

NHS RightCare scenario: **The variation between sub-optimal and optimal pathways**



Abdul's story:
Progressive Chronic
Kidney Disease

NHS RightCare scenarios

This chronic kidney disease scenario is part of a [series](#) of NHS RightCare Long Term Conditions scenarios to support local health economies – including clinical, commissioning and finance colleagues – to think strategically about designing optimal care for people with long term conditions and their carers.

Each scenario is a discretionary resource that highlights potential improvement opportunities through a fictitious but representative patient story. They have been developed with experts in these areas and include prompts for commissioners to consider when using each product.

For this scenario on progressive chronic kidney disease, commissioners, clinicians and providers responsible for long-term conditions care for their population should consider:

- Planning coherent care models to address the long term and progressive nature of chronic kidney disease
- Systematically identifying individuals living with chronic kidney disease
- Providing tailored care to people with chronic kidney disease in line with NICE guidance, which considers, for example, treatment burden and sharing information to other professions and services
- Using existing resources and data to identify opportunities to improve quality of care for people living with chronic kidney disease

Please contact your local [NHS RightCare Delivery Partner](#) if you would like to explore any of the scenarios further.

The story of Abdul's experience of a progressive kidney disease care pathway, and how it could be so much better

In this scenario – using a fictional patient, Abdul – we examine a progressive chronic kidney disease (CKD) care pathway, comparing a sub-optimal clinical scenario against an ideal pathway. At each stage we have modelled the costs of care, not only financial to the local health economy, but also the impact on the person and their family's outcomes and experience.

This document is intended to help commissioners and providers understand the implications – both in terms of quality of life and costs – of shifting the care pathway of adults living with progressive CKD from a reactive (primarily based on an acute response) to a proactive approach, such as providing an integrated primary care and community-based response.

It demonstrates how the NHS RightCare methodology can help clinicians and commissioners improve the value and outcomes of the care pathway as part of an overall approach to considering quality of care and commissioning.

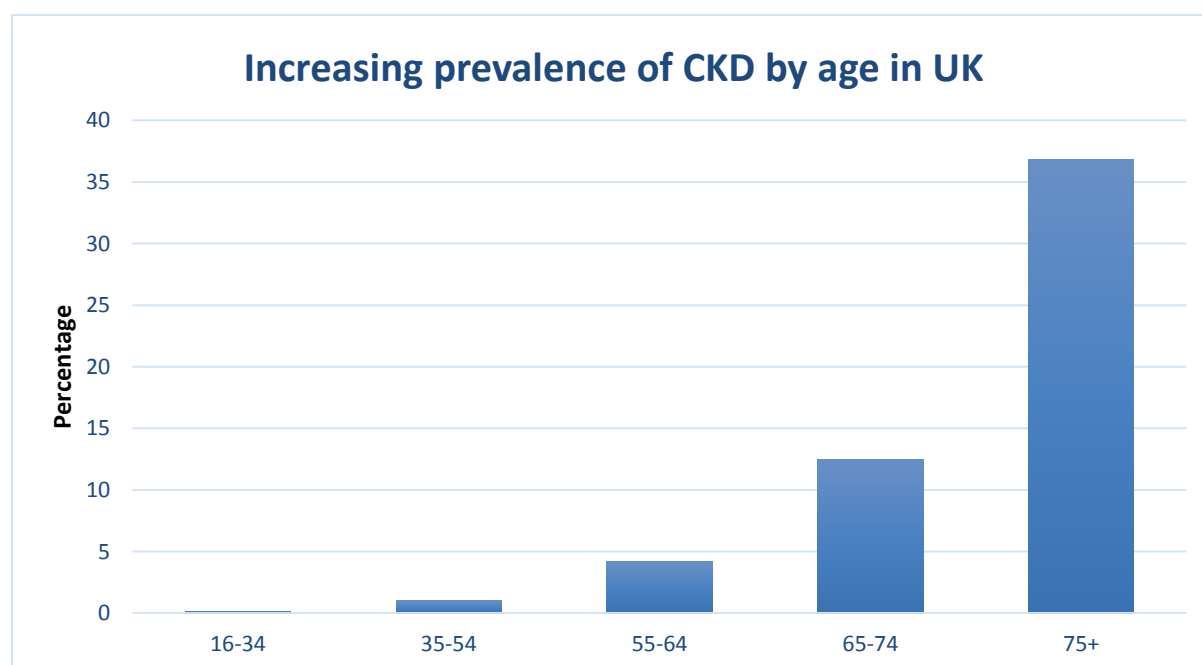
Two summary slide packs are also included as appendices for optimal use by different audiences.

