Derby Hospital Renal Service – Optimising use of home dialysis an SDM approach

Patients with Chronic Kidney Disease (CKD) who reach CKD stage 4 require Renal Replacement Therapy (RRT) or transplant. Specialised renal services provide care for patients with Chronic Kidney Failure. Approximately 6,600 people start treatment for chronic kidney failure in England each year. Across the UK dialysis is delivered predominantly In-Centre (IC). The National Institute for Health and Clinical Excellence (NICE) recommends that all patients who are suitable for home therapy (HT) should be offered the choice.

Evidence shows that home dialysis delivers good outcomes for patients yet there is still considerable variation in approach to enabling this across renal centres in England and unwarranted variation in access. Nationally 11-22% of RRT is delivered as home dialysis (HD) which can be home peritoneal dialysis (HPD) or home hemodialysis (HHD).

The Royal Derby Hospital Renal Unit has achieved one of the highest proportions of patients on HD in the UK. On average out of 350 patients on dialysis, 30-40% are on home therapies with approximately 60 patients on HHD and 60 patients are on HPD. The renal dialysis team have increased the percentage of their patients successfully accessing HD safely and effectively over the last 10 years.

The unit routinely provides on-site dialysis in 1 main unit and 1 satellite unit as well as running, leading and coordinating the home dialysis service.

University Hospitals of Derby and Burton NHS Foundation Trust serves a population catchment area of 1 million. The Royal Derby Hospital hosts tertiary specialist services in a purpose-built renal unit with inpatient and outpatient services. The unit has an advantage of having PD and HD in the same area so that patients can see both options in operation.

SDM throughout the pathway

The decision to use HT starts before the patient reaches End Stage Renal Failure (ESRF) but has progressive kidney disease (step 1 in the schematic pathway representing the Derby approach). At this stage the patient attends the advanced kidney care clinic, otherwise known as a low clearance clinic, which was set up in line with GIRFT recommendations is a multi-speciality clinic which works with patients in the run up to dialysis An iterative conversation begins by identifying what is important to the patient and the expectation is that the patient can ask for the clinical solution to fit with their life goals. It is not completed in one visit, but the decision is refined over 2 years transition to needing RRT. This is where coaching conversations are conducted with patients to find out if the plan they made previously is still right and to help them to make an informed choice, considering risks and benefits of the various options including the ‘doing nothing’ option.

Where an individual patient has expressed a preference for HT they start a programme of education and training. For home haemodialysis (HHD) patients follow a two weeks in-centre programme where they are paired up with another patient to learn about managing their fistula and using the dialysis equipment. This is followed by 2 weeks ‘training’ at home with support from the hospital renal team. The package – an idea generated by one of the renal

team Band 4 nurses and subsequently written and developed by them has been adopted by NxStage[1] to train everyone globally.

Schematic Pathway for Progressive Kidney Disease – the Derby approach. The case study focuses on HHD but patients are offered all options including transplant.

