‘Location of Dialysis Care in Kidney Life’ (LOCAL)

A service delivery intervention for optimising the uptake of home dialysis based on the findings of the Inter-CEPt Study



Foreword

Access to Home Dialysis is not uniform across the United Kingdom.[1] This lack of uniformity cannot be explained by differences in the populations treated, in turn meaning that for patients and their families when negotiating how to live their lives with kidney failure, choosing the location of their treatment is not always prioritised. The Inter-CEPt study[2] was funded to examine this lack of uniformity across services and to use the research findings to propose interventions that may help reduce the current between-centre variation in Home Dialysis uptake.

The resulting *Location of Dialysis Care in Kidney Life* (LOCAL) intervention describes components within service delivery that enable the offer, planning and delivery of treatments to facilitate life participation, recognising that this means different solutions for different people. Some people with kidney failure and families will need much more support than others if they are going to consider home therapies.

We do not set out specific targets for Home Dialysis use, but rather aim to identify ways to enable services to optimise its use in different contexts, recognising this may increase overall uptake. LOCAL takes a person-centred approach, taking reasons for inequity of access into account and focussing on what dialysis centres can do to reduce this inequity by carefully considering their organisational culture. Whilst the research was undertaken in England, the LOCAL service delivery intervention is intended to be applicable to health care organisations across the UK. As it stands, LOCAL is a set of proposals rather than a validated service intervention package and its use in improving the lives of people with kidney failure will require further evaluation.

This report has been developed by the Inter-CEPt study team in collaboration with the study's Patient Advisory Group.

Purpose of this report

This report is intended for patients, their families and carers, healthcare providers and professionals, colleagues in industry and commissioners. In it we describe the proposed LOCAL intervention which is the result of a three-year study funded by the UK National Institute for Health and Care Research (Health Service and Delivery Research Programme). The Inter-CEPt study explored aspects of kidney centre services that either enable or impede the uptake of dialysis in the home. We describe the research and user engagement we undertook to inform its development and give examples of how it could be used, with links to other suggested resources.

Key messages

- Enabling health care to be delivered in people's homes can lead to significant benefits for patients and their families. Home dialysis is such an example but there is significant variability in uptake of home dialysis between centres, especially among ethnic minority groups and those living in more challenging socio-economic areas. There is a pressing need to support ***everyone*** facing dialysis treatment when choosing their *location of care* which for many will be at home where this suits their needs and preferences.

- The Inter-CEPt study sought to provide evidence-based recommendations to reduce centre variation and enable services to support greater opportunities for choosing home dialysis.

- Our research found that home dialysis uptake was associated with a favourable organisational culture rather than any particular pattern of service provision. Centres with a strong clinical leadership that values location of dialysis options, in which staff are adequately resourced to engage in service improvement activities and an approach to care planning that *presumes eligibility* for home dialysis, saw greater uptake by patients from all backgrounds.

- Working together with patients, their families and carers, and with healthcare professionals, we have proposed a service delivery intervention: 'Location of Dialysis Care in Kidney Life' (LOCAL). LOCAL focusses on the following two priorities:

    - Active engagement in service improvement (national, regional or local QI) designed to enhance centre performance in the uptake of home dialysis across the patient pathway.

    - The establishment of dedicated LOCAL roles targeting both clinical reasoning and service management (likely distributed amongst new or existing staff) to address specific service needs, e.g. championing patient engagement approaches, training of staff to discuss service support of home-based dialysis, working with wider networks, and introducing established evidence-based resources and practice.

- LOCAL also identifies specific measures such as providing an Assisted Peritoneal Dialysis service and running Home Dialysis Roadshows which are also associated with higher uptake of home dialysis.

- Our health economic analysis demonstrates the wider cost effectiveness of home dialysis in the NHS and supports allocation of resources to support these interventions. This need for reallocation would be site-specific it is not possible to provide detailed costing but given the cost effectiveness of home dialysis they are likely to be affordable.

Introduction

People that decide to have dialysis to manage their kidney failure can choose from a series of treatment options (see Figure 1: *Chronic Kidney Disease Decision Map*). The type of dialysis they choose does not affect their survival. Haemodialysis can take place either in a dialysis centre or satellite unit or in the patient's home whereas peritoneal dialysis treatment happens where the patient lives. Usually patients and/or their carers can be trained in how to carry out home dialysis, or in some cases can receive assistance from health professionals to enable peritoneal dialysis at home. The decision over *where* to receive dialysis is important as it has considerable implications for lifestyle and wellbeing. Some people will prefer to receive in-centre dialysis, but enabling care in the home can lead to significant benefits for others.

