

Final Report for Closing the Gap through Changing Relationships (award holders)

Programme Title: Yorkshire and the Humber Sharing Haemodialysis Care (SHC)

Lead Organisation: Sheffield Teaching Hospitals NHS Foundation Trust

Partner organisations:

Bradford Teaching Hospitals NHS Foundation Trust
Doncaster NHS Trust
Hull/Fresenius
Leeds NHS Trust
York Teaching Hospital NHS Foundation Trust

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Abstract

This report describes the rationale, planning and implementation of the Shared Haemodialysis Care (SHC) Programme in Yorkshire and the Humber. It was funded in 2010 by the Health Foundation as part of its “Closing the Gap through Changing Relationships” Programme and was led by a multidisciplinary team of professionals and patient partners.

The number of patients requiring renal replacement therapy has grown steadily over many years, placing increasing demand on renal centres across the NHS. Alongside limited physical capacity for the provision of dialysis, the introduction of a Payment by Results tariff has also placed a limit on the “income” available to Trusts with which to provide this life-saving treatment. With growing organisational pressures for efficiency, the quality of care provided to many dialysis patients had been felt to have diminished as a result. A culture of “faster throughput” of patients, with little, if any, opportunity for patients to be involved in their own care, was clearly emerging.

The objective was to deliver a cultural change in centre-based haemodialysis across the 6 main and 19 satellite dialysis centres in the region. The cultural change that we hoped for was to give dialysis patients the opportunity and necessary support to become active partners in their own care. In order to do this we developed a bespoke course for nursing staff providing training necessary to equip them to support patients in this way. We understood during the course of the Programme the domains of health that were impacted on by this initiative – prominent among these were patient centredness, effectiveness of the healthcare interaction, equity of access to care and patient safety.

Written materials were prepared and published including a competency handbook and leaflets for patients, as well as a nursing journal to be used on the course. Measures of activity and engagement were explored through several iterations and have been used to prepare run charts from participating units and have been combined into a census. Qualitative work has evaluated patient and staff experience and provided important information regarding drivers and barriers. We have disseminated the learning through regular meetings across our region and contributions to national meetings. We have written articles for journals, regular newsletters, participated in webEx presentations and learning events are planned.

Not everything has gone to plan. We were over ambitious regarding the numerical change we could achieve in terms of the number of patients undertaking tasks relating to their dialysis, and under ambitious regarding the impact on patients' experience that this change would have. We have not been able to conduct a health economic evaluation, and we would like to see much more robust evidence of hard outcome benefits for patients. We have concerns regarding sustainability, despite the efforts that we have made at several levels to ensure a lasting legacy from this Programme.

Ultimately, we were inspired by the enthusiasm and commitment of our team members including patient partners and nursing staff from across our region. Through this work we glimpsed the possibility of true partnership between patients and healthcare teams in the management of long-term kidney care.

1. Introduction

1.1 Background Knowledge

1.1.1 The nature, severity and significance of the health issue / specific problem / system challenge to be addressed

In July 2010, the situation in most renal haemodialysis units, both nationally and regionally, was that the hospital or satellite dialysis patient was a passive recipient of treatment. In general they lacked knowledge and understanding of their treatment and there was little incentive to change the situation. After arriving for haemodialysis, commonly for a scheduled time, they were called through to the machine by the nursing staff. The patient weighed themselves or was weighed, had their blood pressure measured and sat in the dialysis chair or lay on a bed. The nurse caring for the patient

recorded the observations, and set the proposed dialysis prescription on the machine, opened the sterile pack, prepared the patient, primed and inserted the patient's dialysis needles, or connected the dialysis line and dialysis commenced. During dialysis the nurse carried out hourly observations, recorded and adjusted the treatment. When the therapy was completed the nurse took the patient off dialysis, and recorded the blood pressure and weight, entered data relating to the dialysis session into the patient database. The opportunity of the patient healthcare interaction to educate the patient on aspects of their medical problem and care was missed.

1.1.2 The evidence of best practice and / or innovation

The Department of Health document "Improving the health and well-being of people with long-term conditions" (2010) places the choice of and support for self-care centrally in the planning process. This builds on previous documents (including The Expert Patient) demonstrating that user-led self-management programmes have real value, since they can help people with long-term medical conditions to take responsibility for their own lives. The importance of partnership between professionals and patients is emphasised and that to achieve this, self-management should form part of training for healthcare professionals.

Adult education techniques in self-care have led to benefits in several chronic diseases. For example the Dose Adjustment For Normal Eating training course (DAFNE), providing one-off exposure to structured education in intensive insulin therapy in Type 1 diabetes resulted in long-term (4 year) benefits in patients related quality of life and glucose control (DAFNE study group *BMJ*. 2002 Oct 5;325(7367):746 and Speight J et al *Diabetes Res Clin Pract*. 2010 Jul;89(1):22-9).

Renal dialysis has traditionally been an area where patients have had access to self-care, with home dialysis (both peritoneal and haemodialysis) having been important in the UK, but having declined over recent years for complex reasons. It is clearly possible for patients to take an active role in their treatment, with evidence that patients who are better informed are better able to manage important outcomes (Smith K et al *J Ren Nutr* 2009 Nov 11). Significantly, patient quality of life is enhanced where there is greater achievement of quality indicators among patients on dialysis (Lacson E et al *Am J Kidney Dis*. 2009 Dec;54(6):993-5). The option of self-care on the dialysis unit potentially provides many of the advantages of home dialysis while being accessible to a wider range of individuals. It is, however, not commonly practised in the UK.

Guys and St Thomas's initiated a Programme to promote self-care on their dialysis units in 2003 (www.gsttcharity.org.uk/grants/results_mikidney.html) and presented their results as a poster in 2007. They found that almost 10% of patients had become completely self-caring, a further 50% were self-caring to some degree, and that patient choice in terms of treatment options had increased. Furthermore, unit capacity had increased, the culture had moved from dependence to independence, patients' reported higher levels of satisfaction and staff reported higher levels of treatment concordance.

1.1.3 The evidence of patients' views

The challenges and opportunities presented by self-care dialysis were explored at two meetings across the region, firstly the NHS Kidney Care "Improving Choice for Kidney

Patients' event in Leeds on 4 May 2010, the Yorkshire and the Humber Home Therapies and Self Care Forum held in Sheffield on 29 June 2010 and attended by 50 individuals including patients and their carers. Barriers to self-care dialysis were discussed in one of the breakout groups at this forum with the opinions of patients, carers and healthcare team members carefully documented for incorporation in the Programme design.

Detailed discussions were also held with the Kidney Patient Associations in Sheffield and York and there was email correspondence with patients from across the region. Meetings were held with collaborative partners to review the concept, design and outcome measures contained in the Programme.

Finally, the patient partners involved in the original application confirmed the benefits that they personally experienced from becoming more involved in their own care, and that they would not wish to return to the previous passive role. This point in particular supported the notion that once patients have become active partners in their care they will not wish to give up the level of independence that they achieve.

1.1.4 Gaps in the quality of care (clinical / patient experience)

As only a small proportion of patients undertake haemodialysis at home, with the documented benefit which that brings, there is a gap in the quality of care for those who are unable or would prefer not to dialyse at home.

Patients taking control of their own treatment will be able to perform it more consistently and patients who become better informed about their own medical conditions and involved in their own care are likely to have better outcomes. For example, better understanding around the use of phosphate binding medications will enhance concordance, leading to a slowing of the progression of vascular disease; better fluid control reduces the likelihood of the development of cardiac failure or the risk of sudden cardiac death.

1.2 Local Problem and Context(s)

1.2.1 Geographic scope

The Programme was supported by the Yorkshire and the Humber Renal Network. The scope of the intervention is the 6 main Renal Units in Yorkshire and the Humber and the 20 satellite haemodialysis units.

1.2.2 Target group / population

The target patient population is the haemodialysis patients of the 26 units who wish to undertake some aspect of their own care. On the 31 October 2010 there were 1,828

patients on hospital and satellite haemodialysis in the region, this increased to 1,869 by the 31 October 2012.

1.2.3 Types of organisation / services involved (e.g. voluntary sector provider, NHS acute hospital, mental health Trust)

The organisations involved are NHS acute hospitals with renal services, some of which are contracted to independent sector providers. Haemodialysis is a specialised service which is not commissioned from all acute hospitals.

1.2.4 Significant stakeholders (e.g. patients and service users, types of staff groups, commissioners, other service providers)

The key stakeholders for the intervention are patients and haemodialysis nursing staff. These stakeholders have been supported by three nurse educators. The whole Programme has been managed by a dedicated Programme Manager.

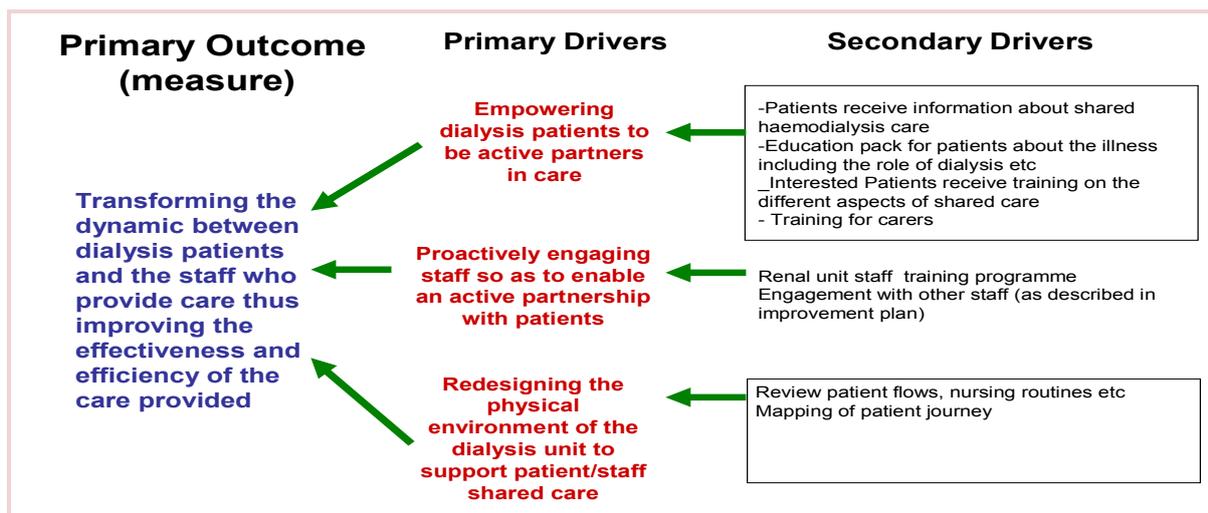
In addition, the Programme board includes the Programme Director, Programme Chair, Programme Manager, Patient Representatives, Clinical Leads from the 6 Main Renal Units, Lead Matrons, Implementation Researcher, Commissioner for Specialised Commissioning for Yorkshire and the Humber, Renal Network Manager for Yorkshire & the Humber, and Finance Lead.

1.3 Intended Improvement

1.3.1 Aims and objectives

The overarching aim was to transform the dynamic between haemodialysis patients and the nursing staff who provide care in all 26 renal dialysis units in Yorkshire and the Humber by June 2013, by changing the relationships between patients and nursing staff so that patients are active partners in their care (rather than passive recipients) and the nurses are educators and facilitators (rather than caregivers).

Aims were set for two key primary drivers (and some associated secondary drivers) which contributed to the achievement of the overarching aim.

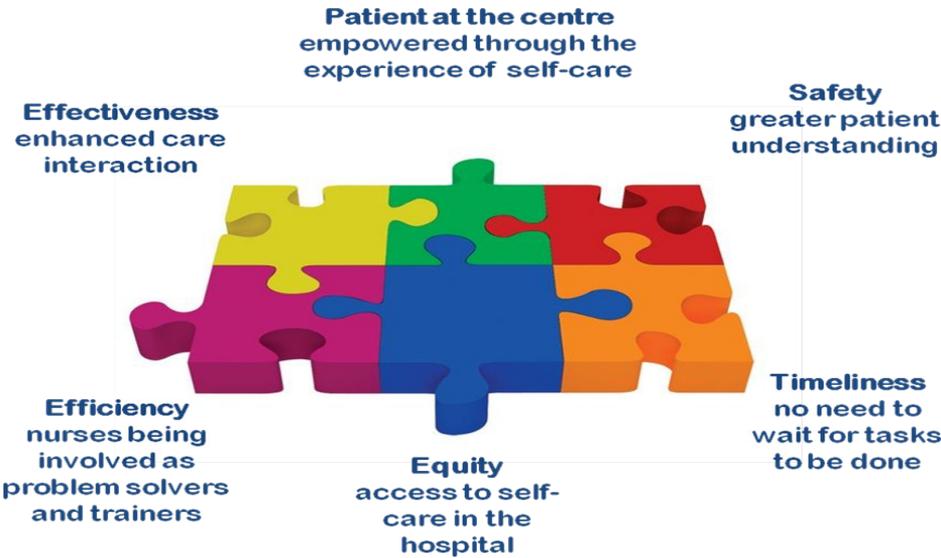


The original application identified that there would be an improvement in all of the quality domains:

Quality Domain	Description of the improvement and how it will be measured
Effectiveness	<p>The benefit of the healthcare interaction with nursing staff will be enhanced due to a cultural change to facilitation, supervision, problem solving and education.</p> <p>Patients taking control of their own treatment will be able to perform it more consistently – an important example is in the area of fistula needling, where a single operator will be taking over from multiple operators.</p> <p>Patients who become better informed about their own medical conditions and involved in their own care are likely to have better outcomes. For example, better understanding around the use of phosphate binding medications will enhance concordance, leading to a slowing of the progression of vascular disease; better fluid control reduces the likelihood of the development of cardiac failure or the risk of sudden cardiac death. For patients who feel able to move to home dialysis, the frequency of haemodialysis treatment can be increased resulting in significantly improved patient outcomes.</p> <p>These outcomes will be measured by a combination of individual interviews with patients and nursing staff to explore their perceptions about: knowledge, skills, role, beliefs about capabilities and consequences, motivation, decision processes, resources, influences, emotion and behaviour regulation, as well as measures of treatment effectiveness (volume management, control of serum markers of dialysis effectiveness, hospital admissions due to intercurrent medical problems).</p>
Efficiency	<p>There is the potential for a reduction in the nursing establishment required to support patients on dialysis. Since nursing costs are a major component of total dialysis cost, efficiency could be enhanced through increasing patient self-care. There may be trade-offs in terms</p>

	<p>of time per dialysis session since patients are likely to take longer to perform the dialysis-associated tasks than trained staff would do. However, this could be off-set against the reduction in nursing requirements. For patients who feel able to move to home dialysis, transportation requirements are reduced with both cost and ecological benefits.</p> <p>Health economic components will be evaluated by measuring alterations in staffing ratios and mix, time taken for treatment sessions, the impact that the intervention has on the number of patients that can be treated at a particular facility, as well as the impact on patient transportation. We will perform a health economic evaluation in partnership with Mr Jonathan Tosh from Sheffield School of Health Related Research (ScHARR).</p>
Person Centredness	<p>This will be defined in terms of the patient becoming empowered through the experience of learning more about their own treatment and having an enhanced sense of control over their treatment. We will evaluate the impact on patient-reported anxiety and satisfaction with treatment. Some patients will become able to opt for home dialysis, where increased treatment flexibility and the option to dialyse more frequently offers considerable advantages for patients.</p> <p>This will be evaluated using qualitative approaches detailed in effectiveness above (Dr L Glidewell).</p>
Equity	<p>This is an important domain since currently there is unequal access to home-based self-care dialysis dependent on either the suitability of patients' homes or the availability of support. Self-care dialysis at the dialysis facility will extend this option to all suitable patients. This will be assessed by evaluating the number of and demographic characteristics of patients who are able to become involved in the programme.</p>
Safety	<p>This will be enhanced through greater patient education, resulting in increased patient understanding of their own condition and its management. Patients will become more involved in the process, strengthening safety control by involving patients in safety surveillance and monitoring the development of problems during the course of their therapy. They will understand in a detailed way the needs of infection control through better education, as well as how to manage contaminated waste etc.</p> <p>This will be reviewed through active monitoring of adverse events by reporting critical incidents to the DATIX system.</p>
Timeliness	<p>Patients no longer have to wait for tasks to be done for them (machine preparation, prescription decisions, fistula needling) since they will be able to do that for themselves.</p> <p>We will monitor treatment times including waiting times for treatment.</p>

Quality Domains of Health - The Jigsaw



Quality Domains of Healthcare

The jigsaw image simply displays the domains of healthcare. The anticipated impact of our Programme on these domains is outlined in the above table. We do not have robust evidence of the impact for all of these domains. During the set-up period the team chose to focus on two domains namely, efficiency and effectiveness; however, patient centredness is intrinsic to this whole Programme and as such we commissioned an independent qualitative evaluation of the patient experience. The reason that we concentrated more on efficiency and effectiveness is that we were keen to find quantitative evidence for our intervention.

Patient Centredness

The qualitative evaluation gives evidence around patient centredness – where patients were asked what they thought about shared care. The responses showed that patients who were involved felt that they were contributing to their care; that they had choice (to do as much or as little as they wished); that they valued being educated about treatment and disease; that they felt confident and competent and that they were taking back a degree of control. On the other hand, those who had not got involved felt that they did not want to know more; they did not want to have to do everything (a misunderstanding since they would not have had to do everything); that patients would be made to dialyse at home (another misunderstanding); that it would be dangerous for them; that it was not for everyone; and that they could not insert their needles (again not necessary to participate). This work is described under section 2.1.2.5 and the findings are detailed in section 3.2.1 under heading *Outcomes achieved on changing relationships and improved quality of care – Qualitative Analysis*.