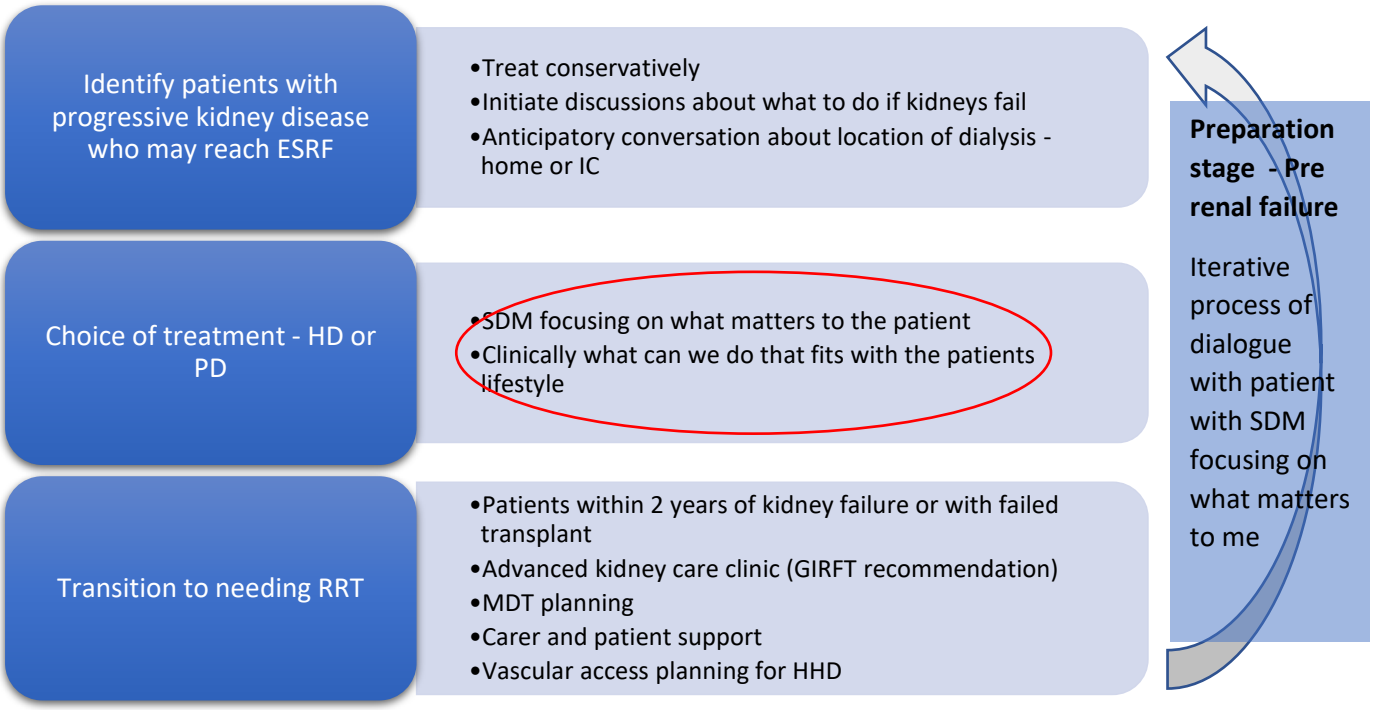


Fig. 1 Schematic pathway for patients with CKD transitioning to RRT using the Derby approach. The diagram focuses on RRT but transplant is offered to all clinically appropriate patients.

[1] The NxStage System One is a simple and portable home dialysis option that fits around patients' lives permitting more frequent, and even nocturnal, HD treatments at home

