are also significant as markers of the degree to which home therapies had become embedded in the culture of service, or whether home therapies were still seen as the preserve of specialist staff. The findings suggest that all of the sites had some way to go in embedding home therapies into the culture of the whole renal service.

Can home therapy uptake continue to increase?

Finally, it is worth discussing whether the four sites in this study might be able to increase the uptake of home therapies, beyond the levels achieved in 2012. Table 3.10 suggests that there is scope for all four sites to adopt actions and strategies which were being used successfully in some of the other sites. It could be argued that if all four sites adopted all these actions and strategies, this would lead to a further increase in the uptake of home therapies. However, as the proportion of patients on a home therapy increases, it may become more difficult to increase uptake rates amongst patients who have less initial interest in, or who face significant barriers to doing a home therapy.

With this in mind, we suggest that the greatest impact on uptake rates would be achieved through a four-pronged approach: firstly, scaling up initiatives designed to widen access to home therapies which are currently being taken up by very small numbers of patients, e.g. assisted PD, lone home haemodialysis and use of the NxStage machine; secondly, improving the quality of pre-dialysis education so that it is much more individualised, and developing it into pre-dialysis counselling, as this has the potential to impact on the greatest number of new dialysis patients; thirdly, improving training arrangements so that all renal staff have basic training about home therapies, with home therapies included in staff induction programmes and SpRs getting direct experience of home therapies alongside training timetabled much earlier in their training programmes; and lastly, offering psychological and emotional support to all CKD stage 5 patients as they approach end-stage renal failure and

in the early months on dialysis, as this would help to reduce one of the more significant barriers to home therapies identified in this study.

Recommendations:

Culture and ethos of renal services

Renal services should increase the attention they pay to how the culture of the service may encourage or discourage patients to consider home therapies. Relatively easy actions include; ensuring there is good quality visible publicity about home therapies in all clinical areas; providing basic training to all staff, including staff in the in-centre haemodialysis units and the wards, and ensuring all staff are equipped to answer patients' ad hoc questions about treatment options.

In-centre haemodialysis units

The contribution that in-centre haemodialysis units can make to increasing the uptake of home therapies needs to be recognised and resourced. This includes: routine provision of self-care opportunities, as a stepping stone to going home for some patients; continuing to educate patients about treatment options and reviewing patients' choice of treatment periodically; and ensuring that staff are trained in home therapies so that they convey positive attitudes to patients and are able to answer their questions about home therapies. There should be no further expansion of satellite units, and Trusts might want to consider reducing capacity in the medium-term in order to encourage home therapy uptake.

Continuing to increase the uptake of home therapies

For renal services wanting to increase the uptake of home therapies beyond the levels achieved by the study sites, this study suggests that the greatest impact is likely to be achieved by using a four-pronged approach: scaling up initiatives which widen access; improving the quality of pre-dialysis education and developing it into pre-dialysis counselling; ensuring all renal staff have some basic training and induction about home therapies, with direct experience and improved training for SpRs; and providing emotional and psychological support to pre-dialysis and established dialysis patients.

5.7 IMPLICATIONS FOR SPECIALIST COMMISSIONERS AND LOCAL EDUCATION AND TRAINING BOARDS/COUNCILS

Finally, although most of this report has focussed on issues of relevance to renal service providers, it is worth reflecting on the issues it raises for specialised services commissioning and the commissioning of training by Local Education and Training Boards (LETBs) and Councils (LET-Cs).

For specialised services commissioners who want to support providers to increase the uptake of home therapies, there are five main implications. Firstly, commissioners should incorporate into future service specifications, the provision of low level emotional and psychological support for all patients as they make the transition to dialysis and in the early months on dialysis. Secondly, a specification for pre-dialysis education should be developed which sets standards and draws on the best and most up to date evidence about effective patient education, and supports a move to more individualised counselling. Thirdly, commissioners should consider requiring Trusts to report separately on the clinical and quality of life outcomes achieved by patients on home therapies, in order to help build the evidence base for the effectiveness of home therapies. Fourthly, further work should be undertaken in each local area to develop an integrated specification for CKD stage 5 services, which addresses the lack of coordination between hospitals and GP practices, particularly over medication and access to counselling. Lastly, commissioners should note that this study found positive evidence that CQUIN targets provide an incentive for accelerated change, in terms of home therapy uptake. However, it should also be noted that the way in which a CQUIN target is introduced is very important, and will benefit from negotiation with staff about the detail and timing of the target and any sub-targets.