We have reported the evidence that we have been able to accumulate during the Programme – specific research studies will be required to find more robust evidence and we are working on these.

Domain 1: Effectiveness - *empowered and activated patients are likely to have better healthcare outcomes*

- We struggled to finalise our indicator(s) of effective care (considering control of serum markers, volume management, and decrease in hospital admissions due to recurrent medical problems).

Domain 2: Efficiency - *time efficiency for both nursing staff and patients - nurses will have more time to focus on other important quality issues and patients will have less “needless waiting”*

- By June 2013 we will reduce by 50% the amount of nursing time spent preparing the patient and the equipment for dialysis (this includes observations, preparation of "putting on" pack and preparation of dialysis machine).

1.4 Changes along the way

1.4.1 Health economic evaluation

When the Programme was originally designed we were keen to explore whether getting patients to do more for themselves might lead to financial savings for the healthcare system, although this was not a key “driver”. We also wanted to be able to prove that the intervention (SHC) would lead to improved hard outcome measures for patients. With these two pieces of information we hoped to be able to make an irrefutable argument for undertaking SHC.

Part of the original objective was to explore the opportunity for cost savings and to this end we commissioned health economists from the SchARR to join the Programme. Their advice was that we should develop a “time-task” instrument which we could use to measure the change in the duties performed by nursing staff as patients took on a greater role in their own care. We ran through several iterations of this instrument using the PDSA iterative approach before we finally realised that the dialysis nurses multi-tasked to such an extent that this information could only be collected by a trained observer and we did not have the resources for this. It was at that point that we had to review our priorities and decided that other parts of the Programme were going to take priority. We therefore closed down the health economic evaluation workstream. This does not mean that economic evaluations cannot be done, however this will require a separate initiative and it is important to emphasise that this would not necessarily be about generating “cost savings”, but adding value, by nurses undertaking different roles and enhancing care.

1.4.2 Focus on a smaller number of meaningful measurements

The original intention was to collect information and data using different outcome, process and balancing measures to determine the change of relationship and effectiveness of the intervention. One of the measures around empowering patients to be active partners in their care was to document how many of the 14 dialysis tasks patients

were undertaking. Having collected these data for a number of months at the pilot sites it was determined from the measures that the majority of patients were participating in at least one task, such as patients weighing themselves, but very few had achieved the original 50% of the tasks and those patients achieving all tasks were usually already on the home haemodialysis (HHD) Programme.

To provide a more stretching goal and demonstrate sufficient change from the baseline, we adjusted the measures from 50% of the tasks to 5/14 tasks. We arrived at this number because it would be relatively easy in many units to accomplish 4 of the most basic tasks. Moving up to 5 tasks would be significant and demonstrate a commitment to SHC from the patients' point of view, as opposed to doing just what is normally expected within the dialysis setting.

We also felt it was important for staff morale to demonstrate that they were making a difference to patients. Fifty per cent of the tasks was seen as too high a standard to achieve within the timescale of the Programme. We learned that it is preferable to make small but measurable changes in order to motivate both staff and patients.

1.4.3 Improvement in the quality of care – effectiveness domain measure

We adopted this measure since there is evidence that patients who put on large volumes of fluid between dialysis sessions have a worse outcome. We wanted to provide an objective measure to link SHC to better health outcomes for haemodialysis patients. We made the assumption that if patients understood more about their condition and treatment, that they would comply with restrictions to their fluid intake and diet. To measure this we collected data as part of the monthly audits which asked whether patients had kept to a standard fluid restriction of 2 litres. We then linked those that kept to their restriction to those who were doing 5 or more tasks.

Proof that this question was full of variables became clear when patients were questioned during the audit, exposing a number of flaws in the measurement.

Some of the reasons for this are:

- Patients confuse fluid weight with body weight (fat and muscle) and the discussion around the weight gains is quite complicated. Nurses were having difficulty explaining the process around this measurement and what it was for.
- The 2 litres is rather arbitrary – since it means something different for a 50 kg patient compared with a 100 kg patient.
- It is rather meaningless in patients who continue to pass urine – since they have smaller weight gains between dialysis sessions irrespective of how much they drink.
- Patients who have a better appetite tend to drink more, whereas those who do not eat much do not tend to drink much either. Therefore this measure has greater impact on younger, more active and generally healthier people.

It was therefore not considered meaningful and removed from the measurement set.

1.4.4 Improvement in the quality of care – efficiency domain measure

We initially measured the time it took patients and staff to perform dialysis tasks. We hoped to demonstrate a correlation between time saving and patient engagement as opposed to nurse-led treatment. However, as described above, this measurement was difficult to perform and we could not demonstrate a time saving. We concluded that our emphasis should be on patient experience, personal motivation and achievement in order to improve quality of care.

1.4.5 Equity domain measure

We measured how many patients had been asked whether they wished to participate in SHC. This was on the whole a successful measure highlighting those who had not been approached and providing the opportunity to target information to those who were unaware. Our number of the percentage of patients who has been asked if they would like to participate in SHC was reduced from 100% to 95% to reflect mental or physical barriers to responding. We have been able to demonstrate that the opportunity of SHC has been offered to all patients. See section 3.2.1. Education and Resources relating to SHC have been shared with pre-dialysis care providers so that the process of patient engagement is commenced at the earliest opportunity, also see section 5 on Resources to share.

1.4.6 Satisfaction measures

We struggled to develop a satisfaction tool that would be easy to use on a monthly basis and would provide an objective measure of any patients' satisfaction with SHC. Part of the reason for this was that not all patients were able or willing to participate.

We found that since patients were being cared for to an adequate standard, and that this had always been the norm for them in their dialysis unit, they were unlikely to express dissatisfaction in their dialysis care. We found that we had focused on the wrong approach, resulting in many months of data which told us that the majority of patients were satisfied with their care, but did not have any other experience to compare the care with.

Therefore we changed our satisfaction tool to one which asks if the patient would recommend SHC to another patient whether they themselves are participating or not (detailed in section 3.2.1).

Piloting of each change of audit using the PDSA iterative cycles proved very useful, particularly when communicating changes to the wider region. We were able to rationalise our changes having tested them out.

1.4.7 Patient census

We struggled to get a sense of the number of patients around the region involved in SHC – as the data from the monthly measures only provided a random sample of 20 patients.

Therefore we asked all 26 units in the region in January 2013 to collect a census on the number of patients undertaking at least 5 out of 14 tasks of their haemodialysis therapy. This also served the purpose of asking every patient what they currently did and what they would like to do in the future. This was very important since we needed to understand the impact of the Programme by firstly knowing our starting point – baseline. Results of the census are in section 3.2.1 of the report. The second census would be organised in January 2014 to establish and measure the progress made. The aim is to continue to do a census every 12 months post-Programme end.

1.4.8 Terminology

This had also been adapted at the pilot stage of the Programme. The team felt strongly that the term self-care could dissuade patients from participating in their own care and send the wrong signals. It was important to emphasise the ‘collaborative’ aspect of the intervention, highlighting that both the patient and healthcare professional are working together therefore the term “shared haemodialysis care” has been used to identify the Programme.

2. Methods

2.1 The Intervention

2.1.1 What the intervention(s) to change the relationship was (were)

The intervention had 3 key components:

Nurse Training Course

Central and unique to the Programme is a Nurse Training Course. Matrons, clinical nurse educators and a patient lead were involved in developing the course curriculum, nursing journal and a portfolio of course materials for staff targeted at all levels in the nursing hierarchy right from the Chief Nurse down to the Healthcare Assistant. The course focuses on giving dialysis nurses the skills they require to train and support patients to take a greater role in their own care. The 3-day course focuses on adult learning techniques, motivational interviewing, practical microteaching and working with patients using the educational materials.

A Purpose-Designed 14 Competency Patient Handbook

Patients are trained in a range of competencies according to their level of interest/ability and these are documented in the patient handbook. These competencies range from patients undertaking self-observations, hygiene (infection control), preparing the basic pack, lining and priming a dialysis machine to needling their arteriovenous fistula.

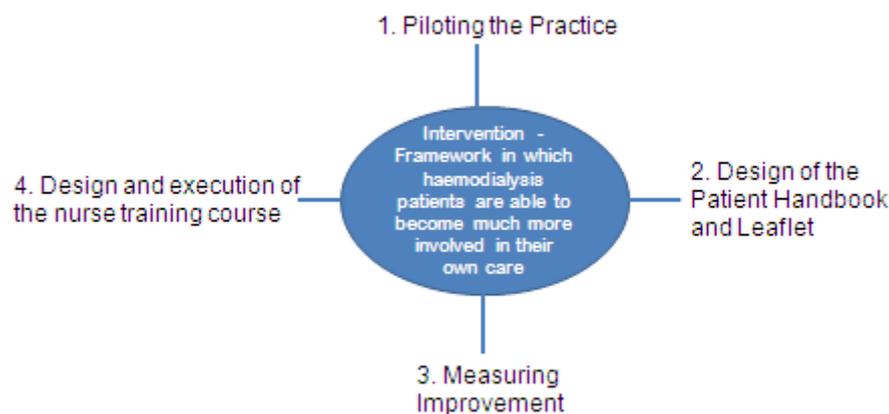
Supportive literature, including posters, leaflets and banners, were developed with our patient partners. These were made available to the participating units.

A Research Study to Identify Perceived Patient and Professional Barriers to the Uptake of SHC

We did not understand why interventions to support self-management in other conditions have variable effects or how to optimise the delivery of SHC. A study was designed to identify perceived patient and professional (nurse and healthcare assistants) barriers to the uptake of SHC and to use these data to identify intervention components to optimise care.

2.1.2 What you actually did – how was the intervention carried out

How the intervention was carried out



2.1.2.1 Piloting the Practice

A questionnaire was devised by the Matrons of the two pilot sites in York and Sheffield which was given to all dialysis patients. Patients were asked which aspects of their haemodialysis treatment they were currently undertaking and which tasks they would like to do for themselves. This information was used to group together patients interested in participating in their own dialysis care. The implementation was also piloted with this group of patients.

2.1.2.2 Design of the Patient Handbook and Leaflet

A patient handbook was designed to record patients' progress so, as patients were taught the skills of dialysis, their progress and subsequent competency were recorded within the handbook. This handbook was designed using focus groups of both patients and staff who were asked to comment on all aspects of the handbook, such as ease of understanding, usability, illustrations, font and colour schemes.

Patients and staff were also asked to contribute to the redesign of an existing patient information leaflet about taking control of their renal disease. This existing leaflet was

used for patients intending to do HHD so a separate SHC leaflet was required. The outcome of this was a leaflet designed to support the SHC philosophy and encourage patients to participate in the Programme.

2.1.2.3 Measuring improvement

It was clear for any quality improvement Programme that transparent measurement was required to show the starting position and document improvement as we went along. Therefore, monthly audit measures were carried out by the shared-care educators with sample groups of patients to assess satisfaction and progress (detailed in section 3.1).

2.1.2.4 Design and execution of the Nurse Training Course

Design: The two Matron leads from the pilot sites devised a course template which was piloted in autumn 2011. It was reviewed externally by Liz Hill-Smith (Berkshire Consultancy) and internally by the team members. Following this evaluation, various aspects of the course were refined such as duration, content, venue and teaching styles and it has subsequently gone through iterative evaluation based on delegate evaluations. As a result, we now have a bespoke course which we believe addresses the needs of delegates throughout the region where it is running recurrently, with the prospect that it can be used nationally too.

Execution: We intended that 25% of dialysis nurses (junior sisters, staff nurses and level 3 healthcare assistants) from the participating dialysis units would attend the 3-day course. Of senior nurses 100% attended a 1-day course that focused on evidence and strategic components. In addition to this we provided work-placed training for nurses on the dialysis units, cascaded by those who had attended the 3-day training course. This process was supported by educational materials, a patient handbook and a communications workstream team to develop relevant information for patients and carers.

2.1.2.5 Structured interviews with patients and professionals

We successfully interviewed a range of patients and professionals who did or did not participate in SHC. To undertake these interviews we received ethical approval to conduct them while patients were on dialysis. In order to do this we obtained the required permissions for a patient and a carer to act as interviewers.

Coding unique stories to the theoretical domains framework has allowed us to better understand the barriers to implementing SHC from a staff and patient perspective. This framework has been used in other healthcare conditions to systematically identify the factors that affect change. There are 14 different factors (e.g. knowledge, skills, beliefs about capabilities etc.) based on psychological theories that can explain why behaviour change occurs or not. Other researchers have used these factors to identify what else needs to change.



Why patients and healthcare professionals are / are not involved in SHC

2.1.3 The membership and roles of the group/team leading the work

Engagement from individual stakeholders and organisations was necessary to develop awareness, involvement and commitment to the Programme. Our Stakeholder Engagement and Communication Workstream developed a comprehensive strategy to provide key messages both externally (national level) and internally (regionally and locally) to target audiences through purpose-designed communications.

2.1.3.1 Externally to the Programme

The Health Foundation - The SHC Programme was funded for 2 years by the Health Foundation through the Closing the Gap through Changing Relationships Programme, with valuable additional advice and support through several agencies – Berkshire Consultancy, Quality Improvement Advisor and Office of Public Management. Timely progress, quarterly learning reports and visits from the Health Foundation to the unit as well as the National SHC Learning Event that we organised allowed the Programme to build a national profile and connect with other areas of the “renal world”. In addition we have showcased the Programme at a national renal event hosted by the Health Foundation – important for making connections and building relationships.

NHS Kidney Care - Connection with this organisation and the National Director for Kidney Care has enabled the Programme to receive additional funding for a SHC Nurse Educator and support for 2 National SHC Learning Events, as well as publicity through 2 e-seminars with over 50 people attending each.

The Yorkshire and the Humber Renal Strategy Group (RSG) – the Programme has been a standing agenda item on the RSG meetings and became embedded in the home therapies and self-care strategy that was developed for the region.

Externally several trusts in the region are considering the redesign of dialysis services to allow for areas where patients can be much more independent with their own treatment –

with the potential for greater flexibility in dialysis schedules. York has advanced this the most.

SHC Programme Advisory (Virtual) Board – highly influential stakeholders both nationally and regionally were updated regularly on progress of the Programme and rotationally were asked to provide “senior leader comments” on the quarterly reports submitted to the Health Foundation – this was a good way to keep them up-to-date and engaged.

2.1.3.2 Team members of the Programme

Senior Clinicians – who brought clinical expertise, authority and influence to the Programme, both from a renal medicine perspective and from their own organisational perspectives.

Senior Specialised Commissioning Lead – who brought the NHS commissioning perspective to the Programme, ensuring recognition of SHC in the new service specifications for hospital and satellite dialysis.

Senior Nurses/Nurse Educators – who brought the haemodialysis nursing expertise and perspective to the Programme, as well as their leadership, influence and commitment.

Patient Leads – were vital in bringing the patient perspective to the Programme, and help us to engage with other patients and carers, as well as contributing effectively to developing the qualitative research, the Programme materials and a communication and engagement strategy.

Qualitative Research Lead – undertaking important work in understanding the quality improvement our Programme has brought to haemodialysis patients, as well as understanding barriers.

Programme Manager – who has been actively involved across the whole of the Programme, ensuring that timelines were met, facilitating work programmes and holding the Programme together.

3. Results – Outcomes

3.1 Measuring the Outcomes of your Programme on Changing Relationships and Improved Quality of Care

3.1.1 Measures used

a. Empowering haemodialysis patients to be active partners in their care

- 10% of all haemodialysis patients in Yorkshire and the Humber will undertake all aspects of their haemodialysis care by June 2013
- 75% of all haemodialysis patients will undertake at least 5 aspects of their haemodialysis care by June 2013
- 95% of all haemodialysis patients will be asked whether they would like to participate in their SHC by June 2013

b. Proactively engaging staff so as to enable an active partnership with patients

- 100% of Matrons and Senior Sisters in Yorkshire and the Humber will have completed a purpose-designed 1-day training Programme by June 2013
- 25% of nursing renal staff in Yorkshire and the Humber will have completed a purpose-designed 3-day training Programme by June 2013
- All other nursing and support staff will go through a combination of learning on the renal unit (e-learning, group sessions and 1:1s with the trained nursing staff)

c. Improvement in the quality of care – efficiency and effectiveness domain

- 100% of fluid gain between dialysis sessions to be less than or equal to 2 litres for patients undertaking at least 5 aspects of their SHC for a 2-day interdialytic interval by June 2013
- Zero episodes in bacteraemia for patients undertaking SHC

3.1.2 Rationale for choosing the measures

a. Empowering haemodialysis patients to be active partners in their care

There are 14 aspects of a patients' dialysis treatment broken down into a set of tasks (see table below).