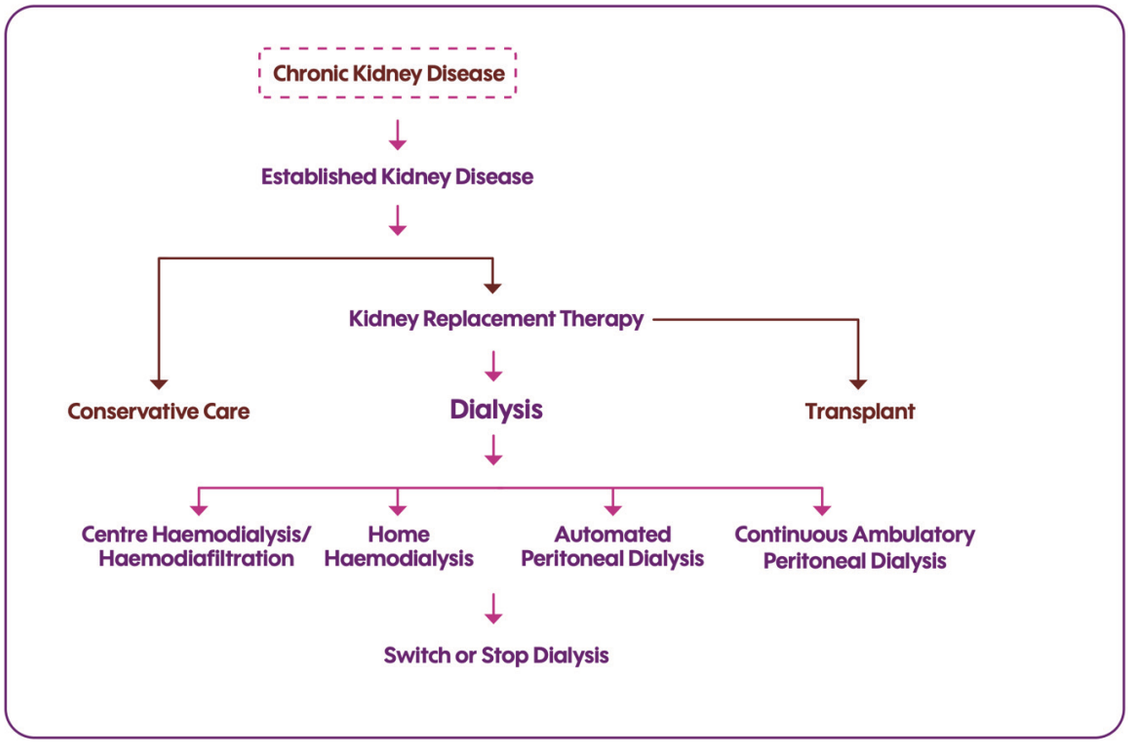


Figure 1: Chronic Kidney Disease Kidney Decision Map reproduced here with permission from the Dialysis Decision Aid Booklet: *Dialysis: making the right choices for you*. For many people living with kidney failure over a lifetime will mean that they use more than one of these treatments at different times and in a differing order. See section on Resources for an online link to this Decision Aid.

Despite encouragement from the National Institute of Health and Care Excellence (NICE) and patient led organisations (Kidney Care UK and the National Kidney Federation) rates of uptake of home dialysis have remained stubbornly low for many years. This is especially the case among ethnic minority groups and people from more socioeconomically challenged backgrounds. Although our research has shown an encouraging trend towards increased uptake of peritoneal dialysis by ethnic minorities there is still

marked inequity in transfer rates from centre to home. The numbers on home haemodialysis are so low that trends are difficult to determine. There are also striking differences in the proportion of patients using home dialysis between kidney centres across the country (see figure 2), with a regional pattern in England (see figure 3).

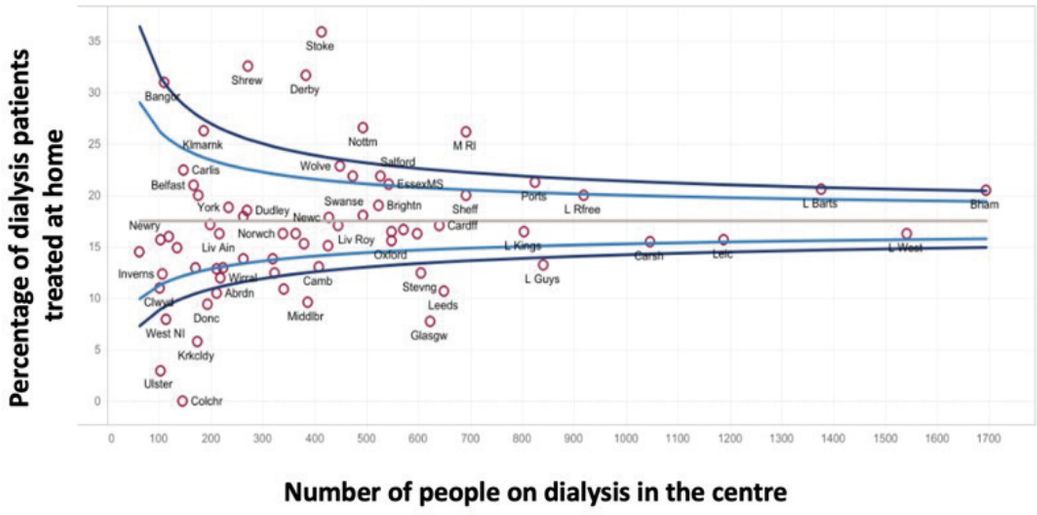


Figure 2: Proportion of dialysis patients using Home Dialysis in 2021 (Renal Registry Report[3]) in UK dialysis centres – plotted against the centre size. The average is 17.5%. The GiRFT report suggests that the target for all centres should be 20%.

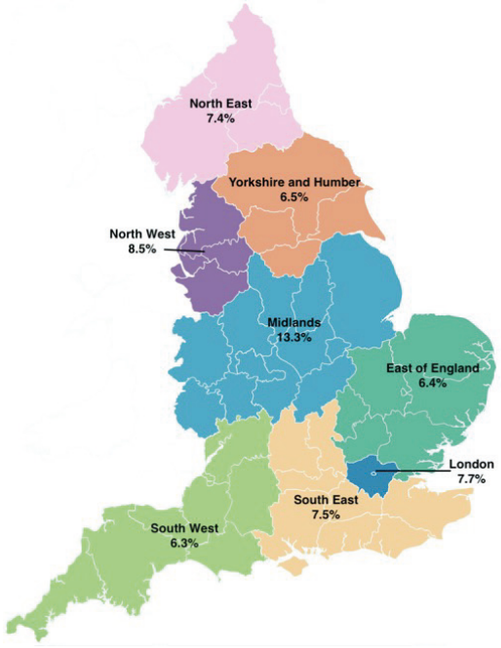


Figure 3: Mean home dialysis uptake by renal network region, shown here as the percentage of all treatments, including transplantation in 2021. Data from UK Renal Registry 25th Annual Report[3] (https://ukkidney.org/audit-research/annual-report/25th-annual-report-data-31122021)

Previous studies have identified potential reasons for these differences. For example, patients may not receive adequate education, communication and support when deciding how and where to receive dialysis. Staff working in kidney centres may also require more effective training, resources or incentives to facilitate patients in making these choices, and services need to adapt workflow systems to integrate innovation to practice. More widely, there may be systemic issues within centres, local or national incentives that influence the behaviours of kidney centre staff and patients.