For LETBs and LET-Cs, there are two main implications. Firstly, training programmes for SpRs need to include significant content about home therapies early on in the programme, and they should ensure trainees gain direct experience of patients being treated at home (PD and home haemodialysis). Secondly, specialist training should be made available to staff involved in pre-dialysis education to support a move to individualised pre-dialysis counselling, with staff being trained in counselling skills.

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APPENDIX 7.1 : RESEARCH ETHICS AND GOVERNANCE

This Appendix provides details of the ethics and research governance processes and how sites, staff and patients were selected.

Ethics and research governance An outline research protocol was submitted to NRES in May 2011, and was judged to be an evaluation not requiring NRES ethical approval. The detailed research protocol was discussed with renal clinical leads and research staff at the four Trusts. The University of Birmingham gave ethical approval to the detailed research protocol in July 2011, with minor amendments approved in August 2011.

The approved research protocol was then submitted to each Trust's R&D office, along with supporting documentation (NRES exemption; University of Birmingham ethical approval; Patient and Staff Information sheets and confidentiality forms). The following checks were undertaken by the Trusts' R&D offices and approval documents issued prior to data collection starting:

	Site 1	Site 2	Site 3	Site 4
Checks on research team				
Enhanced CRB certificates	√	√	√	√
Curriculum Vitae			√	√
Documents issued by Trusts				
Letter of no objection	√		√	√
Letters of Access		√	√	√
Trust honorary contracts for research team		√		

Site 1 also required a confidentiality agreement for researchers who observed a number of out-patient clinics as part of planning the research.

Data storage and confidentiality

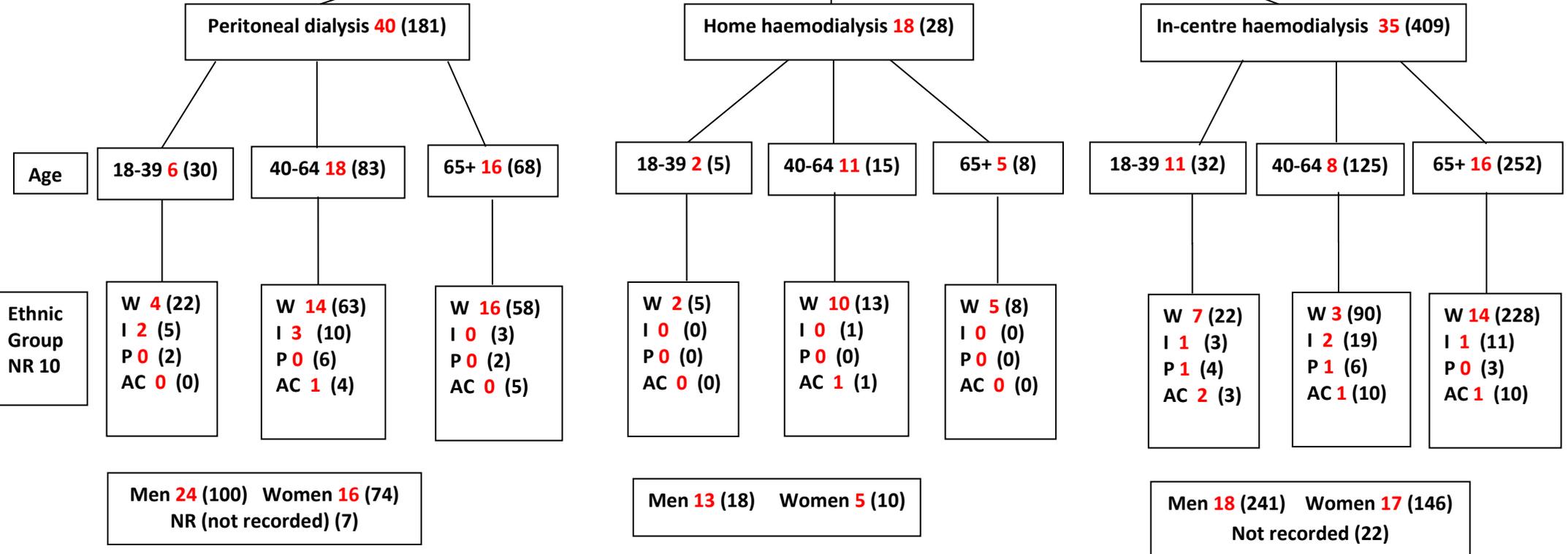
The proposed arrangements for contacting, recruiting and interviewing patients, and the storage of confidential data, were reviewed by each Trust. Site 2 required these arrangements to be formally approved by the Trust's Information Governance Manager. These arrangements were signed off in the other three sites by the renal consultant clinical leads.