14 Aspects of treatment broken down into a set of tasks

- 1 Takes weight
- 2 Takes blood pressure & pulse
- 3 Takes temperature

- 4 Washes hands & arm
- 5 Lines machine
- 6 Primes machine
- 7 Prepares dressing pack ready for access
- 8 Programmes machine using prescription
- 9 Inserts one or both needles into AV Fistula/Graft or prepares tunnelled line for dialysis
- 10 Hooks up, bleeds out & commences dialysis
- 11 Has completed 'Problem Solving Competency' in SHC Handbook
- 12 Discontinues dialysis by hooking up & washing back
- 13 Presses needle sites after removal
- 14 Administers any injections via dialysis machine or subcutaneously

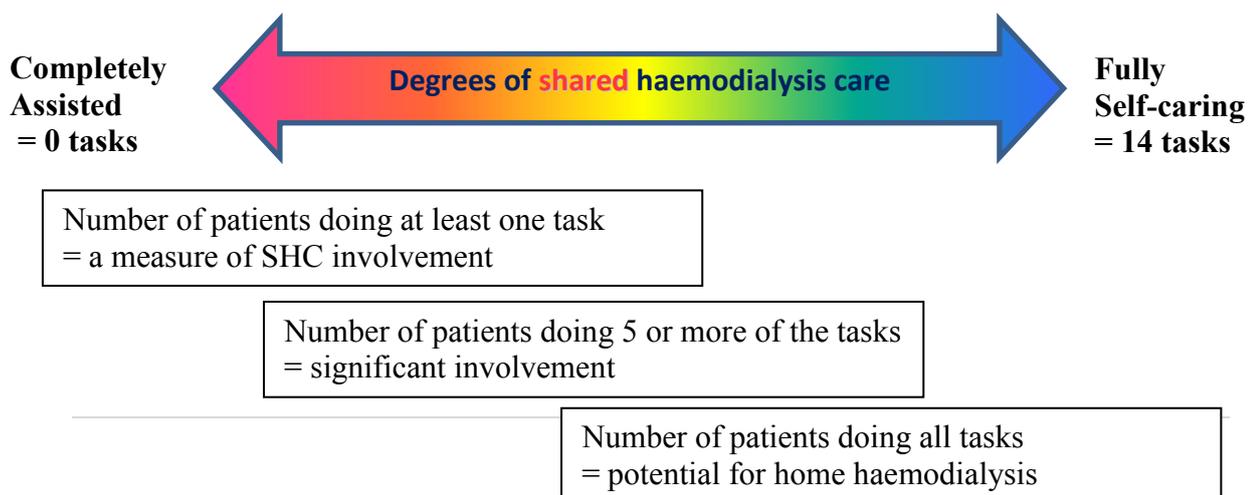
- *10% of all haemodialysis patients in Yorkshire and the Humber will undertake all aspects of their haemodialysis care by June 2013*

Based on the existing data in relation to the number of patients on home haemodialysis across the region we estimated that 10% of all patients would be undertaking 100% (all 14 aspects) of their care either at home or at in-centre.

- *75% of all haemodialysis patients will undertake at least 5 aspects of their haemodialysis care by June 2013*

We wanted to be able to measure the increase in the number of tasks that patients participated in. Prior to the start of this Programme, some patients were regularly participating in up to 4 tasks. We decided that doing 5 or more tasks would represent a significant example of patient engagement. These data were collected on a monthly basis from 20 randomly selected patients from all dialysis shifts at each unit in question as a measure of patient engagement.

The figure below illustrates the potential spectrum of patient involvement:



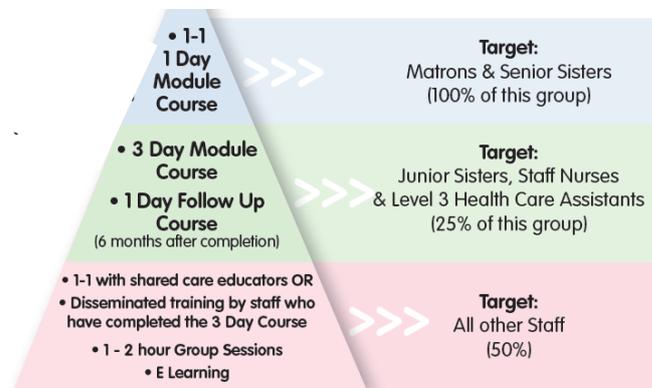
- *95% of all haemodialysis patients will be asked whether they would like to participate in their SHC by June 2013*

We measured how many patients had been asked whether they wished to participate in SHC in order to ensure that the opportunity is offered to all patients. Our target of 100% was altered to 95% to reflect mental or physical barriers in responses.

b. Proactively engaging staff so as to enable an active partnership with patients

We focused on measuring the amount of staff training that was delivered since this was central to the Programme.

We believed a purpose-designed training Programme tailored for the nurses based on the renal nursing hierarchy would engage nurses and help facilitate the change in relationships; therefore a 3-tiered training model was designed (see diagram below).



- *100% of Matrons and Senior Sisters in Yorkshire and the Humber will have completed a purpose-designed 1-day training Programme by June 2013*

It was recognised that senior level engagement is imperative for the intervention to be adopted, spread and sustained therefore the target was 100% of Matrons and senior sisters trained through 1:1 meetings or the 1-day training.

- *25% of renal nursing staff in Yorkshire and the Humber will have completed a purpose-designed 3-day training Programme by June 2013*

Given the capacity, resources and Programme delivery timescales the maximum nurses that could be trained through the 3-day course was 25% - which is why this target was set.

- *All other nursing and support staff will go through a combination of learning on the renal unit (e-learning, group sessions and 1:1s with the trained nursing staff)*

Given the middle tier training target was 25%, we had to develop a mechanism to cascade the training more broadly to other staff. We considered that a 50% target of training “all other staff” would be a “tipping point” that would facilitate the spread of the Programme, so that over time SHC became the norm for dialysis units across Yorkshire and the Humber.

c. Improvement in the quality of care – efficiency and effectiveness domain

- *100% of fluid gain between dialysis sessions to be less than or equal to 2 litres for patients undertaking at least 5 aspects of their SHC for a 2-day interdialytic interval by June 2013*

We adopted this target since there is evidence that patients who put on large volumes of fluid between dialysis sessions have a worse outcome. We wanted to provide an objective measure to link SHC to better health outcomes for haemodialysis patients. However this turned out to be a very complicated question (see section 1.4.3 above for more details).

- *Zero episodes in bacteraemia for patients undertaking SHC*

Infection is a serious adverse event for patients on dialysis. In order for patients to be able to needle their dialysis access themselves we adopted the “button hole” or fixed site needling approach. Although this has considerable advantages from the perspective of patient acceptability there is the possibility of increased infection rates associated with this approach. We therefore determined that blood-borne infection (bacteraemia) would be a measure to adopt. Thankfully bacteraemia was not a significant concern associated with the Programme as it developed. This has been a subject of detailed study by the renal team at Leeds lead by Dr E Garthwaite, who presented her results at the British Renal Society meeting in Manchester in May 2013.

3.2 Results Achieved

3.2.1 Outcomes Achieved on Changing Relationships and Improved Quality of Care – Quantitative Analysis

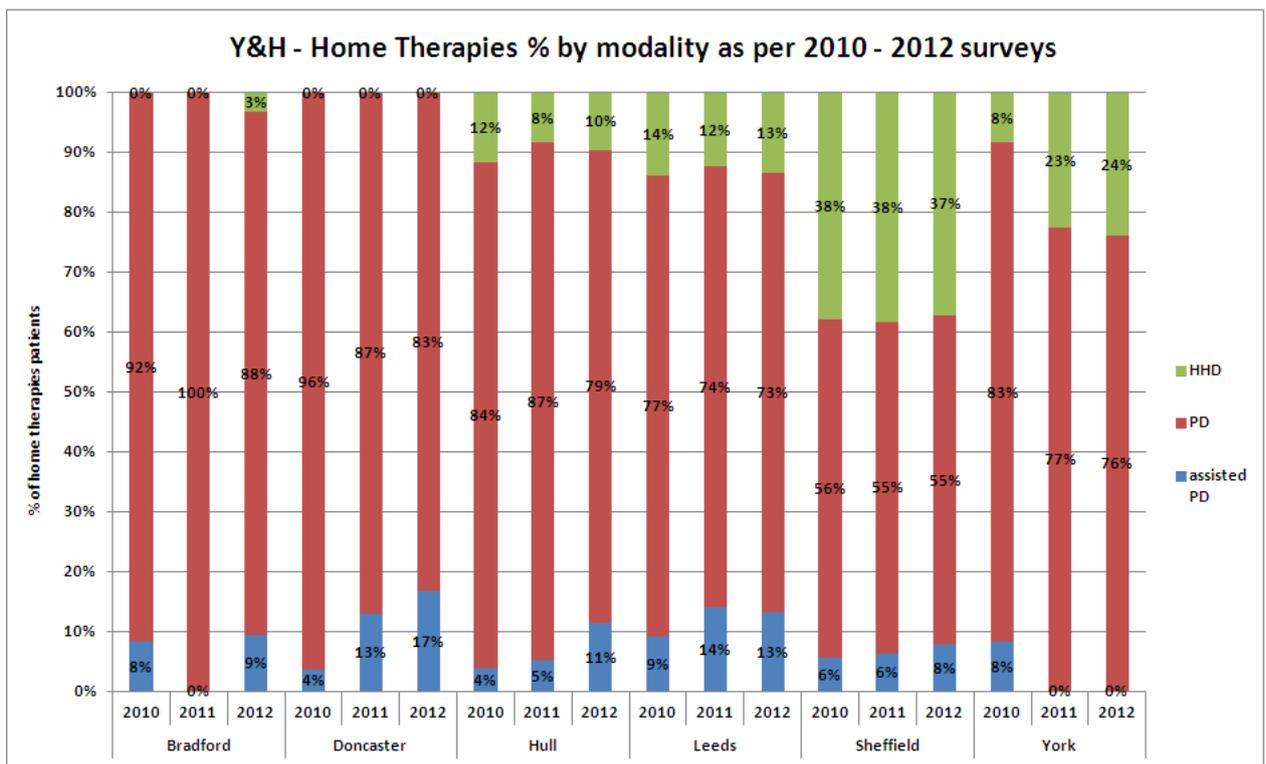
- a. Empowering haemodialysis patients to be active partners in their care*

- *10% of all haemodialysis patients in Yorkshire and the Humber will undertake all aspects of their haemodialysis care by June 2013*

At the time that we made the application to the Health Foundation for funding for this Programme, approximately 5% of all patients receiving haemodialysis in Yorkshire and the Humber received treatment at home. We selected the target of 10% because we knew from national registries that some units had close to 15% of patients receiving haemodialysis at home. We were also influenced by Technology Appraisal Guidance (number 48) published by the National Institute for Health and Care Excellence (NICE) in September 2002, who “*make the assumption that 10% to 15% of dialysis patients, given the choice, would opt for home haemodialysis*”.

In retrospect we had not emphasised that the opinion of the NICE authors was not based on any solid rationale and was principally declared for making service planning assumptions. We have underestimated the lead time to promote HHD as an option; some of the region’s units had no infrastructure to offer HHD in 2010. We had also underestimated the impact of “competing options” for patients. These included peritoneal dialysis, an increased transplantation rate and, most significantly, the expansion of transplantation prior to starting dialysis. These options all reduced patient flows to home haemodialysis, as they tended to be taken up by those patients most likely to progress quickly to home haemodialysis.

There has not been a significant change in the percentage of haemodialysis patients receiving treatment at home in the past 3 years. However, the graph below shows that as a proportion of patients receiving home dialysis (including both peritoneal (PD and assisted PD) and haemodialysis), the fraction receiving HHD has increased and critically, all units who did not offer this option are now doing so, although for Doncaster this has occurred post the census date for these data of October 2012.



Yorkshire and the Humber Home Therapies % - October 2012 Census

- *75% of all haemodialysis patients will undertake at least 5 aspects of their haemodialysis care by June 2013 – monthly measures*

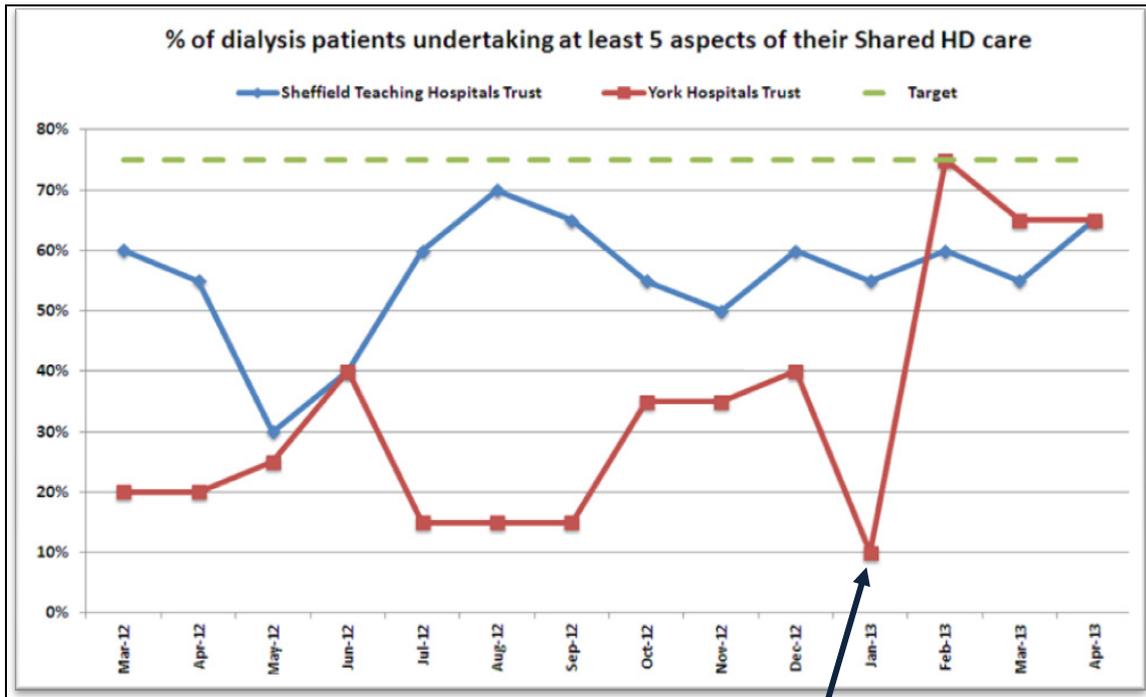
How the measures were collected?

Generically across all the renal sites, we were capturing measurements on a monthly basis. Some units randomly selected 20 patients in total by selecting the third and the sixth patient that arrived for dialysis in a morning shift, afternoon shift or twilight shift or by using a random number generator and auditing the bed spaces. For example at York and its 2 satellite units at Easingwold and Harrogate, we measured across the 3 sites (8 patients in York, 6 patients in Easingwold and 6 patients in Harrogate. Also, at unit level they are keeping a log of individual patients and which specific tasks they are achieving to enable them to identify where improvements can be made.

Phase 1 Sites (Sheffield and York)

The overall mean reliability of Sheffield main site returning data on a monthly basis from March 2012 to April 2013 (14 months) shows at 56% against the target of 75%.

The overall mean reliability of York main site and 2 satellite sites returning data on a monthly basis from March 2012 to April 2013 (14 months) shows at 35% against the target of 75%.



Phase 1 Sites: Sheffield and York

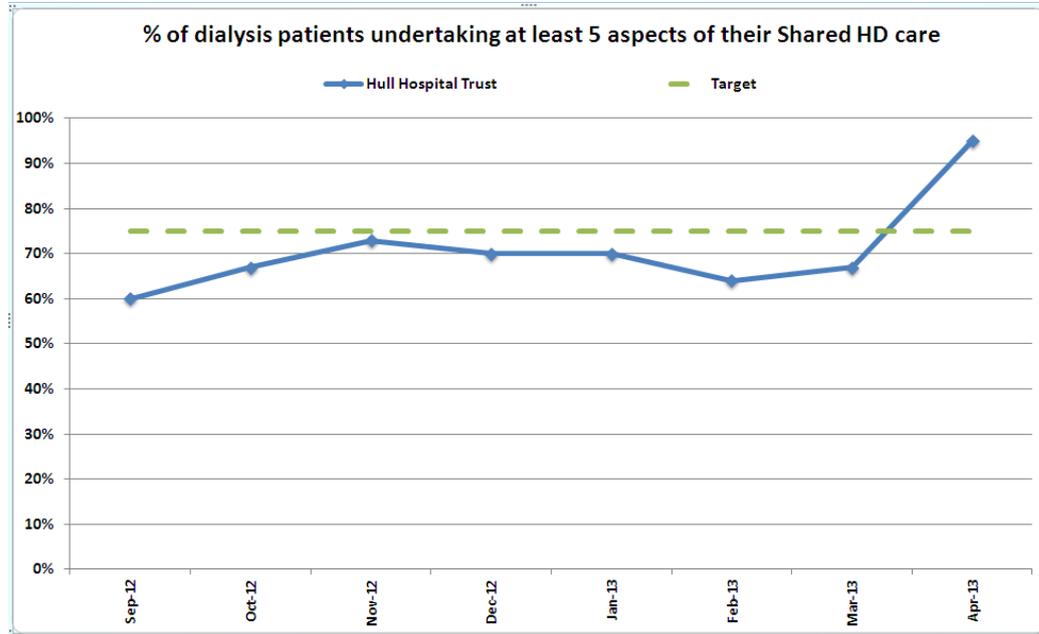
In York, patient engagement increased when it was suggested that instead of waiting for their dialysis stations to be ready, they made use of their time by undertaking pre-dialysis tasks. This incentive reduced waiting times and increased patient engagement.

These data fall into 2 main groups. First, it measures the number of tasks that patients are performing of their own dialysis across the various units of our region. This is evidence of patient involvement. The graphs vary for several reasons – partly because in order to reduce time spent measuring we adapted the measurement to a random sample of 20 patients each month – thus the exact level of patient engagement depended on who we chose. Second, there is a certain patient turnover – with patients being transplanted, moving to other centres or dying, and being replaced by patients who had not been exposed to the Programme. There were changes in staffing, or in the dialysis arrangements that influenced the curves – for whether patients performing shared care were dialysed in one section of the dialysis centre, or were distributed across the unit.

Phase 2 Sites (Hull and Leeds)

- Hull 5 sites (1 main and 4 satellite) 1 / 5 have started collecting data

The overall mean reliability of Hull main and satellite returning data on a monthly basis from October 2012 to April 2013 (7 months) shows at 71% against the target of 75%.



Phase 2 Site: Hull

One of the key reasons for this success is that Hull is a Fresenius renal site with a dedicated self-care area and has been implementing self-care for a number of years now. The results above are taken from this dedicated bay only.