The Inter-CEPt study was designed to understand how all these factors fit together, calculate their relative importance and use this information to develop and propose a service delivery intervention. The *Getting it Right First Time* (GiRFT) report, (see Resources), has proposed a minimum target of 20% of people receiving their dialysis at home. Although this report does not take a view on this target the intervention is designed to help centres increase their numbers treated with Home Dialysis.

What were the main findings of the Inter-CEPt Study?

Overview of methods in the Inter-CEPt Study

- The Inter-CEPt study aimed to understand the reasons for low or uneven uptake of home dialysis and to develop recommendations for improvement
- We interviewed staff, patients and carers, observed multidisciplinary meetings, patient consultations and education sessions in four kidney centres in England (*ethnography*).
- We then surveyed all kidney centres in England to ask about how home dialysis services were organised and delivered (*environmental scanning*).
- We linked these findings to UK Renal Registry data to see which were associated with the odds of a patient receiving Home Dialysis (*quantitative analysis*).
- We shared the results with a stakeholder group (patients, carers and health professionals, industry representatives) and used these to develop the LOCAL intervention (*user-centred design*).
- We undertook a health economic evaluation of Home Dialysis and determined whether allocation of resource to support the LOCAL intervention would add value (*analytic modelling*).

Our research drew on theoretical frameworks of behaviour change, supporting multiple decision makers' reasoning, intervention implementation and service innovation to ensure findings identified variables relevant to individual clinical reasoning (micro-level), team management within services (meso-level), and policy-organisational oversight (macro-level). The study combined several approaches: *first*, a focused in-depth exploration of four centres with a good track record in home dialysis delivery and demographic challenges (ethnography), *second* a survey of 51 services across England (analytic and modelling), *third* an analysis of patient-outcome data (n=32,400), and finally a user-centred design method to identify the components of the intervention.

The Ethnography Study

This method allowed us to carry out a deep dive into how patients, carers and clinical staff in these four services functioned when approaching dialysis treatment choices, the support structures in place, and how their service was organised. The key finding was that each centre aligns its service delivery resources in ways which accommodate patient need, i.e. not a single model for care delivery. ***The common features were attributes of organisation culture*** – for example shared beliefs in the therapeutic options, attitudes towards empowering patients to engage in kidney management conversations, and recognising the role of services to support some patients with complex challenges. However, they also recognised that they had shortcomings and ongoing scope to improve when supporting some of their patients with complex challenges.

What the ethnography found:

- Kidney centres chosen for their overall good performance with Home Dialysis tended to focus on '*the right dialysis for the right people*' rather than on increasing home therapy uptake per se. This was combined with a shared belief in the value of home dialysis for patients and a presumption that it would be possible to deliver care at home if the patient wanted this.

- These teams sought support from a range of places including specialists, patients' families, other services and professional teams and the community. They also recognised and attempted to address barriers faced by traditionally under-represented groups.

- The ethnography underlined the importance of taking a flexible approach. This involved, for example, regularly reviewing decisions about where to undertake dialysis to ensure that patients were using the approach best suited to them at the time.

- Sustained benefit for patients was underpinned by engagement in quality improvement and working with wider stakeholder groups. Overall this suggests that that organisational culture is especially important, and the extent to which this provided a supportive environment in which home therapies were promoted and valued.

although I've seen friends who've been on this type of dialysis with the fistula, until I actually see what's involved, how complicated it actually is, if it's – then I'll take a view of taking the training and having it at home.
(CKD Patient)

I'd say there's a culture of openness. I think it is the combination of having [leaders] that are friendly, open and listening, but also willing to hold people to high standards and follow up when that's not been done. And quite innovative thinkers.
(Consultant)

I say this to our trainees when they come on placement: it's okay to not know about somebody's cultural background but it's not okay to not ask…. So on choosing a dialysis, explicitly ask them about cultural beliefs, about their community, about their religion.
(Consultant)

…those potential issues, we can overcome them. Storage spaces or lack of help for somebody, can we overcome all those things? And if so, we would then discuss all that with the patient, if that was the modality they wanted.
(Nurse)

National Survey

We then undertook a survey using questionnaire methods informed by the ethnography findings across England to see what aspects of a centre's Home Dialysis programme was associated with higher rates of Home Dialysis uptake.[4] We used insights from the ethnography to design questions related to dialysis centre culture, and a wide range of other centre level characteristics and practices. Fifty one of the 52 centres responded, with an average of three responses per centre.

The findings were striking. There were differences between kidney centres in how they delivered education to support patients making decisions about dialysis and conservative care. Many reported offering one-to-one education sessions, peer support that involved families and carers, use of interpreters and information in multiple languages, and engaging with charities and local Kidney Patient Associations. However, none of these examples of good practice were obviously correlated with Home Dialysis use. Instead it was the unit culture that appeared most significant. This was captured from answers associated with *clinical leadership, engagement with service improvement initiatives and support for trying out new approaches to service delivery* (see box).

National Survey – what mattered?

1) Centre staff feel their clinical leaders perceive home therapies to be very important

2) Centre staff are given opportunities to reflect on their practice and learn from others

3) Centre staff are encouraged to try new initiatives and have the opportunity to contribute to research