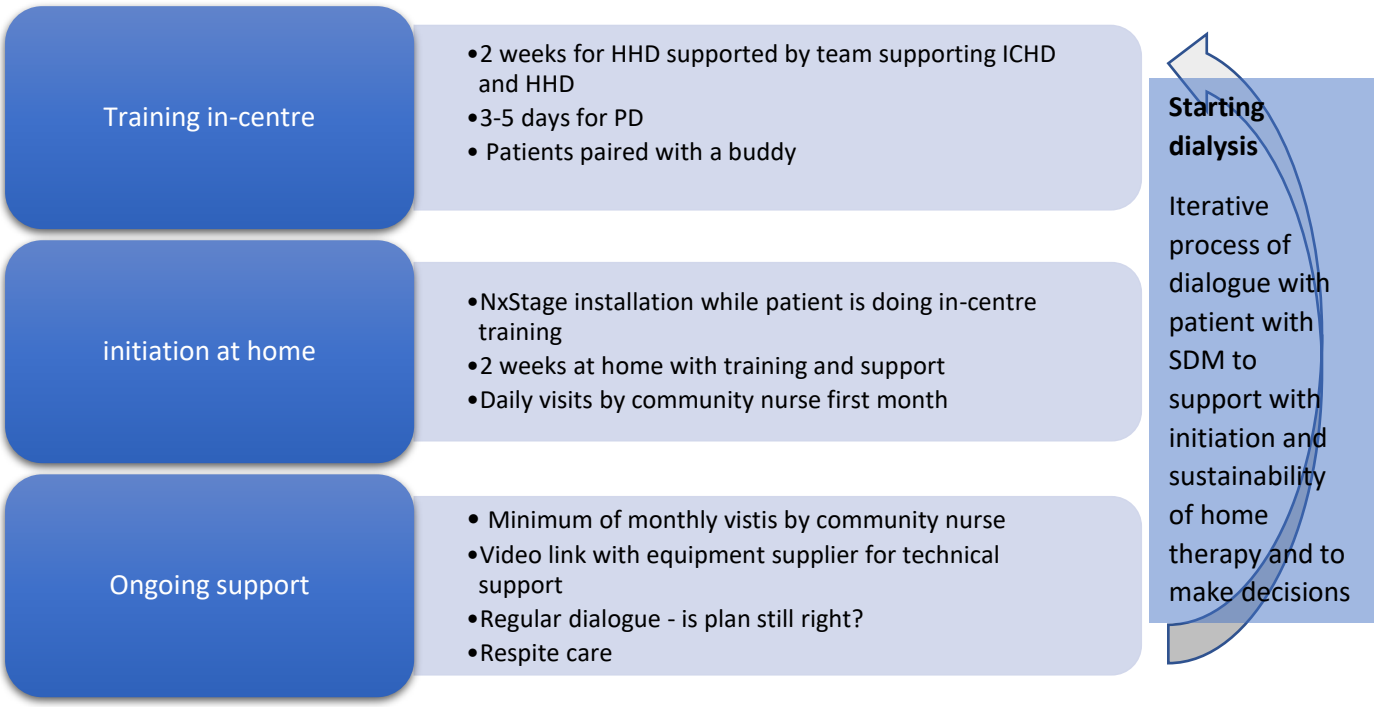


Fig. 2 Schematic pathway for patients with CKD choosing HT using the Derby approach. Patients opting for HHD or HPD go on to this pathway. Similar pathways exist for transplant, PD or ICHD

In Derby empowering patients to express 'what matters to me' and a Shared Decision Making (SDM) approach to conversations is part of the patient centred culture. If as a result, the patient preference is for HT, the role of the clinician is to support this, unless there is definitive proof that this individual cannot manage HT, rather than the individual having to prove that they can, or the clinician indicating that the system cannot support this choice.

The clinical team in Derby do not use formal decision support aids with the patients. Their approach is more around developing a pathway where interactions with the clinical team are focussed on the 'what matters to me' approach, through using coaching and motivational interviewing techniques.

"You are involved in a two-way dialogue to refine what is an important decision for the patient."

This is not based on an assumption that the clinicians 'do this anyway' but from an evolving organic SDM culture grown over many years, through the continuous improvement approach and extensive knowledge around embedding the broader aspects of SDM that are prerequisite to sustainable SDM within a pathway.

"It's not just about giving patients a pack of cards with information on HD, PD, transplant or conservative care. Now go away and come back with a decision. My job is to coach the patient to talk through and challenge their decision where appropriate, then choice is made as a joint effort rather than saying I'm absolving myself of your rubbish decision because you are the patient, and you made the choice. That's not how it works it is a two-way dialogue because we look after these patients until they die." (Richard Fluck)

Consequently, discussions with patients start from a 'what matters to me' perspective and include all the options including 'do nothing' and those which the clinical team might not necessarily wish the patient to select. Including a frank discussion around risk and benefits.

When the patient has made their decision the team then work with them to enable this. In reality it may involve clinicians proactively supporting patients to prepare for home dialysis even when, in their clinical opinion this is not the best option. The aim is to enable patients to be able to demonstrate that they can manage home dialysis, rather than to prove that they cannot.

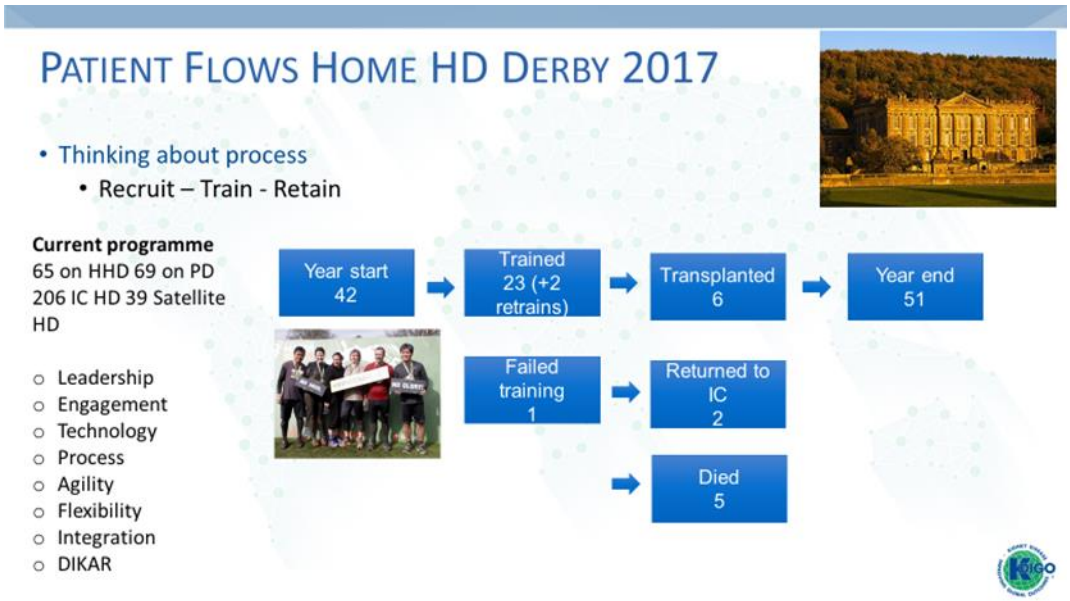
If this means that the service and system need to be flexible to support a patient to dialyse at home, this is considered a reasonable 'ask'. Thus, the conventional dynamics of a medical model approach to the dialysis pathway becomes much personalised for the individual; a more 'honest and open' relationship between patient and the clinical team. Over time this facilitates patient confidence and knowledge and further facilitates their ability to manage home therapy successfully.