Background

The prevalence of CKD rises steadily with age, approaching a prevalence of 35% in individuals over 75 years old (as shown in Figure 1 below). CKD is associated with a high risk of premature cardiovascular disease¹. Patients with CKD are more likely to suffer Acute Kidney Injury (AKI)² and a small proportion (<1% per year) will progress to end stage kidney disease requiring dialysis or transplantation³.

Filtration by the kidneys is performed by individual filtering units called nephrons. Every person is born with a fixed number of nephrons (usually around one million per kidney) and they start to fail at a rate of about 10% per decade after the age of 40 as part of the normal ageing process. In progressive CKD there is underlying disease which slowly destroys the nephrons at an accelerated rate over many years. Examples of these damaging processes include cyst formation, diabetes, high blood pressure, vascular disease and inflammation (glomerulonephritis). Detecting early signs of change is the key to preventing progression but the clues may be subtle. However, the reward is substantial as intervention may arrest the underlying destructive process.

Figure 1: Increasing prevalence of CKD by age in the UK



Source: Aitken et al., 2014

¹ Chronic Kidney Disease Prognosis Consortium et al., 2010

² Hsu et al., 2008

³ Marks et al., 2014

The kidney is a simple organ since there are only four basic parameters that indicate underlying damage:

- High blood pressure
- Raised creatinine⁴ level in a blood test (and a reduced calculated estimated Glomerular Filtration Rate⁵ (eGFR)). This is a direct measure of how well the nephrons are functioning to filter the blood
- Protein in the urine; this is a measure of whether the nephrons have become damaged and leaky
- Abnormal anatomy (e.g. cysts or scarring)

The key to detecting early disease and thus preventing progressive CKD is to recognise abnormalities in these parameters at the earliest opportunity and to take appropriate evasive action. It is important that those who are at risk are tested at appropriate intervals so that CKD is identified early, with the opportunity to initiate appropriate management to:

- Prevent progression of renal disease (i.e. rising creatinine level)
- Prevent cardiovascular disease (CVD) complications
- Prevent episodes of Acute Kidney Injury (AKI)
- Ensure appropriate drug prescribing

Most patients with CKD will be identified and managed by their GP and there are a number of Read codes used by practice computer systems, which identify these patients and enable a practice register to support regular monitoring and treatment decisions. There is good quality evidence to suggest that optimising treatment of patients with CKD will improve outcomes⁶ which is reflected in relevant NICE Guidance: [Chronic kidney disease in adults: assessment and management](#)

As only a minority of patients with CKD will need to be referred on to kidney specialists in secondary care, there is the opportunity for patients to obtain substantial health benefits from high quality care in general practice.

In most cases, advanced CKD doesn't appear suddenly. It is a progressive condition that develops often over many years, which suggests that more could be done before a health crisis occurs. As with any other long-term condition, when people living with CKD are supported to share in their treatment decisions and to manage their long-term condition(s), they are less likely to reach a crisis, require urgent care or experience poor outcomes. There are a number of tools and techniques available to support [Shared Decision Making](#) and a national programme called [Think Kidneys Transforming Participation in CKD](#) aimed at supporting patients to make informed decisions about their preferences for care.

⁴ Protein released by muscles in body that reaches a steady state in the blood and acts as a surrogate measure of renal function i.e. it rises when renal function deteriorates

⁵ A measure of the kidneys' function according to the amount of blood filtered (Normal = 80 -120 mls/min/1.73m²). This roughly correlates to percentage of total function since normal is approximately 100mls/min/1.73m²

⁶ Baigent et al., 2011, Lv et al., 2013

Introducing Abdul



Abdul is a 30-year-old man who works in the car retail industry living in the Midlands together with his wife and two young children. He is active and enjoys football, running and walking with his wife and two young children.

Abdul's sub-optimal journey

Abdul was a healthy young man who did not suffer from any major illnesses in his childhood. He was always interested in cars and after school he joined a local Ford motor dealership in the sales department. He married his wife at the age of 26 and they had two children when he was in his late twenties. Abdul played football for a local team and played 5-a-side with some friends once a week. He also took his children swimming at the weekend and he and his wife would enjoy taking the children to the local park where they would often meet friends who also had young children.