- Leeds 8 sites (2 main and 6 satellites) 8 / 8 have started collecting data

The overall mean reliability of Leeds main and satellite returning data on a monthly basis from September 2012 to April 2013 (8 months) shows at 23% against the target of 75%.

There is variation in data collection in Leeds sites from 1 month to 8 months (total months 35) across the 8 units. So the overall mean reliability of Leeds main and satellite returning data from October 2012 to March 2013 is 23% against the target of 75%.

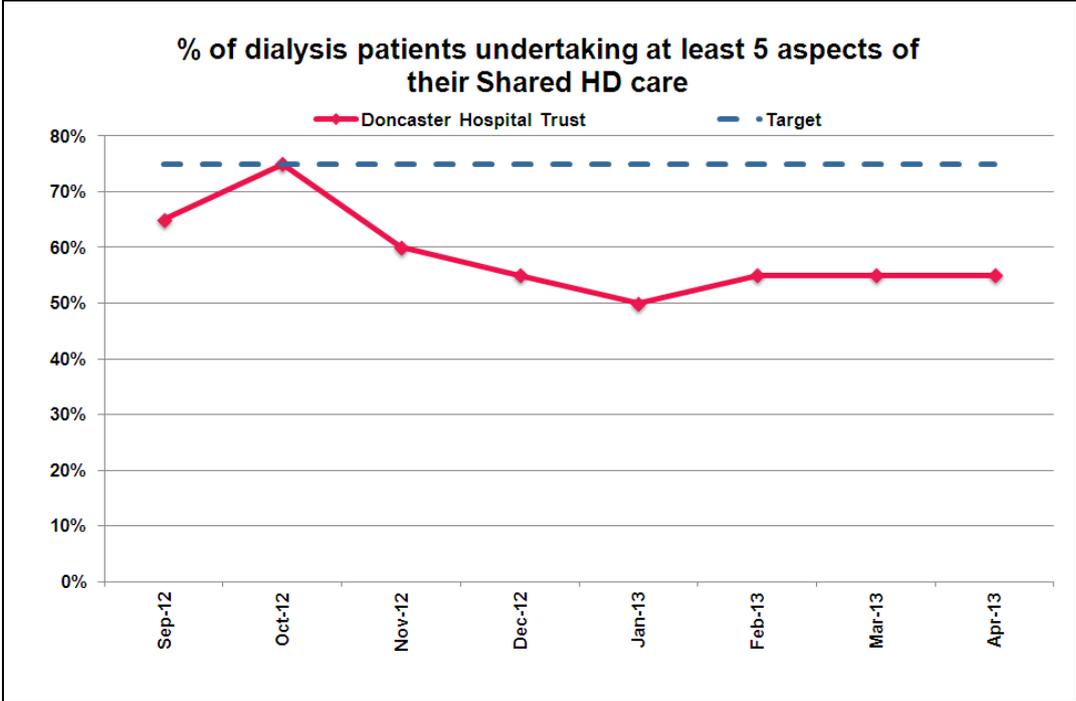
Phase 3 Sites (Bradford and Doncaster)

The overall mean reliability of Bradford main and satellite units returning data on a monthly basis from November 2012 to April 2013 (6 months) shows at 4% against the target of 75%.

Bradford uses a Modified Early Warning System (MEWS) for observations. So a baseline set of observations at pre dialysis is done by the patient, which does not include the temperature (one of our measured tasks). However, a second set of observations within the first hour of dialysis is done by the staff using the MEWS which

does include the temperature. Therefore, patients are only achieving 4 out of the 5 minimal non-invasive tasks and nothing to do with the machine (weight, blood pressure and pulse, wash hands and arm, prepare dressing pack ready for access).

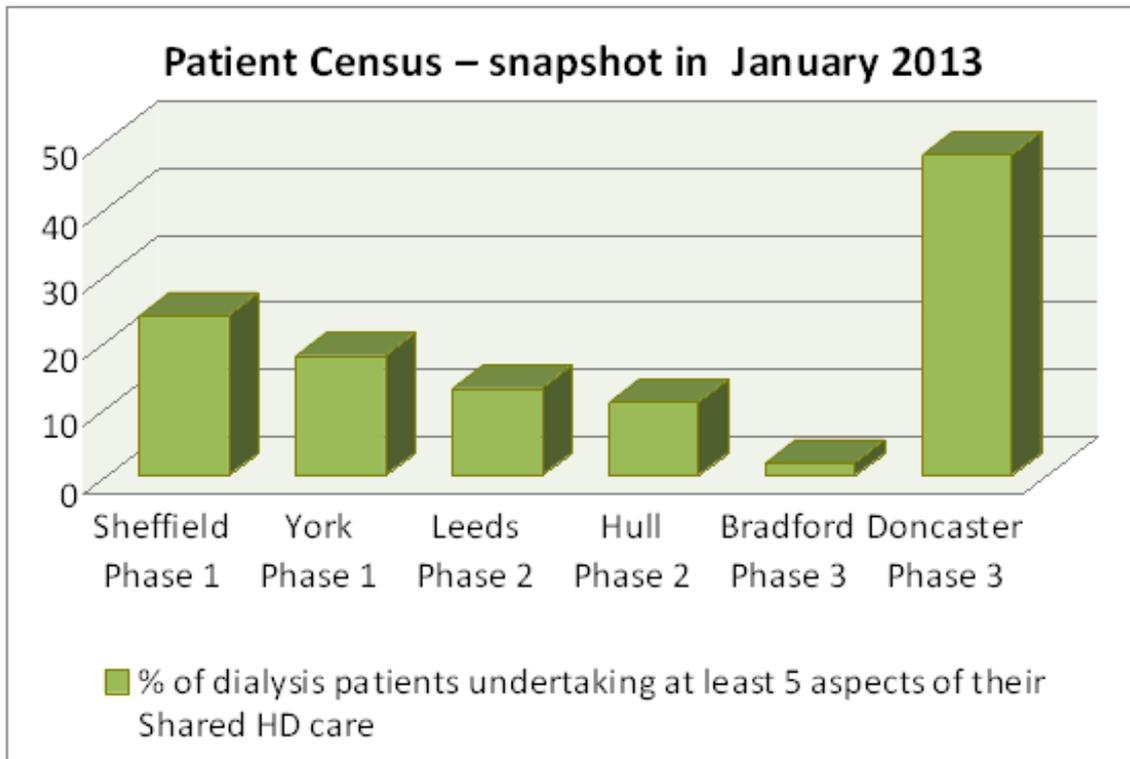
The overall mean reliability of Doncaster main site returning data on a monthly basis from September 2012 to March 2013 (7 months) shows at 59% against the target of 75%. This intervention has had a significant impact on patients and dialysis staff and has also caught the attention of the Trust Board. One of the key reasons for the huge success at Doncaster is having a dedicated nurse with “protected time with the patient”.



Phase 3 Site: Doncaster

- 75% of all haemodialysis patients will undertake at least 5 aspects of their haemodialysis care by June 2013 – census data

We asked all 26 units in the region in January 2013 to collect a census on the number of patients undertaking 5 out of 14 tasks of their haemodialysis therapy.



Overall, from our census (conducted in December 2012) we could see that many centres had not obtained a considerable level of patient involvement by that stage, however there were particular examples of where things had gone really well, most notably in Doncaster. It is instructive to understand the reasons for this – a motivated champion given dedicated time to concentrate on the Programme, senior support and enthusiastic patients.

We did not quantifiably measure the change in the relationship between patients and healthcare professionals. However, non-quantifiable evidence from patients performing their own treatment (which they were not doing before), has come from the interviews, patient stories and quotes.

Statistical results cannot demonstrate the richness of the impact that engagement in treatment has on the individual patient. Patient stories and anecdotes give a much more robust account of the positive change in dynamic between patient and nurse:

“The one thing that helped me gain more confidence and helped me with my treatment was enrolling in the shared care Programme where I felt that I was in control of my treatment and not the dialysis ruling me..... You can choose what you are comfortable doing where you start with the basicsFor me I have found it has really helped me understand my treatment and feel like I am helping myself..... It has definitely made me more confident about doing my own treatment.” (Mike May, Hull)

“This has given me so much confidence that I find myself more confident in life with a self assurance that has now replaced the feeling of I will never manage that!” (Jane Evans, York)

“Shared Care has changed my life!” (David Pargeter, Sheffield)

“Shared Care gives me control over the situation that I thought I didn’t have any control over.” (Anonymous, Leeds)

“Having the choice of Shared Care has allowed me to learn to needle myself, something I never thought I would do!” (Anonymous, Hull)

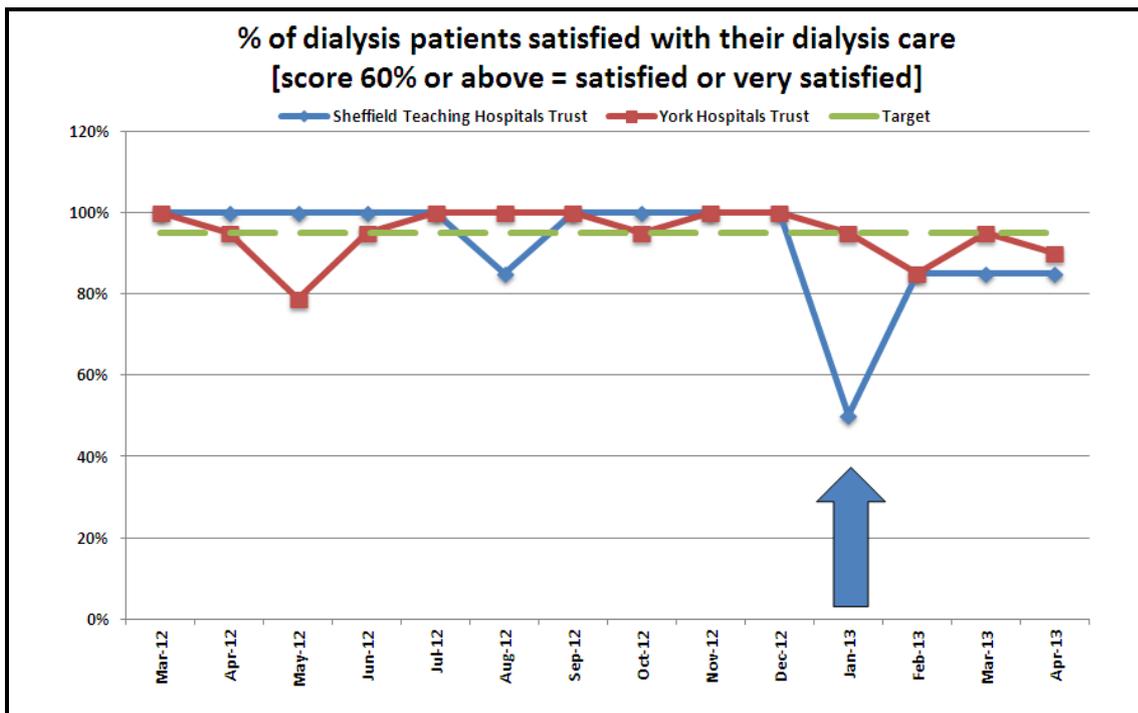
- 95% of all haemodialysis patients will be asked whether they would like to participate in their SHC by June 2013

The graph below illustrates the results from the patient question:

“Are you satisfied with the care you have received today?”

This question did not give us any meaningful responses directly relating to SHC. The blue arrow indicates the point at which we changed the question to:

“Would you recommend SHC to another patient?”

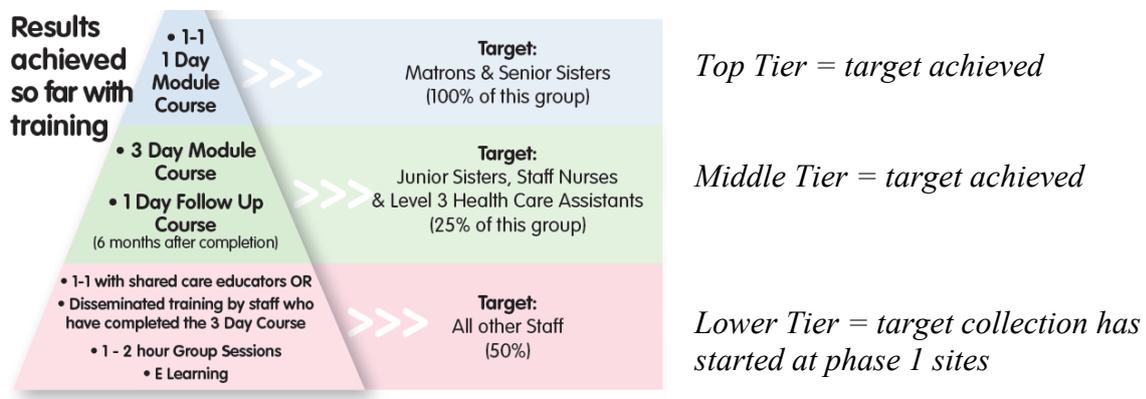


The second question from January 2013 mirrors the Department of Health Initiative-NHS Family and Friends Test

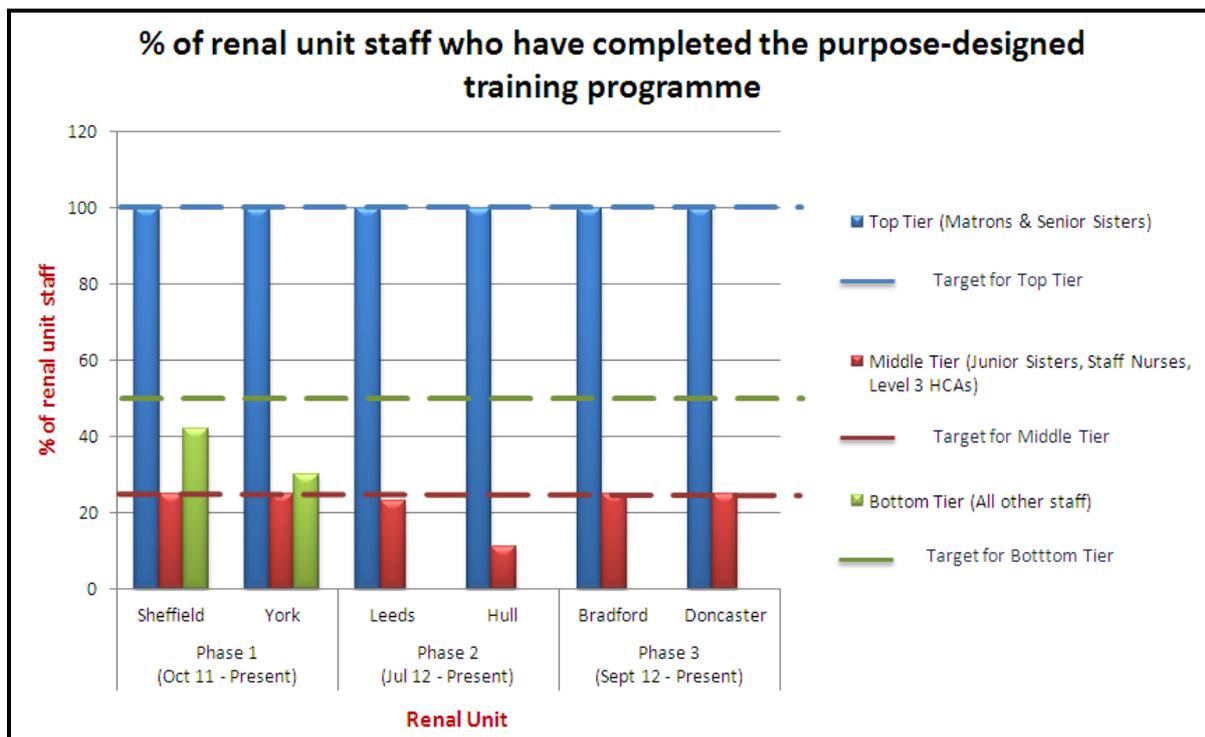
(b) Proactively engaging staff so as to enable an active partnership with patients – Monthly Measures

- 100% of Matrons and Senior Sisters in Yorkshire and the Humber will have completed a purpose-designed 1-day training Programme by June 2013
- 25% of nursing renal staff in Yorkshire and the Humber will have completed a purpose-designed 3-day training Programme by June 2013
- All other nursing and support staff will go through a combination of learning on the renal unit (e-learning, group sessions and 1:1s with the trained nursing staff)

The results achieved so far against the above measures:



The graph below breaks down the results achieved by phases of implementation for the top, middle and bottom tiers and by each of the main renal units:



There were a number of challenges and successes to the implementation of this course that was designed to train nurses to support greater patient engagement in haemodialysis.

For a variety of reasons there was some difficulty in engaging all senior sisters prior to the commencement of the middle tier training schedule. As a result, some middle tier staff found their managers not immediately supportive compared to those units whose senior staff had been trained.

In addition, if middle tier staff attended in isolation from other staff on their unit they had much more difficulty initiating SHC. To rectify this situation, unit managers were asked to send their staff on concurrent courses to introduce continuity in training for individual units.

Some delegates reported difficulties in completing their competencies because line managers were not yet ready to “roll out” SHC on their unit and therefore delegates were prevented from engaging and training patients. Some delegates were slow at completing the performance-based section of their own competency, but despite this were still able to engage and train patients and were able to cascade their knowledge to other staff. This could be attributed to the fact that the competency isn’t yet embedded in existing renal unit staff competencies.

The Sheffield pilot site has resolved this by including the theory and practice of SHC within their existing renal competencies, thus ensuring that nurses are exposed to its ethos during every aspect of their own haemodialysis training. This ensures that SHC is embedded into the culture of the unit and becomes part of the everyday routine.