4) The centre promotes engagement with quality improvement initiatives

5) Home therapies are perceived to be cost saving

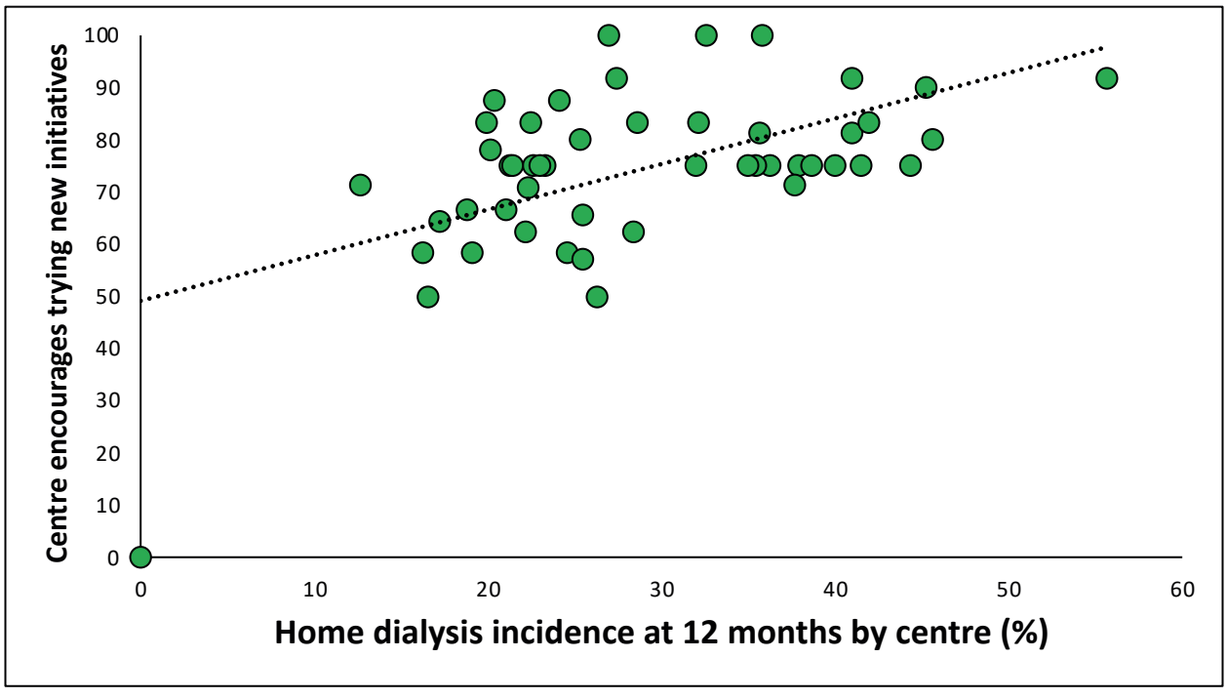


Figure 4: The strongest relationship we observed with uptake of home therapies was with centres that reported a culture that values trying new initiatives

Putting it together with patient-level data

We combined these centre-level findings with a detailed analysis of how 25,000 individuals in these services were managed for kidney failure over some years, using anonymous data from the UK Renal Registry. This allowed us to investigate patient-level and centre factors associated with Home Dialysis. As expected from previous UKRR analyses, older people are more likely to have dialysis in centre, and the effects of ethnicity and socioeconomic status were associated with lower home dialysis uptake. Other factors were how far people lived from their dialysis centre (being further away meant they were more likely to have Home Dialysis) and whether or not they were diabetic (people with diabetes were less likely to be on Home Dialysis). The centre-level factors associated with home dialysis were:

- **Quality Improvement:** If a centre had engaged in a service improvement initiative in the last five years then Home Dialysis uptake was twofold higher
- **Perception of stress by staff:** stress associated with a lack of capacity was associated with substantially less use of Home Dialysis
- **Assisted Peritoneal Dialysis:** offering this service was associated with use of Home Dialysis
- **Home Dialysis Roadshows:** having hosted a home dialysis roadshow in the community in the last two years was associated with higher uptake of Home Dialysis

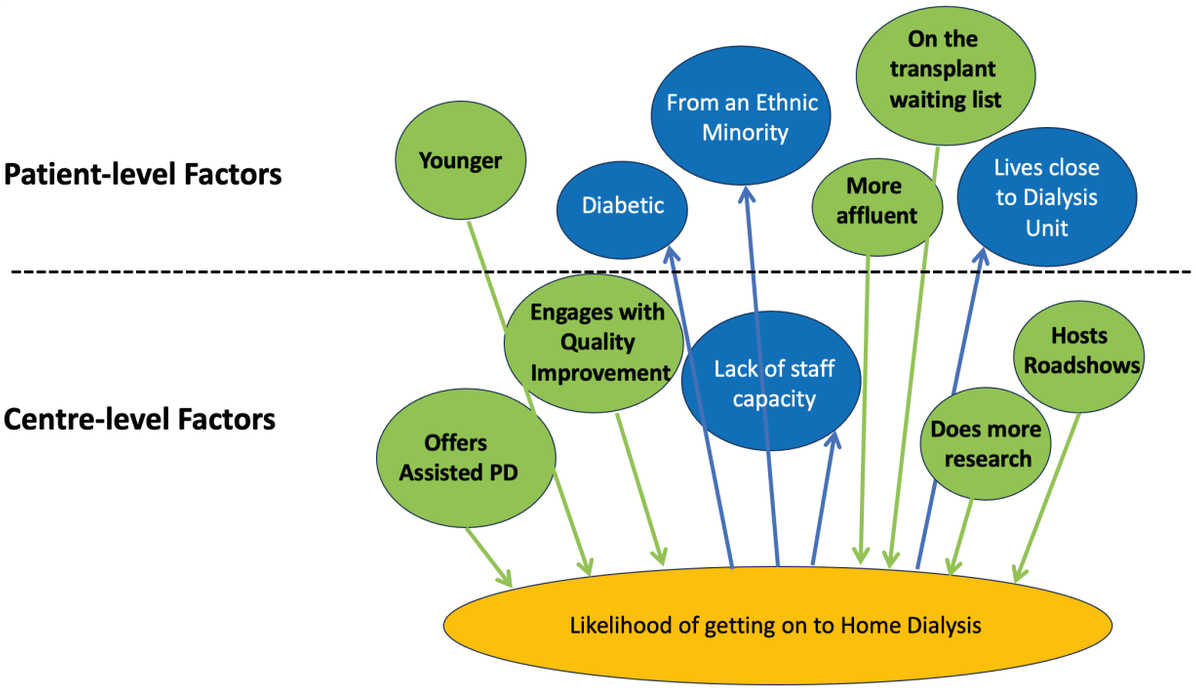


Figure 5: This figure shows the factors linked with the likelihood of someone being treated with Home Dialysis. Those that increased the odds of Home Dialysis are shown in green, those that decrease the odds are shown in blue.