Shared decision making is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care. It could be care someone needs straightaway or care in the future. It involves choosing tests and/or treatments and interventions based both on evidence and on the person's individual preferences, beliefs, circumstances and values. It means making sure the person understands the benefits, harms and possible consequences of different options through discussion and information sharing. This joint process empowers people to make decisions about the care that is right for them at that time (with the option of choosing not to have treatment always included

What has been the impact on the service?

The unit does not collect any formal patient feedback but patients report feeling well supported. The unit has the advantage of having everything on one site and one level and patients can learn about PD and HD by observing both modalities.

The SDM approach has been part of the successful progress and success with more patients choosing HHD and HPD rather than the conventional IC option.



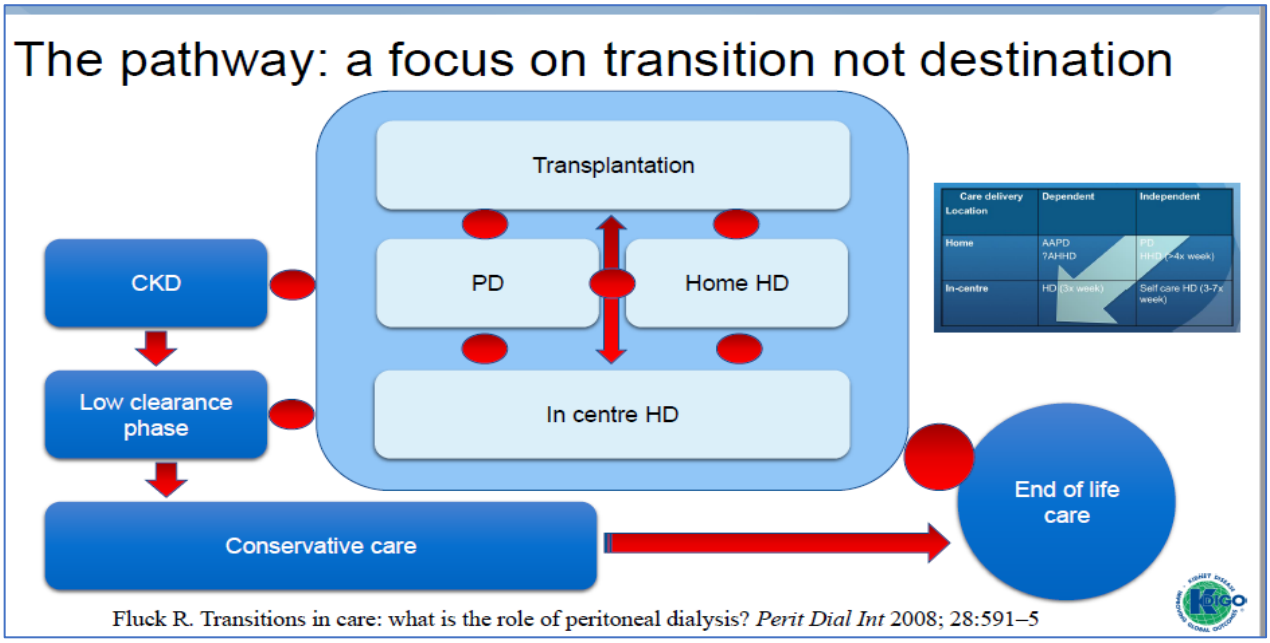
Slide adapted from Controversies Conference on Home Dialysis – KDIGO May 2021. Richard Fluck – Drivers for Home Dialysis

The team is supported by a consultant who strongly believes in HHD and this instils confidence in patients and staff. The team doesn't work to targets but has an improvement mindset aimed at increasing uptake, reducing dropout.