We used a “spread control log” to ensure that nurses were being enrolled and trained equitably from all the units as part of the 100% top tier and 25% of the middle tier targets and these were reported back to the Programme Board through quarterly updates.

c. Proactively engaging staff so as to enable an active partnership with patients –Staff Morale Survey

Prior to introducing the nurses to the purpose-designed SHC nurse training course we wanted to establish whether staff had any awareness or knowledge of the Programme as well as the confidence to deliver training to patients. Therefore a baseline staff morale survey was designed by OPM and undertaken with the phase 1 (York and Sheffield) units in March 2012 and the follow-up survey of staff working in phase 1 Programme sites (York and Sheffield) was undertaken in February 2013. Some of the key findings from the analysis report developed by OPM are highlighted below.

Rationale for a Staff Morale Survey

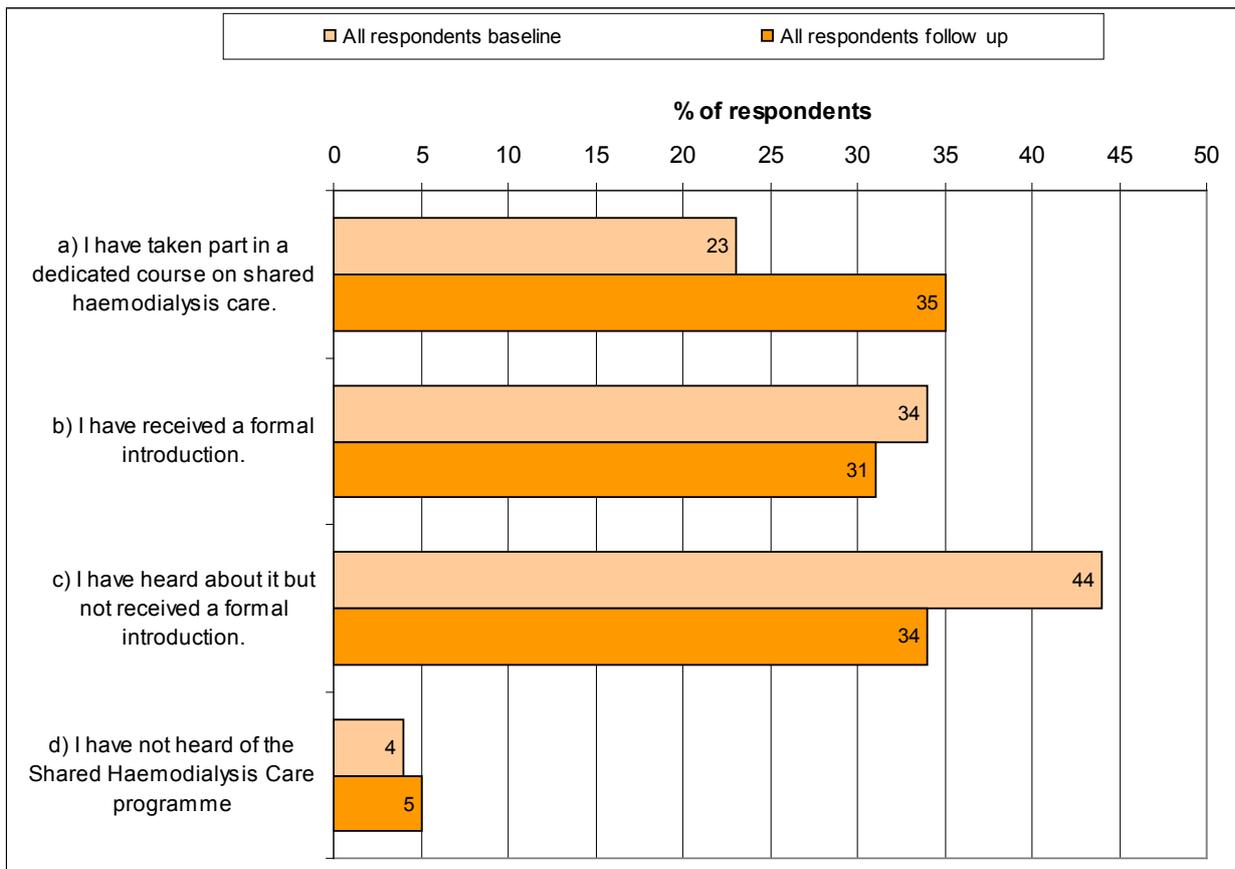
- To assess the impact of introducing a purpose-designed training course for nursing staff
- To assess the impact that shared care has on staff morale
- To assess the changing relationship between the nursing staff and the patients by introducing the intervention of shared care

Profile for Sheffield and York (pilot) sites

- Sheffield Teaching Hospital:
 - 1 main site and 4 satellite units (122 stations)
- York Teaching Hospital:
 - 1 main site and 2 satellites units (36 stations)
- A baseline survey of staff working in phase 1 sites (York and Sheffield) was undertaken in March 2012 and the follow-up survey was undertaken in February 2013
- The data in the graphs have been presented as percentages or proportion of respondents
- The figures should be treated with caution as the sample sizes are less than 100 so that small variations in numbers can lead to large proportionate changes

Survey Sample Profile

- Less than half who completed the baseline survey also completed the follow-up survey. Therefore the results are not directly comparable and any differences should be treated with caution and seen as indicative
- The sample for the baseline survey was 82 (20 from York and 62 from Sheffield)
- The sample for the follow-up survey was 91 (28 from York and 63 from Sheffield)



Awareness of and involvement in the SHC Programme

Staff were asked: why these factors are significant in successfully delivering SHC

“In order to be able to train patients in shared care, I believe staff must firstly be up to date with their own skills and knowledge”

“Patients require encouragement and enthusiasm from staff...to motivate them to learn and staff need the skills in order to do so”

“All that is really needed is staff who understand how to talk to and train patients. Working with patients in partnership to increase their understanding and skills to become as independent as they would like to be”

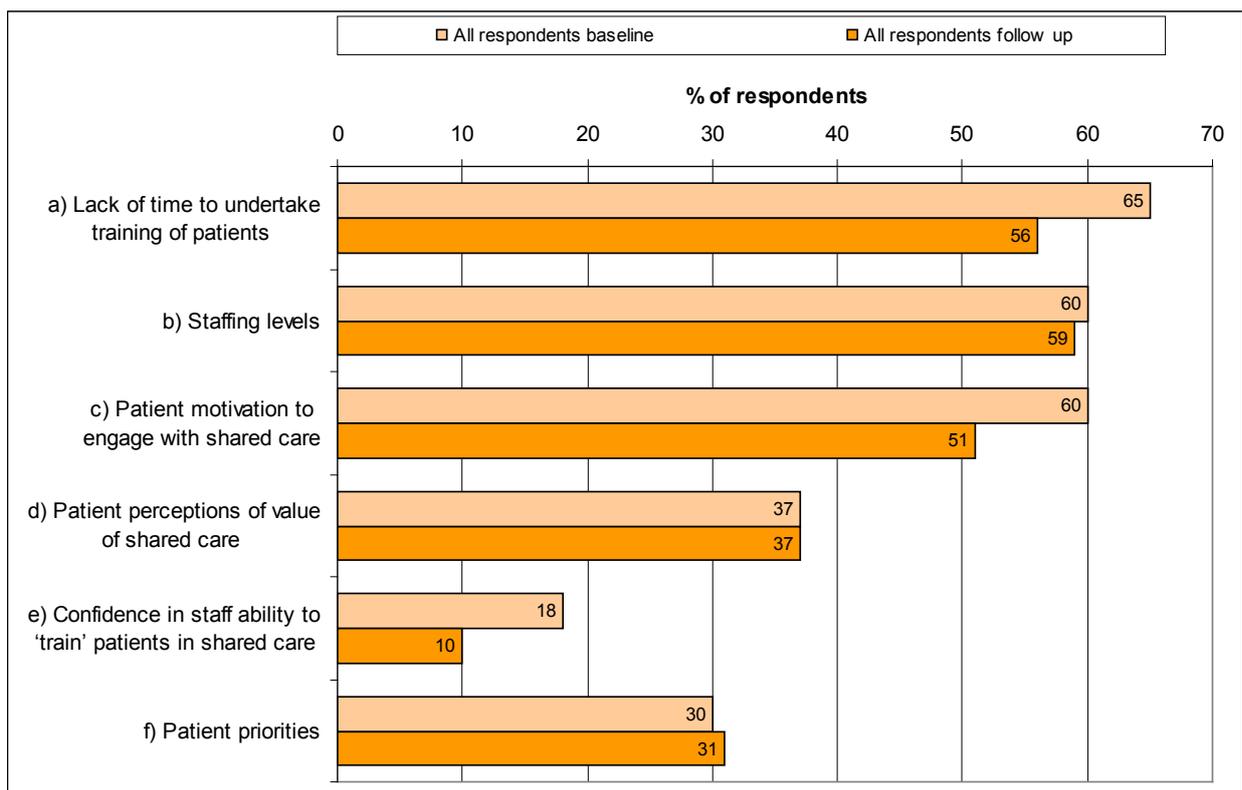
“I think every member of staff has to be involved in this and not just a chosen few”

A few other suggestions were:

“ introduce SHC whilst patients were in Out Patient”

“have a longer slot between dialysis e.g.5–6 hrs before the machine is required again”

“more staff” which was mentioned frequently!



Barriers faced by respondents in delivering SHC

Staff were asked why these factors act as barriers in delivering SHC?

“Lack of time means that shared care is low on the list of priorities”

“Some patients need higher levels of training than others, so you need more one to ones and if staffing levels are low not always able to deliver”

“If you expect staff to teach patients then you need more staff”

“Time is short you need to spend more time with each patient and explain in a way that they understand”

“If patients don’t want to be involved, it can be hard to motivate them”

“In my experience I have found a lot of patients feel staff may lose their jobs. This is a strong opinion and not easy to change”

“If patients don’t want to be involved, it can be hard to motivate them”

Challenges for the SHC Programme drawn from the survey results:

- The majority of staff feel positive about the benefits of the SHC Programme but this was reduced slightly in the follow-up survey

Why?

- Staff face the realities of trying to implement SHC, keep patients involved and motivated during a challenging time for the NHS
- One of the challenges going forward will be to maintain staff enthusiasm and motivation for the SHC Programme
- To maintain the training Programme within the region

Outcomes achieved on changing relationships and improved quality of care – Qualitative Analysis

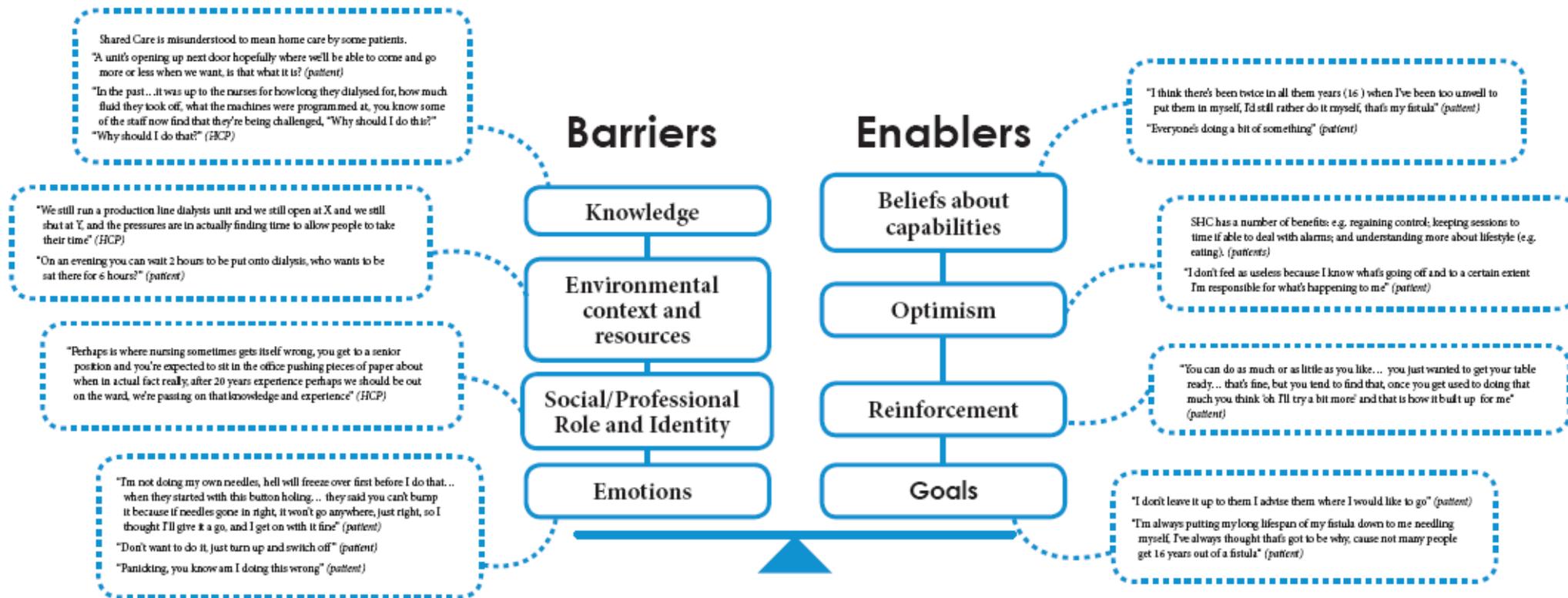
We did not understand why interventions to support self-management have variable effects or how to optimise the delivery of such care; therefore the purpose of this study was to identify perceived patient and professional (nurses and healthcare assistants) barriers, and to use these data to identify intervention components to optimise care.

Qualitative interviews were conducted in two renal units and their associated satellite centres in the Yorkshire and the Humber region. Patients and professionals categorised as:

- 1) those undertaking all elements of shared care
- 2) those undertaking some shared care and
- 3) those opting out of shared care who were interviewed.

We qualitatively explored the personal perspectives of patients/professionals who participated in shared care, and those who did not. We coded these data to behavioural theory to systematically identify the barriers and facilitators to all patients being able to participate in their care at a level appropriate for them.

Our interview data analysis suggested a number of contextual factors (diagram below) that we believe would be necessary for successful implementation such as knowledge, beliefs about capabilities, skills and environmental context and resources.



Identified Barriers and Facilitators to participating in SHC

The findings indicate that there are a number of barriers to implementing SHC. Knowledge of shared care is limited in some patients. Some patients understand shared care to equal needling, even when they are undertaking other competencies. Healthcare professionals may not see education as part of their role due to time constraints and the nature of the clinical setting (e.g. managing acute and stable patients). In parallel some patients do not see shared care as their role, haemodialysis already impacts significantly on life without any additional responsibility. Some patients identified a fear of needles, while others have overcome this fear with the support of staff, button holding procedures, time and graduated practice.

These data also indicate a number of enabling factors to implementing SHC. Healthcare professionals have generated a sense of optimism in the clinical setting. Reluctance expressed by nursing staff has been outweighed by optimism from healthcare assistants. Patients have had the opportunity to explore their intentions, to set individual goals, and to meet and surpass these goals. Each patient varies in their involvement, and utilises more nursing care on some days. Good practice has been reinforced and continues to be monitored.

Identifying barriers and facilitators has allowed us to develop a tailored intervention strategy to optimise the implementation of SHC to benefit patients that focuses on providing:

- a) Patients with information about the shared nature of care, how to read prescriptions and use machines
- b) Professionals with skills, protected time to teach both professionals / patients and provide ongoing review is most likely to improve the implementation of SHC and be acceptable to stakeholders

We have developed an intervention strategy to improve the implementation of SHC for patients and professionals. While this intervention strategy has been systematically developed using behavioural theory it should be rigorously tested in a subsequent evaluation study to ensure that haemodialysis care can be delivered equitably, efficiently and safely for all patients.

“It is hard to understand how soul destroying it is to turn up for your dialysis 3 times a week and have everything done to you and then leave. For some this is the limit of their expectation or indeed ability, but for others the empowerment of being able to conduct aspects of your own care, under the watchful eye of the professionals is a fantastic feeling. Some 3 years ago having the freedom to be able to conduct elements of your own care was met with some friction, and it very much depended on ward managers and individual HCPs (unit pressure plus fear of something going wrong perhaps) whereas now we have trained nurses who are able to train their colleagues and where managers are able to review how a unit is managed. This has shifted the tide to where most HCPs keen for you to ‘have a go’, have the confidence and understanding to help in a proactive way and where the patient needs and wants really are at the centre of the unit”.

SHC Programme Patient Lead, York

b. Improvement in the quality of care – Efficiency and Effectiveness domain

- *100% of fluid gain between dialysis sessions to be less than or equal to 2 litres for patients undertaking at least 5 aspects of their SHC for a 2-day interdialytic interval by June 2013*

Hard outcomes have proved very difficult to measure as this turned out to be a very difficult question as explained above in section 1.4.3.

- *Zero episodes in bacteraemia for patients undertaking SHC*

See section 3.1.2 above explaining this.

3.2 What has been the Overall Impact of your Programme?

Outcomes at a range of levels

Individuals – Patients

- Patients are seen as part of the team rather than passive recipients who question nothing and accept all treatment without any collaboration with their nurse
- The team has observed that in the SHC areas there has been greater dialogue between patients and nurses and between patients themselves, and the atmosphere has been more positive. As patients become more knowledgeable about their condition they are comfortable talking about it with others
- Barriers have also been breaking down between patients and clinicians as clinicians begin showing greater respect for patients who are proactively managing their care
- Patients report greater control of their illness
- Patients report an increase in ability to cope with coming to the unit 3 times a week and 1 patient report stated: *“I was really depressed when I first started haemodialysis. However, since I’ve started SHC I actually look forward to coming for dialysis”*
- Another patient stated: *“I have a more meaningful relationship with the nurses. I feel we are more on an equal footing and work as a team rather than me just lying there and not being involved”*
- Patients report an increase in confidence and feel more able to question nurses about their treatment

Patient quotes when asked how we could help patients improve their ‘satisfaction score’ in supporting them to become active participants in their care:

- *“Continuous practice & encouragement at my own pace”*
- *“By learning how to do things & encouragement from staff”*
- *“Practising on the machine & learning how to do things myself”*

Consistent themes from patient quotes from phase 2 implementation sites:

“Able to become more involved, and feel I have more control over my treatment”

“SHC has given me my confidence back and made me feel safer about my care”

“I feel more in control of my care also give me more understanding of my treatment”

“SHC gives me control of a situation that I thought I didn't have any control over”

“Helping me to understand every aspect of my care. The nursing staff are extremely helpful and supportive. Would recommend that all patients at least have a try if they are able”

Patients from the Leeds renal units

“Doing SHC has given me more understanding and control towards my treatment”

“I never thought I could do it - I just looked at the machine ... but now I can and it feels so good!”