Staff and patient names and contact details, interview transcripts and analysis spread sheets were stored on a secure folder on the University IT system, which could only be accessed by the research team.

APPENDIX 7.2 : SAMPLING OF PATIENTS FOR INTERVIEW

ELIGIBLE PATIENTS
 Patients aged 18 and over who have started their current dialysis treatment within the last 24 months n=618.
Interviewees n=93 (shown in red)
 (Eligible patients shown in brackets in boxes below)

Key to ethnic groups
 W – White
 I – Indian
 P – Pakistani
 AC – African-Caribbean
 A – African
 NR – not recorded



APPENDIX 7.3 : DIALYSIS PATIENTS BY TYPE OF TREATMENT

TREATMENT TYPE			2009	2010	2011	2012	% point change 2009 - 2012
Peritoneal dialysis (PD)	Site 1	N	159	153	167	155	-0.8%
	Site 2	N	72	73	82	83	+2.7%
	Site 3	N	51	72	71	88	+8.3%
	Site 4	N	29	22	35	40	+3.7%
	W. Midlands	N	482	586	544	n/a	
	Rest of England	N	2871	2802	2739	n/a	
Home haemodialysis (HHD)	Site 1	N	20	29	47	54	+3%
	Site 2	N	6	16	15	26	+5.3%
	Site 3	N	3	5	10	12	+2.2%
	Site 4	N	3	6	10	16	+5.3%
	W. Midlands	N	52	77	123	n/a	
	E. of England	N	23	38	52	n/a	
	Rest of England	N	465	538	624	n/a	
In-centre dialysis	Site 1	N	845	829	847	876	-1.8%
	Site 2	N	295	279	303	255	-11.5%
	Site 3	N	297	310	297	277	-12.6%
	Site 4	N	192	217	177	169	-15.6%
	W. Midlands	N	2544	2556	2537	n/a	
	Rest of England	N	15130	15496	16087	n/a	
Total dialysis patients	Site 1	N	1024	1011	1061	1085	
	Site 2	N	373	368	400	377	
	Site 3	N	351	387	378	386	
	Site 4	N	224	223	222	241	
	W. Midlands	N	3078	3120	3204	n/a	
	E. of England		1635	1643	1688	n/a	
	Rest of England	N	18466	18858	18466	n/a	
Home therapies (PD & HHD)	Site 1	N	179	182	214	209	
		%	17.5	18	20.2	19.3	+1.8%
	Site 2	N	78	89	97	109	
		%	20.9	24.2	24.3	28.9	+8%
	Site 3	N	54	77	81	100	
		%	15.4	19.9	21.4	25.9	+10.5%
	Site 4	N	32	28	45	56	
		%	14.3	12.6	20.3	23.2	+8.9%
	W. Midlands	N	534	586	667	n/a	
		%	17.3	18.8	20.8	n/a	
	Rest of England	N	3291	3340	3363	n/a	
		%	17.8	17.7	18.2	n/a	

% - home therapies as a % of total dialysis patients. N/a – data not available.