The wider impact

The team at Derby has optimised the uptake of home therapy through making it an accessible option for anyone for whom it is clinically appropriate.

Optimising the number of patients having a transplant is the aim of the unit and approximately 80% of patients having a transplant transition from HD.



Impact on clinical teams and patients

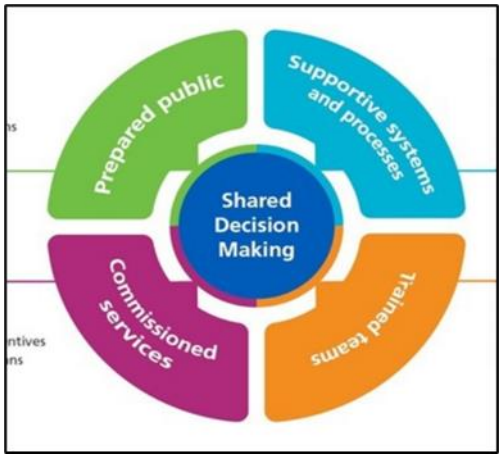
The traditional view has been that only the fittest patients would be suitable for HHD; those awaiting transplant or younger patients. That in most situations this should be 'offered' to only these patients as/when deemed appropriate by clinicians.

A SDM approach is not always an easy step to make for clinical teams. Firstly, because it empowers patients to express their values and wishes which may not align with the clinical team's perspective of their renal disease and secondly because it doesn't always fit easily with the pathways created by clinical teams/commissioners to treat them. These factors can create some tensions for clinical teams who are trying to do what, in their opinion is best for the patient.

By putting patient choice central to the Derby ethos, the renal service has placed their service in a position where not only do they have to work proactively to enable patients, but they have to develop a flexibility across their service to support those choices too. Consequently, they have developed a model where their agile clinical team can work confidently in centre or in patients' homes. They have learned about other aspects such as costs of dialysis equipment, supplies and suppliers, maintenance, water supplies and plumbing; the practical aspects of being able to set up services in home for those patients conventionally seen as barriers to home dialysis previously. Then to work holistically with more stakeholders, to facilitate the patient choice.

Other challenges - clinical factors such as frailty and pregnancy previously deemed barriers to HHD are not ruled out if SDM is part of the pathway. The team's continuous QI thinking supports them with a solution focused approach to manage this aspect. They have a good example of how this translated into practice that involves a pregnant patient who was approaching End Stage Renal Failure (ESRF) in which circumstances the normal clinical advice would be around terminating pregnancy. The individual was supported through to term on HHD successfully because this was 'what mattered to her' To support her SDM a bespoke plan was created using a nocturnal programme to maintain her blood biochemistry at optimal levels for a safe delivery at 35 weeks ; by pre-empting the requirement for vascular access and preparing the fistula early, and by providing her with a pathway of education and training for nocturnal HHD.

The 4 components of SDM



Prepared patients

This is partly supported by the culture and approach of the workforce who engage with the patients across the pathway. In addition, the education and support package are tailored to enable and assist; to facilitate patient choice and empowerment.

There are resources available nationally that can be used to support this.

https://www.thinkkidneys.nhs.uk/ckd/tools-for-change/ask-three-questions/

The team at Derby use patient information produced by Kidney Care UK

https://www.kidneycareuk.org/about-kidney-health/order-or-download-booklets/

Patient decision aids can be used to help support and improve the process of communication between people using healthcare services and healthcare professionals in making shared decision.

Decision support aids have been developed by kidney research UK for use in this context.

https://www.kidneyresearchuk.org/DialysisDecisionAid Kidney health information - Kidney Research UK

Similarly, the BRAN tool as developed by the Perioperative care for Older People Service (POPS) outpatient service adopts SDM within this process, using resources including the BRAN tool

https://www.guysandstthomas.nhs.uk/our-services/ageing-and-health/specialties/pops/overview.aspx

Four 'BRAN' questions to ask my doctor or nurse to make better decisions together

1. What are the Benefits?
2. What are the Risks?
3. What are the Alternatives?
4. What happens if I do Nothing?

Trained teams

SDM in Derby has become the norm for experienced clinicians. Good patient conversations are part of the culture. New team members get some support with the approach which is not called SDM training but an enabling process through conversation.