Requirements of a service delivery intervention

For patients, equity of access to Home Dialysis should not be dependent on the beliefs (and prejudices) of their clinical teams. Rather systems should be in place to empower all patients and their families, regardless of their background, to make a considered choice over location of care. Findings from the Inter-CEPt study suggest that a key aim of any service delivery intervention should therefore be to address those aspects of centre culture that might prevent this. In the next section, we introduce and describe the LOCAL intervention.

What is the proposed 'LOCAL' intervention?

Summary

- The LOCAL intervention is designed to help staff in kidney centres support their patients when considering the location of their dialysis treatment.
- The first part of LOCAL is a recommendation to follow a service improvement approach to identifying problems and solutions in each kidney service.
- The second part is a recommendation to develop dedicated roles in each kidney centre whose function is to foster an environment (culture and workflow) in which patients can access their optimal location for dialysis care.
- In addition, recommends the use of resources to offer assisted peritoneal dialysis, running roadshows introducing Home Dialysis to patients and carers, and provide resources to promote proactively home dialysis care options.

How was LOCAL Developed?

LOCAL is a service delivery intervention designed to support kidney centres to ensure that every patient gets the opportunity to have their dialysis treatment where it suits them best. Drawing on our research evidence and the published literature, we worked with stakeholders (patients, their families and carers, clinical staff involved in all aspects of patient care and with representatives from industry, see photo) to devise a series of recommendations that would enable staff to be flexible and innovative when delivering their home dialysis service. The two main components of the intervention derived from these stakeholder deliberations were:

1. A strong recommendation to engage in service quality improvement cycles that address patient empowerment, optimising the care pathway and embedding a supportive culture for Home Dialysis; QI projects could be either centre-based or undertaken at regional network level or with "DayLife"

2. Adoption of dedicated 'location of care' roles within multi-disciplinary teams. These are designed to address service-level barriers to Home Dialysis.

For most kidney services, implementation of LOCAL will require some allocation

or redirection of resources. To assess whether this intervention was viable we undertook a detailed health economic analysis of Home Dialysis. This found that Home Dialysis was very likely to be associated with both quality of life and cost benefits. It provided strong evidence that allocation of resources leading to an increase in Home Dialysis update is justified.



Stakeholder workshop in progress

Stakeholder Workshop outcomes:

Ten things to consider when implementing LOCAL

- Expertise in innovation and improvement
- Home dialysis training for service staff
- Resource hubs
- Networks for sharing evidence-based resources and good practice
- Dedicated home therapies champions and co-ordinators
- Community engagement and promotion of home therapies
- Information and data on home therapies uptake and outcomes
- Leadership support
- Commissioning and financial incentives
- Patient empowerment and support

How should the LOCAL intervention be implemented?

The LOCAL intervention, summarised in Figure 6, is designed to be useful in a range of settings, recognising that kidney teams and services have different resources to draw on and can face a variety of challenges when considering how to improve use of home dialysis. It is important to recognise that each kidney service is distinctive, working with a team made up of different specialists and expertise, a patient population with varied needs and resources, and a service infrastructure with different quality improvement structures. LOCAL is intended to empower teams, irrespective of these differences, to present patients with the full range of treatment options, and support services to meet improvement priorities.

An important underlying principle is the focus should be on the optimal location of care rather than pushing for specific treatment modalities. Not all patients will wish to do home dialysis, but they should be given equitable opportunities and support to choose the best option for them, recognising the need to revisit management choices in light of any changes in their clinical and life circumstances. The LOCAL intervention aims to provide the scaffolding for centres to develop strategies achieving this change. The LOCAL intervention requires teams to identify where the local barriers and good practices might be within their services, and empower staff, patients and relatives to do things differently where necessary.

The Inter-CEPt findings emphasise the need to focus on organisational culture and workflow infrastructure. Success will depend on local ownership, willingness to innovate and, where necessary, change infrastructure and processes. It is also clear that the intervention will require leadership and management, as well as the dedication of some resources – especially human – in order to have a significant impact. Applying relevant methods, we were able to show that home dialysis is cost-saving. Therefore, the intervention can incur costs while increasing home dialysis use and still be cost-neutral to the NHS or represent good value for money.