“Having the choice of SHC has allowed me to learn to needle myself, something I never thought I'd do!”

The physical space of a unit enabled other patients to see others participating in their own care, including those traditionally excluded (i.e. older people, those with a learning disability etc.).

Patients from the Hull renal unit

However, not all experiences were positive. There were patients who became frustrated with the rate of progress, with the different level of engagement of staff or that they had hoped to be able to go home to dialyse once they had learned how to do it – but were unable to do so for logistical reasons. Other issues included frustration that dialysis machines differed in design from each other and having learned on one machine the patient might then unexpectedly have to use another for logistical reasons. Again at least one patient who learned how to perform their own dialysis, then started to use the prescription in a way that the nurses felt was unsafe and this led to tensions.

Individuals – Nursing Staff on the ground

- Staff report an increase in job satisfaction. They put this down to a change in role from delivering quick efficient haemodialysis under pressure to engaging with the patient in a timely but more meaningful way

- Nurses have a new or renewed respect for patients as a result of patients verbalising how it feels for them and because nurses can see patients become experts
- Both nurses' and patients' attitudes are changing from one of resistance to acceptance as they see and experience the benefits
- Both staff and patients are beginning to "own" the concept of SHC and it is slowly starting to become an accepted practice

Staff who returned after 6 months since completing their original 3-day training course reported:

- *"Patients actually talking to each other i.e. understanding blood results and machine alarms what it could be"*
- *"More patients participating in SHC. More enquiries and interest from newer patients"*
- *"The SHC patients have become more confident and this spreads to other patients"*
- *"The staff attitude has changed to liking the SHC concept and realising it does not mean taking away their skills"*
- *"Increase in patient interest in SHC"*
- *"Patient who insisted she'd never get involved and definitely not needle has in fact learned to Programme her machine and self-needle. Has given her more self-esteem"*
- *"I have helped change staff attitudes towards SHC"*
- *"I have increased staff awareness of SHC through discussion and PowerPoint"*
- *"I have followed up my patients on SHC and provided information and given support to both staff and patients"*
- *"I have educated patients about hand washing and fistula care and helped integrate SHC on the unit where there was an initial divide"*
- As a result of SHC, nurses engage more closely with their patients before, during and after dialysis. This fosters a more open dialogue in which the patient feels more able to talk about issues such as treatment, diet and lifestyle. As a result patients demonstrate a greater interest in adhering to a renal diet etc.
- As SHC patients become more independent, this releases staff to give more attention to more dependant patients thus improving their quality of care
- More patients are requesting the button hole procedure – this is another way of cannulating (putting needles in) your fistula. It requires putting the needles in the exact same spot at the same angle and depth every time your needles are inserted.

Organisation / wider system

The collaborative relationship forged between the 2 Matrons and 3 SHC Educators across the pilot sites of Sheffield and York has played a fundamental part in ensuring the Programme of education to inform staff about SHC/Programme was instigated in the first place. In addition, this relationship has led to an extremely cohesive and successful implementation of both the 1- and the 3-day SHC training course across Yorkshire and the Humber region. Furthermore, this relationship contributed to the content of the course itself and ensured it was successfully formulated, piloted and refined to a high and relevant standard.

This has contributed to building skills in changing relationships with the following:

On a regional scale, the relationship between nurses on the course and nurses back at their individual units:



"I feel more confident to promote SHC back in my unit"
Delegate, Course 9

"Sharing ideas helped me deal with the barriers in my unit"
Delegate Course 9

"Given me the incentive to get my staff involved and support each other"
Delegate Course 9

"The realisation that barriers can be overcome, broken down, discussed and no longer exist!"

On a regional scale, the nurse/patient relationship and the perception nurses have about patients' abilities both in terms of haemodialysis skills and their contribution to improving services:



"I now see patients as partners in their care"
Delegate Course 6

"Compassion has been put to the top of the list – it's all about the patient"
Delegate Course 5

"Audrey's story made me look at patients in a different way"
Delegate Course 7

"This course has been worthwhile and effective in helping staff to develop patient/nurse relationships and collaborative care"
Delegate Course 7 (6-month review)

"Building up rapport with patients and them trusting you – it's a privilege! SHC has given me this!"

On a regional scale, the relationship between nurses at unit level and higher management at both Matron and Chief Nurse level:



“Chief Nurse has a heart. Makes you feel proud that she has taken time to come and talk to us” Delegate Course 7

“Senior nurse input good as they don’t just pooh pooh it”
Delegate Course 6

On a regional scale, the inter relationship between individual units and the value of networking:



“Meeting people from other units and sharing ideas, has been extremely beneficial” Delegate Course 5

“Learned a lot from other participants hopes and fears”
Delegate Course 6

“Nice to hear other people have similar problems, all in it together”
Delegate Course 6

“Don’t feel alone. Feel better knowing that other units have similar problems”
Delegate Course 9

Beyond the life of the Programme the shared care ethos is now becoming the cultural norm and as such will remain well and truly embedded in patient haemodialysis care across Yorkshire and the Humber without the cohesive and regional approach to training

6-month review study day where delegates meet up 6 months after their 3-day course:



“I am now doing SHC without thinking”
Delegate Course 6

“Need to do SHC everywhere and with everyone. Needs some work, but will reach this one day and will achieve the goal”
Delegate Course 5

Unexpected positive outcomes

We did not anticipate the popularity of the course and the nurses’ keenness that we (SCEs) should continue regional educator unit support beyond the “end” of the Programme.



“More sessions to accommodate more staff to attend this training”
Delegate Course 9

“Ongoing visits later in the year from SCEs to talk about how SHC is going and to feel supported”
Delegate Course 7 (6-month review)

“Definitely increased staff and patient morale”
Delegate Course 7 (6-month review)

“The most informative and motivating course I have been on in years. Thank you”
Delegate Course 7(6-month review)

Unexpected negative outcomes

We did not anticipate the difference in structural hierarchy and business model between the NHS and the privately funded units. This affected the Programme by reducing staff recruitment staff to both the 1- and 3-day course. Furthermore, although individual delegates attending the course were enthusiastic about SHC, some delegates described not receiving senior support back in their individual units.

“Would be happy to cascade this down to patients/staff but I don’t feel I have any support from regional and band 7 managers”
Delegate Course 9

Partner organisations

Doncaster – Patients, Staff and Trust Executive

Many of the patients who are engaged in this Programme felt for the first time in their illness they are valuable and they can do a lot to help themselves. They started to have the feeling that coming for dialysis is not any more a painful experience. Many of them had become rather compliant with their treatment. This Programme built the confidence of many of them again.

The flexibility of the patient participation has generated interest in many to contribute. Anecdotal evidence has shown patients have a better quality of life, feel less depressed and have become very enthusiastic to have HHD treatment.

Staffs have perceived this Programme as the best way forward for patient-centred care. It has improved the staff/patient relationship. There was a friendly competition between the staff to see who achieves more skills with their patients. They felt coming to work is rewarding by seeing the effect they have on patients’ mood. They see some of those patients who were reluctant to have dialysis treatment because of the needle phobia doing a good number of the competency skills which is a real success. One of the staff is now doing a higher degree discussing the impact of this Programme.

Due to the high number of patients interested and achieving high levels of their own care has led to the development of a strong business case for a *HHD Programme* for Doncaster as at the moment HHD patients are referred to Sheffield renal unit – this option would otherwise have not been viable given the economic challenges.

Bradford Teaching Hospitals NHS Foundation Trust

Bradford is only at the early stages of the SHC Programme as it was in phase 3. We started this Programme at the same time as introducing the concept of HHD to our patients with a dedicated HHD nurse.

For one patient this has already resulted with her starting with SHC and progressing to HHD training. Certainly not a path she started on but helped with the joined up working with SHC and HHD.

The SHC Programme appointed a Cultural and Health Improvement Officer to facilitate communication with and education of our South Asian patients. Following an audit on the number of South Asian patients who can/cannot read in Urdu the SHC patient handbook and leaflet was translated into their first language for those patients to engage and feel included in their care.

York Teaching Hospital NHS Foundation Trust

SHC got off to a flying start in York in 2010. York was unique in a sense because all three dialysis units started simultaneously and all our patients were given the option of taking part. About a year into the Programme, our progress stalled. This was not because of patient, staff or organisational engagement in the process.

Factors which have impacted on the spread of SHC are:

- Patient demographics – our elderly population are happy to be involved in SHC but might not be capable of doing a significant number of tasks
- Dialysis capacity issues and lack of acute dialysis facilities in Yorkshire and the Humber – are competing issues and
- Our SHC nurse taking on the regional nurse educator role to the SHC Programme for 2 years was focused away from York. We should have planned for our staff to take over for continuity

A business case approval of over £500k by Harrogate and York Trust Boards for the Harrogate self-care unit as well as Trust approval to plan for York and Selby self-care units demonstrates that this is a high priority at executive level. In addition, North East clinical alliance has provided us funds (£50,000) to review and design patient pathways transitioning from SHC to self-care.

Health economy including commissioners

No specific economic benefits have been realised from the Programme, but this was not part of our strategy. In terms of healthcare organisations across the region benefitting, the Programme has enabled all 6 renal units to work, learn and share their experiences together, and has brought equity of opportunity to both haemodialysis nurses and patients. It has also allowed us to continue to develop effective partnerships with our colleagues in the independent sector, and to share our learning and materials with renal centres nationally.

National policy

This Programme has been part of a ground swell of renal opinion in the United Kingdom on the delivery of haemodialysis treatment in main hospital or satellite haemodialysis units which has been very successful in achieving large increases in the number of people receiving treatment, has had the unintended consequences of institutionalising patients. It may have also dis-incentivised both patients and provider services from treating patients in their own homes.

This realisation has led to individual Programmes at several units to reinvigorate the option for HHD treatment. The National Kidney Federation and the Kidney Alliance, 2 of the largest patient representative groups, had also expressed concern about the reduction of opportunities for patients to receive home treatment. The All Party Parliamentary Group on Renal Disease hosted a summit in February 2013 which heard from a number of individuals in senior management positions in the health service exploring the current trends of reduction of home treatment and what might be done to reverse that trend.

In the medium-term probably the most important influence to national strategy in England will be the fact that **shared dialysis care** will form part of the National Service Specification that will apply to all provider units in England from April 2013. This specification will specifically provide an obligation on provider units to deliver SHC.

The Programme described in this report has given provider units the tools to achieve this with its training course, patient aids, booklets and literature. Changing the culture of care delivery in a whole country and then sustaining that change of care will not happen overnight, but this is now part of national renal policy, in England.

3.3 Economic Impact

3.3.1 Details of Programme costs

Initial Programme costs submitted as part of the bidding process was comprised of a Health Foundation grant of £399,000 as well as contributions (in the form of staffing resource) from the Yorkshire and the Humber Renal Network and Sheffield Teaching Hospitals Foundation Trust and further contributions from NHS Kidney Care associated with nurse educator resource and 2 national learning events.

The Programme budget was managed on a day to day basis by the Programme Manager with oversight from the renal business manager at Sheffield Teaching Hospitals who acted as finance lead, reporting on financial and budgetary matters to the Programme Board. The Programme budget was revised and updated as the Programme progressed, in line with the evolution of the workstreams and deliverables that emerged from their developing strands of work.

The main Programme costs are indicated in the table below:

The majority of the Programme cost was linked to dedicated staffing time, in particular for the Programme Manager, 2 nurse educator and 6 consultant lead posts across the region. Travel expenses also formed a major part of the budget as the Programme found that despite conducting much of the workstream and Programme management business virtually, it remained necessary to get together in person at times for things to really move on. Also the nurse educators' delivery of courses and support across the region was a vital part of the sustainability workstream.

The delivery of the course and the branding, marketing and advertising of the SHC philosophy required a significant budget to deliver handbooks for haemodialysis patients, journals for the nurses working on the wards and posters and flyers for promoting SHC as well as contributions towards journal articles to publicise the successes of the Programme. The leaning events funded by NHS Kidney Care reinforced and spread the Programme learning across the region and nationally.

Type of Cost	Description	Value
Staff/Pay costs	Consultant PAs	3 x PAs across region
	Programme Manager	1 x Full-time post
	Shared-Care Co-coordinators / Nurse educators	2.2 x Full-time posts
	Admin Support	0.5 Part-time post
	Senior nursing (Matron)	Occasional Overtime
	Language worker	
	TOTAL	£377,000
Non-Pay costs	Printing and Stationery including all course material and communications materials	£20,400
	Health Economist Fees	£2,300
	Qualitative Researcher Fees	£27,000
	Patient Involvement Fees/Travel	£6,300
	Travel Expenses for Programme team	£26,200
	Learning Events x 2	£16,500
	TOTAL	£95,900
	GRAND TOTAL	£472,900

Programme costs as at March 2013.

Learning Points – Finance and Budgeting

- Travel expenses were much higher than programmed – the necessity of running a regional wide Programme – managing this budget is challenging as travel can fluctuate widely and relies on quick submission of claims
- We had no initial budget for communication and printing which formed a vital part of the Programme branding
- As we reached the end of the Programme more and more ideas kept following which required financial support. By working closely with the team we ensured that these were affordable and that we did not overspend.

3.3.2 Results / lessons learnt from the economic evaluation work

By the time we discontinued the health economic evaluation we had learned through our work that the focus of the Programme should be more about getting the best use of existing resources (using nurses in altered roles as teachers and facilitators to enhance the quality of care) rather than trying to save money by getting the patients to do the work. An important clue to this altered emphasis lies in the terminology change that we made several months into the Programme – from *self* to *SHC*. This reflected a change in our perception from one where we were trying to demonstrate a cost benefit to one where the focus was supporting patients to do as much or as little as they wished to do. In this scenario it is much more difficult to demonstrate the outcomes that we had originally hoped for – more patients going to home dialysis, reduced healthcare costs, and improved hard outcome measures.

3.3.3 How you intend to use / build on the findings from any economic evaluation

One of the concerns that we have heard from patients and staff was that we would make nurses redundant through this initiative – and indeed patients have cited this as a reason for not participating. On the other hand, managers have asked us when we will start seeing the financial savings. There have been times when I (clinical lead) had reservations about starting the Programme in the first place as I did not want to provide a way of stripping the staff out of the dialysis units. We believe, therefore that there is a complex message that needs to be delivered from this work. The message is that we are using the cultural change of greater patient involvement to enhance patient experience and to improve the professional role of nurses – rather than to deliver increases in patients going home or cash savings. The objectives require to be more modest than we had originally envisaged, but at the same time more realistic and patient-centred.

3.4 Assessment of the quality of the data.

3.4.1 Qualitative Measures

3.4.1.1 Potential barriers to obtaining good quality data

- We attempted to interview a range of patients who participated or not in SHC. Interview packs were mailed by nurses familiar with each patient. This could have introduced bias into who was invited to participate.
- Patients were interviewed while they were on dialysis. This reduced the impact of the interview process on patients but may have affected what patients were willing to disclose.

- Healthcare professionals were identified by Matrons and interviewed at their place of work, again this may have altered who was interviewed and what they were willing to disclose.
- Interviews were conducted by a range of people with different backgrounds (implementation researcher, patient and carer) this may have affected what was asked and what was probed for further. However, we believe this improved the quality of our interview content and the data that we collected.

3.4.1.2 Potential limitations in analyses

- Interview data were coded to a previously used framework that has been found relevant to a range of other clinical conditions. There is no guarantee that this framework covers all relevant barriers/enablers to SHC.
- Two researchers familiar with the framework coded interview data. We could not explore the reliability of this coding statistically. Qualitative review of our coding suggested a good level of agreement.

3.4.1.3 Extent findings were validated with stakeholders

- Members of our multidisciplinary team reviewed interview transcripts, the results and the conclusions drawn from our interviews.
- Results and conclusions were fed back routinely to our multidisciplinary Programme board.
- We fed back results of our interviews to a multidisciplinary stakeholder audience at our national learning event.

3.4.2 Quantitative Measures

We wanted to be able to demonstrate a high level of satisfaction with SHC but realised that we were not comparing it with anything and the results therefore were insignificant. Many patients placed themselves in the middle of the numbers and did not relate doing things for themselves as improving their experience, particularly if it was just weight or blood pressure. Others, who were more involved, rated their experience highly. The question excluded and did not compare with those patients not doing SHC.

4. Discussion / Learning

4.1 Summary

4.1.1 *Successes overcome*

- Building a team of enthusiastic partners including key patient partners. The argument for the value of the Programme was strengthened by the enthusiasm of those who joined – each who joined brought their own experience and expertise contributing to an inspirational team. We learned how to respect the diverse contribution of individual team members.
- The demonstration that it is possible to initiate and spread a Programme of SHC on the units of Yorkshire and the humber. Patients were so pleased to be given the opportunity to learn aspects of their treatment and told very strong personal stories of what it meant to them to be able to do this. Many of them participated in our open meetings discussing their individual experiences.
- The development and delivery of training the trainers course for nurses. This was developed by nurses and patient partners, and subject to critical review to evolve to the currently used curriculum. Nurses who have attended the course describe a “light bulb moment” when they realise the value of patients having the opportunity to take part in their own treatment.
- Moving forward the discussion of the role of greater patient engagement in care – through presentations, publications and meetings. This really involves developing the understanding of the issue – with a focus on patient experience, guarding against focusing on saving money.
- A study of the patient and staffing experience of SHC, including a better understanding of the barriers and drivers to patient engagement. This is one of the few academic pieces in this area.
- An understanding of the most appropriate measures necessary to document the uptake of SHC across dialysis units. We have subjected the measures to several iterations of quality improvement, in order that they can balance value of information against the burden of data collection.