Data sources

Renal Registry reports for 2009, 2010 and 2011.

2012 data for sites 1-4 – Data reported by sites to the research team, as submitted to the Renal Registry for December 31st 2012.

APPENDIX 7.4 : OVERVIEW OF ADULT LEARNING STYLES

There is a considerable body of research into adult learning styles, some of it quite contentious. Much of the research suggests that eliciting learning styles and using methods appropriate to that style will improve the learner's satisfaction but may not influence the learning outcome. This appendix draws on the research and attempts to apply it to pre-dialysis education.

Learning styles

The most frequently used system to classify learning styles, is the VAKT method, which is tried and tested in healthcare and has been used successfully by nurses. It describes the preferred learning style of a person, based on their dominant use of three senses:

1) **Visual** – these people prefer to learn by **seeing** and **reading**

Visual learners like to see what they are learning, in words, colours and pictures. You can spot visual learners by their use of phrases such as “the way I see it is...I can't quite picture it... I never forget a face...”. The teacher needs to create a mental picture and provide written instructions. Books or written material on the internet are often the preferred method of learning.

In this group of people, some will have a preference for the written word, whilst others will prefer pictures, diagrams, graphs or videos.

2) **Auditory**- these people prefer to learn by **listening** and **speaking**

Auditory learners prefer to have someone talk them through a process, rather than reading about it first. You can spot them by their use of phrases such as “I hear what you're saying...that rings a bell...that sounds about right...”. The teacher needs to provide verbal instructions which can usually be absorbed while the person is doing a task.

3) **Kinesthetic or tactile**- these people like to learn through **touch** and **movement**

Kinesthetic learners learn by doing. You can spot them by their use of phrases such as “that feels right to me... I have a good feeling about.....I follow your drift...”. They are also often fidgety and have trouble sitting still and listening; they often have pastimes which are active, such as sport, gardening and DIY. The teacher needs to provide hands-on practical tasks, activities such as drawing, manipulating models, or written activities.

There are also examples where these categories have been added to – the commonest is to find out if people prefer to learn alone or in groups. This may be relevant to pre-dialysis education as some patients may prefer to learn in a group setting because they learn best by interacting with others.

Tools for identifying learning styles

There are many tools for identify learning styles. Most are lengthy and could be cumbersome to use and are therefore not particularly suitable for clinical settings. Some of the nursing literature suggests using one or two simple questions:

- What's the first thing you tend to do when you need to learn something new? (prompts could be: read about it in a book or on the internet; talk to someone; teach myself on the job or using a manual)
- What was the last thing you had to learn, and how did you do it?

For pre-dialysis patients, one of these questions could be adapted for inclusion in the self-care record. It is important to note that the research suggests people are not very reliable at identifying their own learning style, which means that it could be best to ask the second question (the last time you had to learn...). Patients could be asked for feedback at the end of their first pre-dialysis session about which methods they found most useful, and this could then be used to help select appropriate methods for future sessions.

Recommendations for adapting educational methods

There is also considerable research into adapting educational methods to take account of different learning styles. A pragmatic approach for pre-dialysis education would be as follows:

- Use strategies that incorporate *all* styles within the same teaching session/topic.
- Create written documents with both words and pictures . . . read aloud/discuss them with auditory learners, allow them to repeat back as they are read.
- Provide highlighters when using written documents so that the kinaesthetic learners can "do something" as they read.
- Have actual equipment, models etc. as part of instruction while talking at the same time and provide supplemental written instructions.
- Provide paper and pencil, white board, chalk board for learners to use to write and/or draw relevant facts as they are presented.
- Allow and encourage movement while teaching. Allow hands on with models and equipment as written documents are reviewed, instructions given.

Adapted from: You teach but does your patient really learn? (McNeill, 2013).