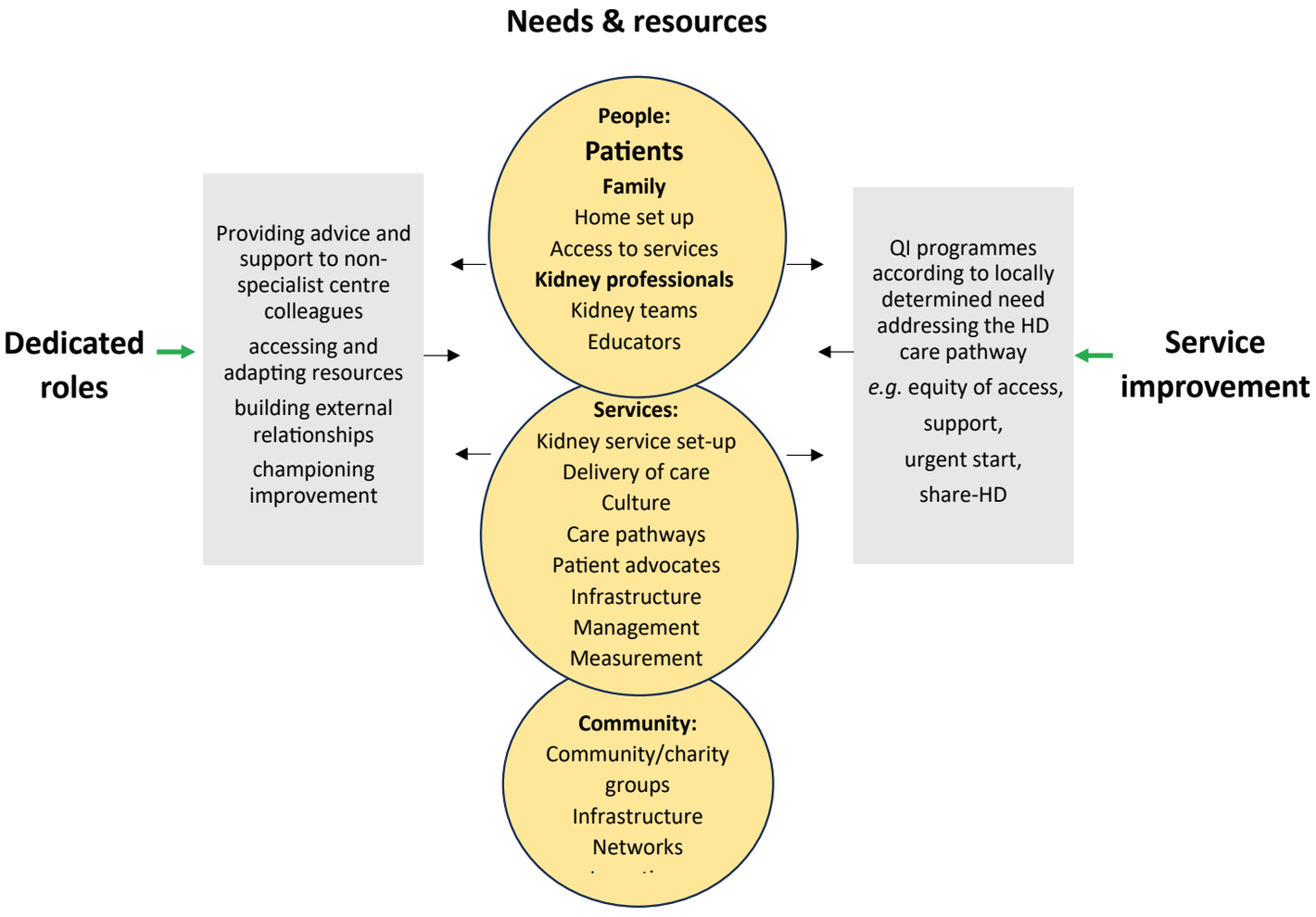


Figure 6: Overview of the LOCAL Service Delivery Intervention. This diagram is intended to capture how the two main parts of the LOCAL intervention come together. In the middle column ('needs and resources') are all of the people, groups and resources required to make the best use of home dialysis and other modes of treatment. Every kidney service will have some areas that can be strengthened. The diagram captures how the dedicated roles and service improvement processes feed into these in order to identify and support improvements.

Suggested Topics for Service Improvement

Although the precise focus of any given service improvement programme will always be context specific, evidence from the Inter-CEPt study suggests that the following areas should be considered:

- **Empowering patients, their families and carers:** incorporation within the care pathway of tools that support empowerment (See RESOURCES section below for some examples), e.g. use of decision aids; introduce peer support; using incremental approaches to support patients or carers in taking responsibility for their care (e.g. SHARE-HD; Winterbottom 2020); supporting dialysis at home (e.g. using assisted PD, providing out-of-hours and weekend support for home haemodialysis); ensuring processes are in place to remove socio-economic barriers to Home Dialysis (e.g. utility bills, adequate housing)

> *If somebody's not got a house to live in, then that is their priority need, and until you can address those things, it's going to be very hard for them to build their confidence and their belief in themselves, because there will constantly be all those other factors that undermine it.*
> **(CKD Nurse)**
>
> *energy bills is soaring, and if someone is going to do home haemodialysis, maybe they will think, I can't afford doing this.*
> **(CKD Patient)**

- **Embedding a supportive culture for Home Dialysis:** e.g. ensuring staff are trained in shared decision making and decision coaching knowledge and skills, identification of unconscious bias, training of non-specialist staff within the centre about the benefits of home dialysis, having an ethnically diverse team.

> *[Having an ethnically diverse team] helps us because we share the same culture, we share the same beliefs. It does make a massive difference in terms of patient decisions and the trust that they give to us.*
> **(CKD Nurse)**

- **Optimising the care pathway:** service improvements that focus on creating a smooth transition from conservative kidney care to dialysis initiation that includes specific pathway modifications for unplanned or urgent start: e.g.

non-surgical PD catheter insertion, urgent start PD, audit of pathways using established tools, e.g. START (*Starting dialysis at home on the right therapy*). Audit of treatment complications to minimise treatment failure (e.g. PD related infections, psychological support to help with treatment burnout).

- **Focussing on patient and community engagement:** this is crucial, especially in light of the inequities of access across different ethnic and socio-economic groups. This is about recognising that different communities will have different attitudes and concerns related to having kidney failure and its treatment. Community actions might include raising awareness and challenging the stigma associated with having kidney failure. This may be tackled by engaging with community leaders.

> *I can think of situations around cultural issues where you can see that in some ways they would really benefit from being at home, but they're so fearful of their community knowing that they have kidney failure, that they won't actually engage with that possibility, they want it to be hidden.*
> **(Counsellor)**

Many NHS trusts will already be engaged in service innovation and improvement and therefore the LOCAL intervention can be worked into existing plans using established support and methodologies. The scale and scope of improvements should be determined locally but good practice often builds up from 'small steps' to more ambitious change.

Key enablers of the successful implementation and adoption include available resources and staff to fund the improvement programme, base-level training in quality improvement for centre staff, linkage to hospital improvement processes, supportive leadership, ownership from networks, engagement with the 'DAYLIFE' project or regional equivalent and commissioner buy-in. Health economic analysis strongly supports this investment.

Service improvement processes should:

- Help to provide a *vision* of the value and role of home dialysis as a viable option in improving patient care and the goals of the service
- Encourage teams to **examine their current practice** and explore opportunities to do things different as well as to continue with good current practices
- Be tailored to **local context** including patient pathways, areas of good practice and any workflow 'blockages' to be addressed
- Facilitate **learning** through openness, sharing of experiences, a willingness to make mistakes, training to use decision support resources, and building of trust
- Find ways to involve patients and other stakeholders in service innovation
- Be focussed on promoting **flexibility and problem solving** in the use of home therapies and adapting systems, rather than working around inflexible rules of practice
- Be **responsive and adaptive** to patient characteristics, recognising the importance of, for example, literacy, ethnicity, deprivation, and loneliness
- Facilitate **shared decision making** practice by enhancing decision and management support conversations within teams, and between staff, patients and their carers
- **Critically discuss** clinical and social needs, and how these change over time, during multi-disciplinary team meetings to provide care options and management plans

Dedicated 'location of care' roles

Working with our stakeholders there was recognition that achieving organisational change is challenging, especially when staff face workforce pressures. They were supportive of the recommendation for additional staff capacity dedicated to supporting the uptake of home dialysis, and consideration of the location of care more widely, while accepting that this may require re-allocation of resource. They concluded that defining specific roles within the Multidisciplinary Team, which they saw as playing a central role in achieving the LOCAL goals, would be key in achieving this.