4.1.2 *Barriers still to over come*

- It is necessary to demonstrate the evidence for SHC using evidence from robust research studies – including safety and outcome measures. It was not possible for us to conduct this level of research during the Programme. In particular it would be very important to be able to demonstrate that patients who insert their own dialysis needles have better outcomes than when nurses do it. This would strengthen the argument for greater patient involvement in their own dialysis care.
- Spread and sustainability – considerable further work is required to ensure that the required cultural change so that patients are given the opportunity of participating in their own care in the context of a supportive environment on each dialysis unit in the UK. We believe that the training for nurses, focusing on the

importance of facilitating patient involvement, needs to continue in order to provide an engine for on-going change. The argument needs to be embedded into the culture of renal units – our message should be that we will help patients to look after themselves where possible – rather than the current system where most patients become passive recipients of care.

- Health economic evaluation – this is around the importance of demonstrating effectiveness versus efficiency, exploring the balance between cost and quality. We intend that nurses will be able to spend more time with patients supporting them in their understanding of their condition – the danger is that SHC is seen as a way of reducing the number of nurses on the unit.
- A greater understanding of the barriers and drivers to greater patient involvement – since this will lead to a better understanding of how to facilitate the change at an appropriate level. It is very important that we listen and understand the reasons why patients may not want to engage.
- Redesign of dialysis services centred around patients – this will take time, but include the opportunity for patients to have a personalised and timely service designed around needs of the patient rather than the service

4.2 Achievements, challenges and things that didn't work out quite as planned.

4.2.1 Changing the relationship – what we hoped for

We hoped to achieve a change in the relationship between patients and staff for people who require centre-based haemodialysis. The approach was to be for patients to be supported to undertake aspects of their own treatment. We knew that it was possible for people to dialyse themselves safely at home and wondered whether this could be applied to the hospital situation. We hoped that greater engagement for patients would result in benefits in a range of domains of healthcare. We also hoped that there would be benefits for nursing staff who would experience an improvement in job satisfaction, as they moved from a role in which they performed repetitive tasks, to one in which they trained and supported patients to take on aspects of their own care.

4.2.2 What we achieved

We achieved much of what we hoped. We were overly optimistic about the numbers of people who would be looking after themselves completely by the end of the Programme, and the numbers of people who would have chosen to dialyse themselves at home. However as the Programme developed and we listened to the things that mattered to patients (evidence from our patient partners and from the people who spoke at the many patient groups that we held) we changed our priorities from numbers to patient experience. We realised that for many people the possibility of being engaged to at least some extent, even if it was not to do all of their own treatment, meant a lot to them and helped them to experience more patient-centred care. We understood that patients who learned to dialyse themselves would not necessarily wish to dialyse at home – that would depend on their circumstances. We realised that equity of access to the opportunity of taking on aspects of care was important – hitherto for patients to be able to do their own

care they had to be planning to go home, now it was possible for all patients to be engaged in their own treatment.

4.2.3 Positive engagement

Engagement at all levels was essential to this Programme and indeed remains central to its success. To deliver as much as we did we relied on input from many individuals. Thus patient partners made the argument in our application, at the initial interview with the Health Foundation, or at meetings and presentations. Patient partners presented their experience in a range of forums and by doing so gave the strongest argument to continue and to develop the Programme. Support from the Yorkshire and the Humber renal network including commissioners and managers provided the structure for disseminating this work across our regions and embedding it into the Home Therapies and Self-Care strategy that we developed during 2010. Our nursing partners provided practical direction on the dialysis unit regarding the implementation of SHC, developed the training course and the supportive materials. We were able to appoint excellent clinical nurse educators who worked very hard to support and persuade patients of the value. Our implementation researcher, Liz Glidewell, developed the qualitative evaluation protocol which was supported by patients and carers who became researchers, including obtaining all the research governance components necessary for that to be done. We had coaching support from the Berkshire agency (Liz Hill-Smith) and from Noeleen Devaney on quality improvement. Our Programme Manager worked hard with us to keep us to the required deadlines and to deliver to the objectives. We received encouragement from our partner Trusts across Yorkshire and the Humber, the Nursing and Midwifery Council, NHS Kidney Care including the director Bev Matthews and Donal O'Donoghue the UK Renal Director. Each of these components, and many others not listed (chair, network manager, commissioner), contributed to the energy and enthusiasm to move this Programme forward.

4.2.4 What worked well

The most successful approaches were persuasion through hearing the patient stories – presented by many patients who wanted to share what it meant to them to be given some responsibility for their own care. The training course for nurses was absolutely key since it allowed nurses to understand, discuss and compare notes on how best to support patients in this endeavour. Clear documentation, through the development of a competency handbook for patients, was essential in order for progress to be marked on an individual basis; and the development of measures was key to being able to see how far we had progressed at individual centres and overall. We held many forums across the region in which people could present experience and learning, and discuss barriers and facilitators, and these forums continue to be important. Central to the success of the Programme is nurses believing that it is important and patients being prepared to try for themselves in a supported environment and then to tell their peers of their experience.

An evolutionary approach that permitted organic growth of SHC was important, allowing a degree of flexibility about how it was delivered at each centre. It was important for individuals to be able to put their stamp on their own approach and to be acknowledged for the work that they had done. We were very keen that individuals presented their experience at meetings. We did learn about resistance and it came in many forms. Thus some centres run by people with strong personalities needed to be in a

leadership position and did not want to be followers – understandably. And we had to find ways of allowing this to happen. But ultimately when we saw developments at those centres, even if the source of the concept was not acknowledged and it was delivered in a different way to that which we had envisaged, we were able to celebrate the opportunity for patients to take greater control.

The main organisational component that helped us was the presence of the Yorkshire and the Humber Renal Network (which has sadly been abolished following the health service reorganisation) and NHS Kidney Care (which has also been closed). Thus we had an opportunity to work on the delivery of a quality initiative across a region and those circumstances have changed since. However, during the course of the Programme we have been able to make strong links between units that we hope will hold strong for the future. We learned how to streamline our approaches and work across units which was really novel and strengthened the work that we were doing.

4.2.5 What we found challenging

We have had difficulties in a number of areas. Firstly, where we did not have managerial control over the dialysis service, we found genuine challenges in disseminating the work, or could only do so partially. When the experience of staffing at a particular area was low, that provided an impediment to progress. Where there were significant competing pressures related to structural organisations or low staffing levels it was difficult. In one centre the case mix included patients with acute kidney injury and such patients were not in a position to take part in learning their own care.

We found engaging clinicians to be challenging and used a number of approaches. These were including payment (we appointed clinical leads for each renal centre and paid 0.5 PA of clinical time for a year), asking clinicians to teach on the course (which meant that they worked hard to understand the agenda) and influenced them through discussions at the renal network and other meetings, including learning events. However, engaging busy clinicians remains a challenge.

4.2.5 To the extent that you didn't achieve what you hoped for, what were the reasons for that?

The main reason to not achieving the penetration that we had hoped for was the scale of the Programme. To expect to get a Programme developed, evaluated and engaged across 26 dialysis units in 2 years was ambitious – but it was important that we were. Anything that was achieved has felt to be on the basis of ambition rather than realism. However, on the ground there were many complex reasons why there were difficulties – some have been given above and others are presented below:

- We were keen to pilot our Programme before spreading it – which meant that those units who were waiting to be engaged may have become frustrated due to lack of progress. The team at Hull visited a pilot site, observed what was going on and made a start themselves before we were able to share with them as we had intended. There were subsequent problems in the area of communication as a consequence, not least because their services are provided by a private partner

(Fresenius). On the other hand Fresenius are very much on board with the concept of SHC as a quality improvement initiative and could potentially spread it to other units that they run across the UK

- There were practical issues around staffing or the logistical arrangements of dialysis units which made it more difficult to engage the teams or spread the concept, whereas in other units SHC was taken up energetically. For example, in Bradford, translation to Urdu has been necessary and we have done some work on this – but there remains much to be done for the concept to be successfully adopted.
- Where there were staffing issues, or competing pressures SHC was more slow to be adopted. Where there was reluctance from senior partners this was also inhibitory.

We adopted a range of measures to try to overcome these difficulties – but at the heart of it was nurse training, patient engagement and communications to try to provide influence at many levels.

In terms of how we would have done things differently we do not think we can identify one particular measure. We have been very fortunate in the way the Programme has developed; we were able to appoint excellent staff to work with us and had an inspirational team. We were supported by a powerful network. We hesitate to suggest that a different approach would have been more successful. The reality is that change is incredibly difficult to effect and we have made some impact, but there is a long way yet to go. This requires the cultural change that we have been discussing.

4.3 Interpretation

There are a number of reasons for the differences between observed and expected outcomes, in the context of both the Programme itself and significant healthcare organisational and national pressures.

The effectiveness of the Programme overall has been significantly influenced by the enthusiasm, expertise and experience, well beyond that which might have been expected at the outset. We have genuinely surprised even ourselves with the commitment and passion that individuals have given to the Programme. We have been driven by the strength of the patient voice and the value that patients have placed in the changes to their dialysis experience.

Although achieving the final model of the nurse training course has proved challenging we are delighted by the recognition this has received, well beyond the geographical boundaries of the Programme. Some of the challenges were initially around differences

in approach within different individuals and organisations. Traditional NHS hierarchies are difficult to overcome.

We have genuinely benefited from our focus on the patient experience.

However, we have struggled to a greater extent than expected with measuring outcomes and providing robust quantifiable data to evidence the change in relationships. This has been due, in part, to quality improvement methodology being a significant area of learning for the whole team (understanding and developing quantifiable, meaningful measures). Embedding data collection on a monthly basis could be considered as an additional burden in already busy environments.

The external NHS environment has had a significant negative impact. Changes to commissioning arrangements, NHS Kidney Care and Clinical Networks created a period of uncertainty which still remains. Pressures in the NHS system, which are currently well documented, continue to place an emphasis on troubleshooting and short term solutions, at the expense of real investment in quality and outcomes. Cost pressures for NHS providers are also expected to increase, hence while we understood the financial and capacity challenges of creating a new environment and culture around haemodialysis, we will continue to experience these challenges. There is also an anxiety that once Programme funding ceases and dedicated resources are no longer available, then long-term sustainability may not be achieved. We will continue to rely on the commitment of organisations and individuals that all will not be lost.

Clinical and patient engagement will continue to be vital. The national service specification for hospital/satellite haemodialysis needs strengthening in its reference to SHC, to ensure that this becomes a genuine choice for patients.

Delivering the ambitions of the SHC Programme will continue to challenge us all!

4.4 Link between interventions, changed relationships and quality of care

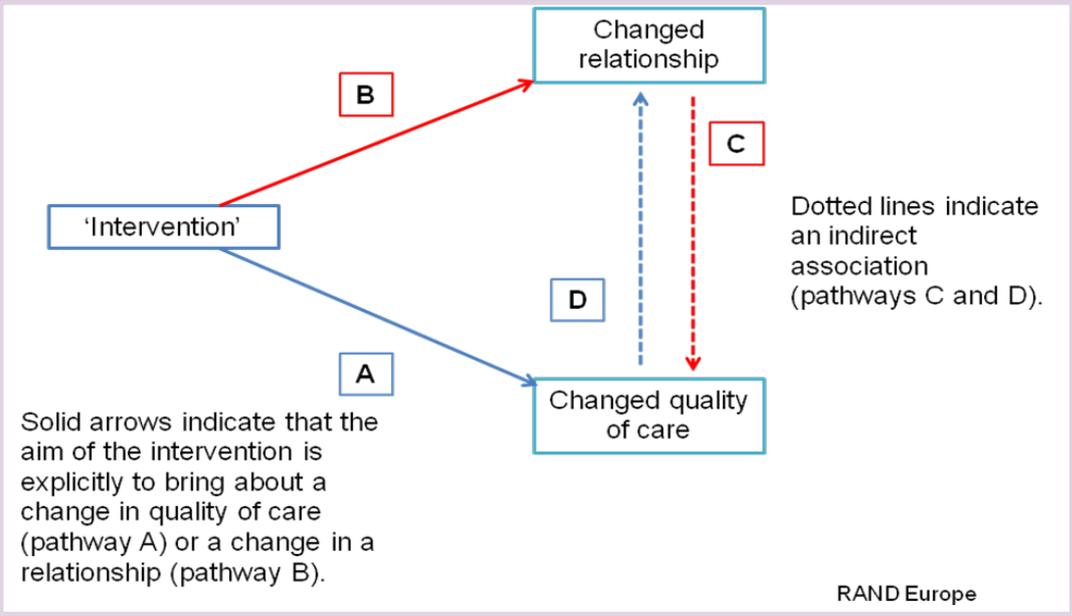
This Programme had the dual aim of both a change in the quality of care for patients receiving in-centre haemodialysis as well as a change in the relationship between the patients and healthcare professionals. In reference to the RAND diagram the multi-faceted intervention that is described in this document was explicitly expected to have this dual effect (A and B) in the haemodialysis units.

We carried out qualitative research to measure the change in experience for both patients and staff and this by work by Dr Glidewell is described elsewhere in section 3.2 Results Achieved for Quantitative Analysis and referenced as a poster in the Resources to Share Section 5. below;

The main driver behind the change in quality of care has been the change in relationship between patients and staff. This change has been from one where the patient has been passive, with the nurse as the “doer”, to one where the patient is much more actively engaged and the nurse has become a facilitator/educator. This change has allowed patients to take a greater role in their own care and the experiences that they have described have come out of that changed relationship. Patients have then been able to learn more about their treatment and have been given permission to take on practical

aspects of their care. The domains of healthcare that we believe this process acts on are a consequence of the patient playing a key role in care delivery (for example safety, equity, timeliness and patient centredness). It is true that structural changes have had to be made in the quality of care – for example the preparation of a competency booklet for patients, and the development of a series of measures that are recorded on a regular basis – but these have evolved as a necessary consequence of the change in the patient–nurse relationship.

There is another facet to the impact of this intervention on relationships and quality of care that is larger than individual dialysis units. This relates to the interactions between healthcare professionals (and patients) throughout all of Yorkshire and the Humber and via the two annual SHC Learning Events for all of the United Kingdom. We did not attempt to measure this and the nationwide adoption is still work in progress. In Yorkshire and the Humber there have been several examples of shared learning and more efficient clinical practice’s adopted from one site by another after learning through this Programme.



5. Resources to share

Shared Haemodialysis Care Products

Patient Handbook



Nursing Journal and Training Course Curriculum



Stakeholder Communication and Engagement

Leaflet



Course Promotional Poster



Handbook Promotional Poster



Shared Haemodialysis Care Posters (x4)



Hand Hygiene poster



Newsletters

Shared Haemodialysis Care Programme Newsletters:

- June 2011
- February 2012
- June 2012
- October 2012
- January 2013



Items in Yorkshire and the Humber Renal Network News:

- December 2010
- February 2011
- June 2011
- September 2011
- November 2011
- March 2012
- September 2012



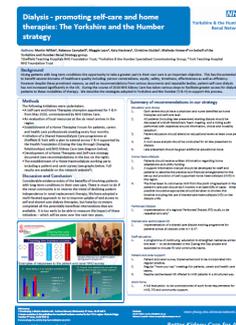
Items in Kidney Care Matters

- July 2012
- October 2012

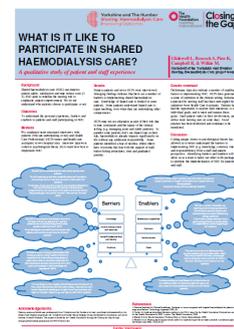
Articles in local Trust and Kidney Patient Association Newsletters

Abstracts and Poster Presentations

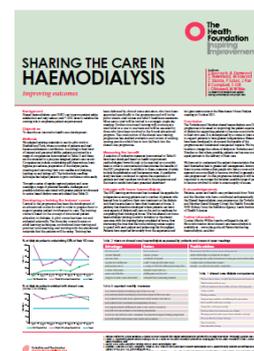
Wilkie M, Campbell R, Lean M, Hackney K, Stubbs C, Howard M: **Dialysis - promoting self-care and home therapies: The Yorkshire and the Humber strategy**, British Renal Society – June 2011



Glidewell L, Boocock S, Pine K, Campbell R, Wilkie M: **What is it like to participate in Shared Haemodialysis Care?** Association of British Clinical Diabetologists, February 2012 & Renal Association, June 2012

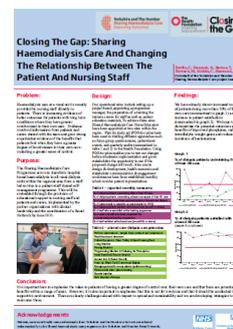


Boocock S, Henwood A, Newstead C, Howard M, Stubbs C, Laboi P, Parr J, Campbell R, Gill S, Glidewell L, Wilkie M: **Sharing the Care in Haemodialysis**, International Forum on Quality and Safety in Health Care, April 2012



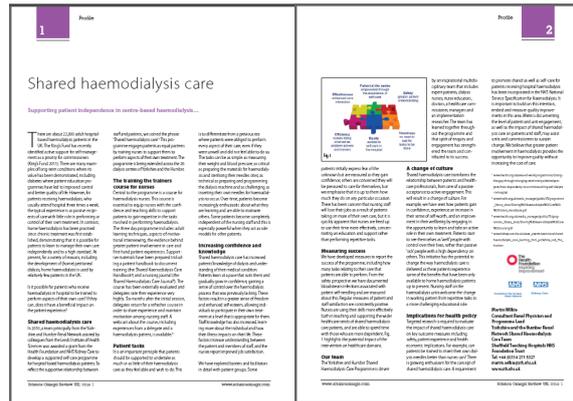
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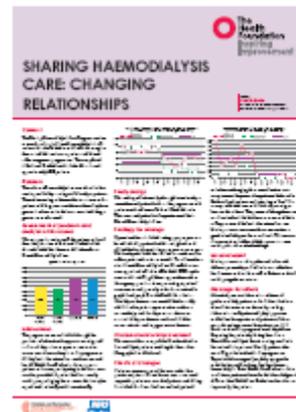


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Publication: Science Omega Review Europe, Shared Haemodialysis Care, by Martin Wilkie, 20 March 2013



Collette Devlin, On behalf of the Yorkshire and the Humber Programme Team: **Sharing Haemodialysis Care, Changing Relationships**, International Forum on Quality and Safety in Health Care, April 2013



Glidewell L, Boocock S, Pine K, Campbell R, Hackett J, Gill S, Wilkie M: **Identifying the Barriers and Facilitators to participating in Shared Haemodialysis Care – A qualitative intervention development study of patient and staff experience**, International Forum on Quality and Safety in Health Care, April 2013



Events

Regional Shared Haemodialysis Care Programme Launch Event – March 2011

National Shared Haemodialysis Care Learning Event – June 2012



Second National Shared Haemodialysis Care Learning Event – June 2013



Patient Advert for the Second National Learning Event – June 2013



NHS Kidney Care E-Seminar – November 2012

Presentations at the Home Therapies Conference, Manchester in September 2011 and October 2012

Yorkshire and the Humber Home Therapies Forum (June 2010, October 2010, January 2011, May 2011, September 2011, January 2012, May 2012, September 2012)

Websites

Yorkshire and the Humber Renal Network – Shared Haemodialysis Care Webpage:

www.yhscg.nhs.uk/Networks/sharing-haemodialysis-care.htm

Huddle – An interactive forum to contribute to the development of the Programme, to share and discuss ideas and to monitor progress.