Commissioned services

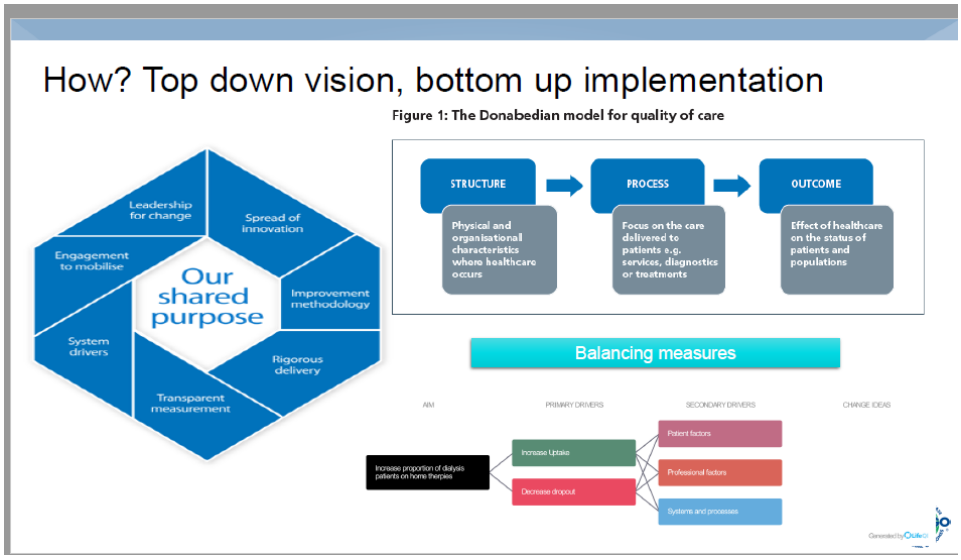
The impact for commissioners on costs for the home therapy programme is broadly neutral. Given the complexities of block funding, savings with one patient balance out an increase in costs for others. Dialysis equipment was redeployed from in-centre to home and staff roles were reallocated and shared between ICHD and HDD.

The benefits are shared across different parts of the system. Keeping patients at home and keeping them well reduces NEL admissions (specialised commissioning funded) whilst reducing transport three time a week for 40% of the patient cohort has a positive impact on the CCG spend. With positive impact on patient experience and quality of life without increasing the risk of harm, reducing potential for transplant or clinical outcomes.

Supportive systems

The system in which the unit works is supported with

- strong leadership advocating HHD in all parts of the system and a 'shared leadership' approach https://wwwf.imperial.ac.uk/blog/pstrc/2019/05/24/why-sharing-leadership-in-healthcare-matters/ via the QI culture
- monthly data to monitor progress, opportunities for further improvement and reflection.
- An integrated system whereby any consultant can refer into HHD
- Enabled patients



Slide extracted from Controversies Conference on Home Dialysis – KDIGO May 2021. Richard Fluck – Drivers for Home Dialysis

Derby Hospital Renal Service – Optimising use of home dialysis an SDM approach

Key message

Maximising patient uptake of HHD has been achieved incrementally over 10 years through strong leadership, organisational culture and an improvement mindset where problems are identified, and barriers broken down at each stage in the patient journey. SDM is positioned central to this in context of an improvement process where the clinician mindset has changed to reversing the traditional construct of patients needing to prove they can do HHD to clinicians having to prove that patients can't.

Patients are coached and facilitated to identify what they want 'what matters to me' and SDM is not just about providing a pack of information and expecting patients to make a choice based on those options. It is not about a paternalistic type of choice where the patient is responsible for the consequences of the choice they have made. A clinician's role in SDM at Derby renal pathway is to coach and inform patients and then, to support the choice they make including managing and mitigating the risks.

For more information about this case study please contact Jill.Lockhart1@nhs.net or jacquie.oshea@nhs.net

If you are interested in establishing SDM within this clinical pathway or another pathway there are many useful resources to support you with this including an Accelerating Implementation Pack for Renal Home Dialysis on the Specialised Commissioning Improving Value Personalised Care scheme FutureNHS platform.