These dedicated location of care roles are intended to create changes in organisational culture and workflow that are barriers to optimal use of Home Dialysis and implement priorities identified in the service improvement processes. These are likely to vary by centre and might include, for example, increasing staff awareness of how to support discussions about managing therapies at home, willingness to develop skills to engage patients in making decision between dialysis modality choices, and

involvement in (re)organising services to support infrastructure needed to enable improved delivery of home therapies.

The details of these dedicated roles will reflect the outcomes of the service improvement process described above and the extent of change required. For example, it is likely that more than one role and more than one individual will be identified as being needed, but the time required may vary considerably. To be effective, it is likely that these location of care leads will be persons with authority, with a formal role descriptor that is supported by appropriate training or personal development, and time allocation to carry out the role responsibilities. They will have a track record of leadership experience in relation to supporting location of care decisions, home therapy management, and an in-depth knowledge of kidney services and patient pathways. For some activities (see box) patients or families with lived experience may be in the strongest position to take on these roles, and in any event involving patients is essential. This should be properly supported and remunerated if appropriate.

Areas the location of care roles are likely to address (see Figure 7) include: appraisal of staff experience and skills; development of a knowledge and skills training programme for local teams to implement initiatives; enabling workflow processes between staff within the unit, key referrals to 'home management' teams, external charities, and patient and community groups; mechanisms for reporting to the centre leadership; linkage with patient representatives; introduction of patient reported experience of shared decision making or patient involvement in care measures.

Some 'enablers' of the successful adoption of this intervention will include available resources and staff to fund the role, supportive leadership, buy-in from wider networks (e.g. regional), and availability of developmental, training and other resources.

Key Role Activities

- **Signposting** to multi-disciplinary teams, resources, education, networks, opportunities and decision aids known to be effective in improving current practice
- **Advising and reporting** to centre and hospital leadership on patient pathways, and to unit staff on how to overcome barriers and develop their practice
- **Staff Support** of engagement in service improvement activities, knowledge sharing, training, and business case development with clinical and peer support colleagues (usually patients or family members with lived experience – preferably remunerated for their time)
- **Connecting** patients, key charity and community networks and groups with services and systems
- **Advocating:** patient empowerment and involvement in decision making about dialysis treatment and management, peer support.

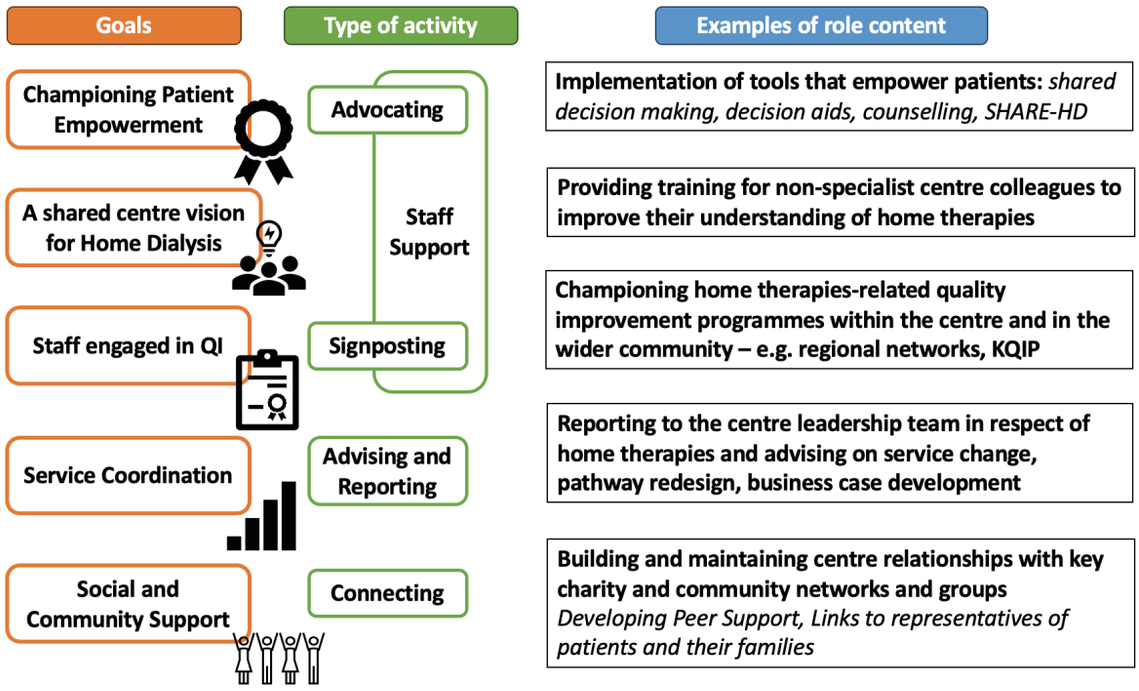


Figure 7: This shows some examples of potential roles in terms of their goals, the types of activity they would involve and examples of their content. Implicit is the need for specific training and skills for these roles to be effective. Not all centres will need all roles, and some will be temporary. They could be undertaken by existing members of the team but there is also a part to be played by patients and their representatives provided this is properly recognised.