Reports

Health Foundation Quarterly Reports

Reports and Presentations to:

- Yorkshire and the Humber Renal Strategy Group and Renal Local Implementation Groups
- Yorkshire and the Humber Specialised Commissioning Operational Group Meeting
- NHS Kidney Care Home Therapies E-Seminars

- North West Shared Haemodialysis Care Framework Group



National Learning Event on SHC, June 2012

“I have been very fortunate in my career to have had the chance to work with a large number of extremely committed colleagues. I have always regarded it a privilege to be able to contribute to the care of patients with kidney disease. The shared learning event brought together these two elements as powerfully as I have ever seen. None of this would have happened without effort well beyond the ‘call of duty’. Many have been involved with the Programme from the beginning others have volunteered as the Programme has evolved. I was very pleased to see colleagues from other parts of the UK who came to share their experiences as there is more than one way to work towards better kidney care, which is of course what it is all about. Many thanks to all, not just the presenters and Programme team, but to the delegates for their part in this event.”

Comments by Dr Chas Newstead, Chair

6. Sustainability

A number of challenges face us in sustaining this important work.

A significant challenge is nursing numbers and time constraints in some of our dialysis units. All NHS organisations continue to face significant pressures for efficiency savings, and most have yet to find more sophisticated ways of achieving savings, other than to simply reduce staff numbers. It is hoped that demonstration of success in some units will help to encourage others to find ways of overcoming this barrier, as the longer term opportunities can far outweigh the challenge of getting over the initial hurdles.

The Programme is also challenged by the radical changes to the NHS as a whole, taking place from 1 April 2013. The Programme has benefitted enormously from being hosted by the Yorkshire and the Humber Renal Network, which will cease to exist in its current format at the end of March. It is hoped that ways can be found to continue an emphasis on kidney care, and to continue to support SHC, under the new network arrangements, and those involved are determined to find a way of achieving this.

Continuing to provide education and training in SHC presents a further challenge to sustainability. Due to resource constraints, it will not be possible, beyond formal Programme end, to continue to provide the current 3-day training course. The Programme is, however, hoping to produce an e-learning module, and to secure a suitable host for this, that will allow access to staff, right across the country, when our formal training courses end in the summer. Securing the culture change required in our haemodialysis units for the longer term remains a risk to the Programme. However, if we have enough people – clinicians, nurses and patients – who remain committed to SHC and continue to champion the cause, then we may well see it being business as usual in the years to come.

Embedding the work of the Programme into business as usual has also been strongly supported by the requirement of all NHS providers to offer the opportunity of SHC to all patients across the NHS, by way of the new service specification. This will eventually contractually oblige providers to make the offer to patients – implementation of the service specifications has been held back, until October this year.

The Programme has delivered the tools necessary for all providers to implement SHC, and together with the e-learning module, should secure its future for both staff and patients. Members of the Programme team have also taken every opportunity to share the learning from and the opportunities of SHC, both nationally and internationally, and have committed to continue to do so. A second learning event is planned for the summer, and it is hoped that the message will continue to extend its reach.

The introduction of patients to the concept of SHC as part of preparation for dialysis, through education and information, should create an expectation from patients, that the opportunity to participate will form part of their treatment, when the time comes. This

continues to place a real emphasis on shared decision-making about treatment options and on choice for renal patients.

Finally, as many will know, the Programme team has been shortlisted for the BMJ Renal Team of the Year Award. A win would provide a further opportunity to raise the profile of our work!

7. Spread

7.1 Explain your plans for spreading the learning and outputs of this Programme

Plans for spreading the learning and outputs from the Programme are alluded to in the above section. Key emphasis is placed on:

- Further learning events
- Further publication of aspects of the work of the Programme
- The continuation of network forums, wherever possible
- The patient handbook and the nursing competencies/journal being made easily and widely available, in formats suitable for appropriate local adaptation
- The development of an e-learning module, hosted by an appropriate organisation, again to allow wide accessibility, and to facilitate regular update
- The continued development of mandated national service specifications for hospital and satellite unit haemodialysis

7.2 How are you promoting your innovation and convincing others of its value?

We have promoted this innovation through several channels which is about to be effectively dissolved, used to run a series of webEx presentations. We were invited to use one of the national and well attended webExs hosted by NHS Kidney Care to showcase the unit at Jönköping where patients have access to the unit for extended hours and take on a large proportion of their care. This we emphasised was a logical extension of the SHC Programme.

The innovation was described in an article published in February 2013 in a free to subscribers' on-line journal *Science Omega Review*.

The Yorkshire and the Humber SHC team was a finalist for the *BMJ* "Renal Team of the Year Awards".

We have presented posters describing our work at international meetings relating to the psychology of patient choice and treatment adherence. We were able to have a session dedicated to SHC at the British Renal Society meeting held in Manchester in May 2013, as well as several linked posters and presentations.

We organised a national learning event in June 2012 that was well attended and hosted an event on 4 June 2013 that was also very successful. In this event we were able to showcase aspects of our initiative and to learn from colleagues doing similar work elsewhere. In that event we set the basis for sustainability for the future of SHC across the UK and plan to hold similar events on an annual basis. In the immediate future the focus will be on achieving sustainability. The fact that provider units are now obliged through the service specifications to offer SHC ought, if Commissioners hold units to this requirement, allow a steady roll out of the idea throughout at least England.

7.3 What advice would you give to someone attempting to replicate your work in another organisation / setting?

7.3.1 What levers should they employ to facilitate change?

Before any other Programmes are embarked on there should be “buy in” from the Chief Executive and the Chief Nurse of the Trust.

7.3.2 What barriers and challenges should they prepare for?

A Matron has to be very visible in her role and be very much operational. Therefore there is a real issue of having sufficient dedicated time to help deliver and support the Programme. There have been barriers from line managers who do not appreciate the benefits of SHC and consider it to be an interference with core duties and responsibilities of the Matrons. One barrier is the view from some finance managers that SHC can mean a reduction in nursing staff levels. This view was sometimes shared by patients who were resentful that they were undertaking some of the nursing tasks. Other patients were worried they might be contributing to a context in which nurses might lose their jobs. The functionality of dialysis can inhibit a nurse responding to patients’ individual needs and learning styles.

7.3.3 What risks should they be aware of?

Other renal centres will want to undertake SHC in their own way but it will be a modified version which they believe is SHC but is self-care. Their statistics will be included in the overall figures but may not actually relate to SHC outcomes. Other risks are that when the SHC Educator posts go at the end of the Programme, there is no one to support staff to run the 3-day course and sustain the Programme in general.

7.3.4 Where should they target their efforts to enhance their chances of success?

Executive Seniors within Trusts such as the Chief Executive and the Chief Nurse. If a change Programme has top level buy-in and commitment this disseminates down the vertical hierarchy making it operationally easier to implement.

7.3.5 What should they do to ensure they are successfully measuring the effects of their intervention and producing robust evidence?

Measurements of success and evidence – ensure data collection and measurement methods are simple, sensible and accurately reflect the clinical work.

“As chair of this Programme Board I would advise anyone who was trying to do similar to try to collect a team with diverse skills. The attributes of the Programme Manager need to be different to that of say a nurse educator. My best advice is to appoint strong people and give them clear devolved responsibilities. Recognise that different personalities have different and equally valuable preferences for team working. The ‘Judges’ with their enthusiasm for clear deadlines and tasks are different from the

‘perceiving types’ who prevaricate until all information is collated. To make a team work well requires effort and careful judgement.”

Comments from Dr Chas Newstead, Clinical Chair of Programme

“Early on it is important that at all tiers of people understand the blocks to cultural change ‘on the ground’.”

“Never underestimate the challenge that to change the culture of care delivery is difficult, but it can be done and the rewards are worth the effort.”

7.4 What do you see as the main challenges to the future diffusion of your work?

7.4.1 Inertia from service provider, professionals and patients

It is easier for patients to just turn up and be dialysed – less challenging. So a cultural change is required in the way that we approach care in which we are not saying to patients with chronic kidney disease (CKD):

“I’m sorry you have CKD – don’t worry, we will look after you”

to a situation in which we are saying:

“I’m sorry you have CKD – we will help you to look after yourself”.

7.4.2 Cultural problem that currently exists

Is one in which we are not prepared to challenge the existing arrangement in which the “sick” are disempowered and suffocated with sympathy. In attempting to overcome these issues we have worked on trying to get sufficient engagement in the participating units in order to achieve a “tipping” point where SHC becomes “the way things are done around here”. However, we cannot be confident that this has been achieved in all units. For example changes to personnel and patient turn-over could erode all the work we have done unless there is an on-going engine to drive this. That is why we believe that being able to run a nurse training course over the coming years would be an important aspect of sustainability. Unfortunately we have not managed to identify funding for this activity.

7.4.3. Lack of evidence around our interventions

This needs to be developed through robust clinical study. An example is the evidence around patients needling their own arterio-venous fistula – if it can be demonstrated that patients needling their own fistulas means that the fistulas last longer that would indeed be a strong argument for greater patient engagement. Equally there is a concern that using the button hole technique may increase the risk of bacteraemia – which it certainly can do if not done well. This perception alone could lead to the outlawing of this very helpful approach to patients dialysing themselves.

7.4.4. A reduction in the skill set and confidence of the dialysis nurses

This is a potential risk for sustainability – since this intervention requires to be supported by experienced, confident and professional nursing teams. Cost savings may erode the existing expertise on dialysis units posing a threat to quality initiatives such as these. For example if a decision is made that renal services will be supervised by a Matron who does not have experience in dialysis then this can have an impact on the understanding and motivation to conduct SHC.

A practical matter is that if the dialysis machines are changed to a different supplier on a particular unit that would mean patients having to relearn some of their skills and this could derail the process at individual centres.

8. Conclusions

SHC has changed relationships due to increasing confidence and control, self-esteem and freedom, also as a result of increased understanding and knowledge. This has been highlighted through the qualitative evaluation.

It should be noted that the qualitative evaluation was innovative in that a patient and carer conducted the interviews. This approach is unique and highlights the importance of the patient within SHC. The importance of the patient within the Programme is also demonstrated by the inclusion of patient leads at all levels of the Programme structure.

“Whilst I understood the benefits of conducting considerable aspects of my own care on dialysis (prior to this Programme starting) including button holing, I remained apprehensive regarding joining a team of Health Care Professionals (HCPs), senior medics and senior NHS/Trust managers, in the back of my mind was whether I was a ‘token’ patient or someone that was going to be humoured and not taken seriously.”

“My advice to those patients that are asked to be involved is to take a ‘leap of faith’ as neither of the above are true and I feel a valuable member of an eminent team of professionals. Whilst the patient perspectives are ‘sort of’ understood by the HCPs, medics and senior NHS/trust managers, there is no better way to confirm these aspects than via a patient that has been through the process or who is outside the NHS and who can challenge methods, procedures, processes etc. as well as ask ‘why?’.”

“This was, and remains a fantastic Programme to be a part of and one which can only ‘mature’ into a natural process in the fullness of time.”

It is acknowledged that more work is required to engage patients both as part of the Programme team and also as participants in SHC. There is much interest in the development of a Peer Support approach. In the meantime, work continues to share the patient story, and more broadly the learning of the Programme, through presentations at regional and national events, e-seminars, newsletters and blogs.

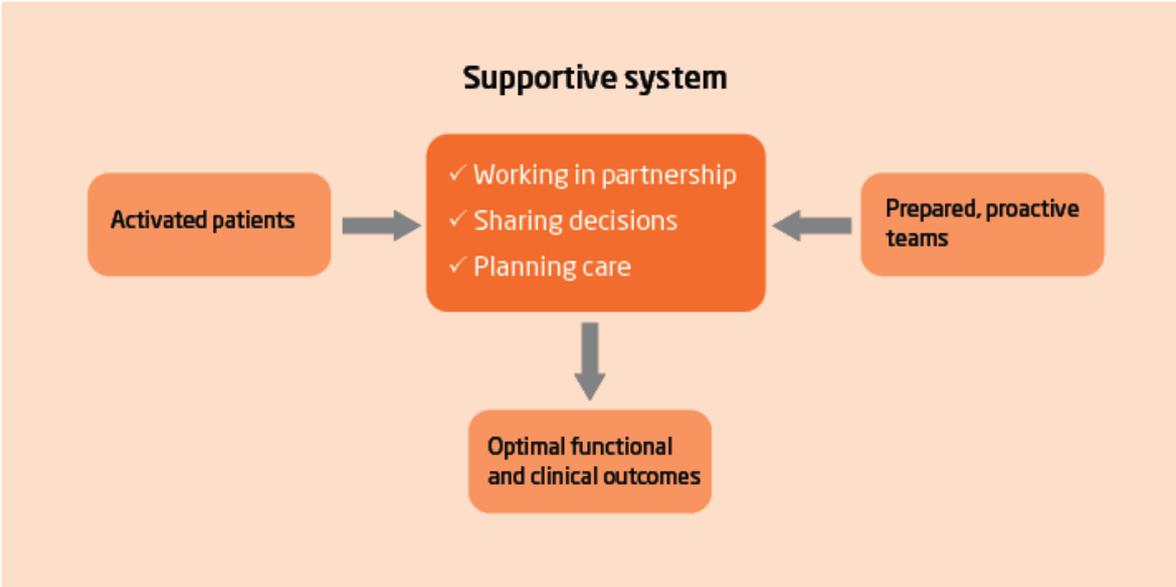
Sharing the learning is important to ensure that SHC is embedded and that a cultural change occurs, for both patients and staff regionally and nationally. The benefits to patients and staff are considerable, but change is not easy to achieve or maintain. The design and implementation of a nurse training Programme aims to facilitate the change. The use of quality improvement methodology has been beneficial and the training course has been planned, tested, reviewed and revised and then re-tested. The course is subject to evaluation and participants are encouraged to reflect on their own practice.

The design of the 3-tiered training course ensured senior level support, training for unit staff and dissemination to those staff who are unable to attend. There is an issue regarding ‘spread’ to ensure that sufficient staff attend the course to embed the changes within the lifespan of the funded Programme. In addition, the course is delivered by the Nurse Educators, who also play an integral role in the overall implementation of SHC, and the issue of ‘sustainability’ must also be highlighted. Another issue of concern to the Programme is the future of the Yorkshire and the Humber Renal Network, and also of NHS Kidney Care, the support of which has been critical to the development of SHC. The Spread and Sustainability Workstream and the Programme Board continue to monitor and address these issues.

Monitoring and measuring success is central to quality improvement. The monitoring of the implementation of SHC includes measurement of patient uptake and the number of nurses trained. Another area of interest is whether an increase in the number of patients undertaking SHC results in an increase in the uptake of home haemodialysis. Measurement is challenging and if sharing haemodialysis increases HHD, it will be as a result of patient choice rather than direction.

Choice is a key element of SHC. Patients are encouraged to do as little or as much as they feel able on any given day. The shared decision-making and care planning approach is very much applicable to this area of care, as demonstrated in the diagram below.

The chronic care model and personalised care planning



Source: ‘The Chronic Care Model’ Wagner et al (1996) in Coulter A, Collins A. Making Shared Decision Making a Reality, Kings Fund 2011.

There are considerable changes and challenges to ensuring that SHC is embedded and maintained. However, the successes to date have been the result of a clear, shared vision and a strong team. Activated patients and prepared, proactive teams will together realise the aim to transform hospital-based haemodialysis from a staff-led service to a patient–staff shared self-management Programme.