Other elements of the LOCAL intervention

These two elements – active service improvement and dedicated roles – are the key components of the LOCAL intervention. However, the Inter-CEPt study findings and our engagement with patient and professional stakeholders indicate that the following are important components of a successful Home Dialysis Programme:

- **Assisted PD:** Although this is now delivered by most centres in England it remained a positive indicator of Home Dialysis uptake due to its absence from a small number of units. This modality has the clear benefit of enabling people from an older demographic with more comorbidity and other healthcare challenges to manage at home. It is also likely the centres who integrated this modality within their services a) provide a workflow supporting its discussion and management within current service provision and b) have identified additional resources within their service to support respite care, changing family circumstances or achieving urgent start or helping patients gradually cover their independence. Clearly there are costs to ensuring home dialysis options are supported equitable and used effectively by services.

- **Home dialysis roadshows:** A roadshow is an event designed to showcase different treatment options for patients and their families who are considering dialysis. It provides an opportunity to meet others with lived experience of dialysis using different modalities and see what home dialysis entails, including the dialysis technology. Services and organisations providing these roadshows ensure a multi-disciplinary team provides information, skills training and guidance enabling patients and their families to explore kidney care management at home, including Dialysis. The Inter-CEPt patient partners endorsed the utility of demonstrating kidney care options outside of the hospital context and in the community. There is further evidence from our research that these events are associated with a positive effect on home-therapy uptake.

- **Networks and Infrastructure:** implementing the LOCAL intervention can be supported by wider networks within the hospital, region and nationally. For example, innovations in service can be linked to hospital QI processes, regional renal networks can play an important role in monitoring outcomes of service improvement, facilitating exchange of good practice, and helping to mobilise resources alongside commissioning bodies.

- **Leadership:** It is a consistent finding that clinical leadership supportive of Home Dialysis is fundamental. Clinical leadership enables the right conditions for the organisation culture and workflow to be assimilated within practice, and between and across professional groups. We found clinical leadership was key to sustaining or innovating location of care resources, innovation and staff capacity.

Next Steps

Having proposed a service delivery intervention designed to help centres improve equity of access to Home Dialysis the next step is to evaluate feasibility, implementation and effectiveness. Existing support to undertake service improvement is available, for example in collaboration with DayLife and there are existing resources (see below) to help centres undertake targeted approaches. Although a number of leadership roles have been proposed it is now necessary to pilot these in centres wishing to change their approach to offering Home Dialysis. These will require the development of job plan templates (including justification that can be strongly supported by the evidence from Inter-CEPt), the identification of specific training needs and trialling, perhaps with the support of centres that have already developed similar roles and responsibilities. Taking this forward will require close collaboration between organisations endorsing this report.

Resources

The following resources were identified through rapid reviews of the literature undertaken at several points during the Inter-CEPt study. They include tools that will support service improvement, shared decision making, process mapping and examples of interventions designed to empower patients and increase home dialysis uptake.

Dialysis Decision Aid Booklet: Dialysis: making the right choices for you
https://kidneyresearchuk.org/wp-content/uploads/2019/05/KR-decision-Aid-DOWNLOAD.pdf

Kidney disease pathways, options and decisions: an environmental scan of international patient decision aids
https://doi.org/10.1093/ndt/gfaa102

Making Informed Decisions Individually and Together (MIND-IT) Framework: Multiple-Stakeholder Decision Maker Roles in Healthcare

- Decision aids to assist patients and professionals in choosing the right treatment for kidney failure 10.1093/ckj/sfad172
- Measures used to assess interventions for increasing patient involvement in Danish healthcare setting: a rapid review 10.1136/bmjopen-2022-064067Critical Review of Leaflets About Conservative Management Used in UK Renal Services 10.1111/jorc.12327

NHS dialysis: Plain language breakdown of dialysis and an introduction to the different types
https://www.nhs.uk/conditions/dialysis/

Difficult conversations: Talking with people about kidney failure, end of life and advance care planning: A guide for health professionals
DifficultConversations_KidneyFailure_TrainingBooklet_Nov2022.pdf

Share HD Resources: Share HD empowers patients to take on responsibilities in their haemodialysis care – one of the outcomes was patients feeling more able to take on home haemodialysis.

- A learning process to deliver virtual staff training involving patients in shared haemodialysis care https://pubmed.ncbi.nlm.nih.gov/37711637/
- A breakthrough series collaborative to increase patient participation with hemodialysis tasks: A stepped wedge cluster randomised controlled trial https://pubmed.ncbi.nlm.nih.gov/34283851/
- Shared Hemodialysis Care: Increasing Patient Involvement in Center-Based Dialysis https://pubmed.ncbi.nlm.nih.gov/31350275/

The economic considerations of patients and caregivers in choice of dialysis modality
https://doi.org/10.1111/hdi.12424

START: Starting Dialysis on Time, At Home on the Right Therapy (START): Description of an Intervention to Increase the Safe and Effective Use of Peritoneal Dialysis
https://doi.org/10.1177/20543581211003764

Assessing the efficacy of coproduction to better understand the barriers to achieving sustainability in NHS chronic kidney services and create alternate pathways
https://DOI:10.1111/hex.13391

KQUIP and DAYLIFE Quality Improvement Resources
https://ukkidney.org/kquip/improving-journey-home-dialysis

National Kidney Federation: Increasing Home Dialysis in the Context of Covid-19 in the UK
https://www.kidney.org.uk/recommendations-of-the-2021- home-dialysis-report/

And one year on:
https://www.kidney.org.uk/Handlers/Download.ashx?IDMF=72852b84-6ef3-43da-9261-e4ac15b9db31

National Kidney Federation: National Peer Support Service
https://www.kidney.org.uk/peer-support

Kidney Care UK: There's no place like home – an introduction to home haemodialysis
https://kidneycareuk.org/get-support/free-resources/patient-information-booklets/theres-no-place-like-home-an-introduction-to-home-haemodialysis/

GIRFT target: Getting it Right First Time is a national programme run by NHS England, designed to improve the treatment of patients by reviewing services and presenting data-driven evidence to support the change.
https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/Renal-Medicine-Sept21k.pdf

KDIGO: Kidney Disease Improving Global Outcomes is a global organisation that designs and implements evidence-based clinical guidelines for kidney disease.
https://kdigo.org/wp-content/uploads/2017/02/KDIGO-Dialysis-Initiation-conf-report-FINAL.pdf

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KQuIP

DAYLife Helping more patients dialyse from home