When he was promoted at the age of 30 he underwent a BUPA Well Man health check as part of his company medical insurance. The examination was normal except for a urine dipstick examination which revealed that he had 'blood and protein' in his urine and as a result his GP was notified. He was treated for a urinary tract infection with a course of antibiotics with a plan to review him in a fortnight. He had no symptoms after treatment and soon after he moved house to another area where he did not make any further appointments with his new GP. [Go to Learning / Opportunity 1](#)

During the next decade Abdul gave up playing football but he remained active, supporting his children's activities and helping out with his son's football team as well as getting out walking with the family whenever he could. He remained well but at age 40 he was invited to, and attended, his GP practice health check. He received some lifestyle advice and was noted to have high blood pressure, measured at 152/98 by the practice nurse. As a result, she booked him an appointment with his GP who confirmed the blood pressure to be marginally elevated. In the absence of any other cardiovascular risk factors she told Abdul that she suspected that he had 'white coat hypertension' and advised him to return in a month for a repeat test with the practice nurse. However, he felt well and with a hectic life schedule he did not make a further appointment. [Go to Learning / Opportunity 2](#)

At age 44, Abdul became unwell with a chest infection and went to see his GP. He was treated at home initially with oral antibiotics but his condition worsened and he required hospital admission. He was admitted to his local hospital where his condition deteriorated necessitating admission to the intensive care unit. He was diagnosed with severe community acquired pneumonia and received intravenous antibiotics. During his admission, he required temporary renal dialysis and ventilation. However, he recovered after a total of three weeks in hospital and on discharge he was told that he had suffered acute kidney injury secondary to the underlying pneumonia. He was told that his kidney function would probably recover. His discharge summary informed his GP of this diagnosis and advised follow up blood tests after four weeks. His eGFR was measured as 25mls/min/1.73m² on admission, fell to 10 before starting on dialysis and was 35 when he was discharged (Normal >80 mls/min/1.73m²). This is a level at which a patient might be considered to have moderate to severely reduced kidney function. His blood pressure was 'low normal'. Unfortunately, he failed to make an appointment with his GP since he felt well and returned to full time work. [Go to Learning / Opportunities 3 and 4](#)



Following this admission Abdul became more anxious about his health and he became less active. He felt more tired than he had when he was younger, took less exercise and began to gain weight.

Age 48, Abdul was admitted to his local hospital A&E department feeling weak and breathless. His blood pressure was 190/126. His eGFR was 7 and his haemoglobin (Hb) was 83. His potassium was 7.6, a level that is considered immediately life threatening requiring urgent treatment. He spent 48 hours in the local hospital intensive care unit receiving filtration for 'acute kidney injury and hyperkalaemia' before a renal ultrasound demonstrated that he had small shrunken kidneys. He was informed that there was no chance that his kidneys would recover since he had been suffering from kidney disease for many years. He was transferred to the local renal centre for further assessment. [Go to Learning / Opportunity 5](#)

The renal specialists agreed that his kidneys would not recover and advised him to start dialysis to improve his symptoms which included nausea, weight loss and profound fatigue. He therefore had a central venous catheter inserted into a major blood vessel in his neck and commenced hospital based haemodialysis. There was a delay in finding a regular dialysis slot since the hospital was currently running at full capacity so he had to remain as an inpatient throughout this period. After three weeks he was allocated a regular dialysis session but unfortunately his three

sessions were on a Tuesday, Thursday and Saturday morning. His employer was not willing to accommodate these within his full time role; therefore he had to switch to part time work in his job as a manager of a car showroom. As a result Abdul's wife, who worked part time as a teaching assistant in the local primary school, had to increase her hours in order to make up the loss in earnings. After three months he was transferred to a satellite dialysis unit nearer to his own home once a space became available. Abdul became anxious following his diagnosis. He was less able to engage in activities with his family and he was concerned about the financial impact of his reduced hours and the need for his wife to work longer hours.

He was seen by the vascular surgical team and plans were put in place to form an arteriovenous fistula in his left wrist for the purpose of haemodialysis. Unfortunately, while waiting for this procedure he developed an infection related to his catheter and he had to be readmitted to hospital. After ten days of intravenous antibiotics he was finally discharged and his line had to be changed. He took one month off work and then commenced a phased return.

Abdul continued on dialysis through the central venous catheter whilst awaiting surgery on his arm. After six months he had a fistula formed. Other forms of home based dialysis were briefly mentioned by his dialysis nurse but they never seemed to get round to having any form of in-depth discussion. After a further six weeks his fistula was ready to be used and he was put on the list to have his central venous catheter removed at the main dialysis unit. However, before this could be done he presented again with high fevers and malaise. Bacteria grew in his blood cultures and responded slowly to intravenous antibiotics. Further investigations including an echocardiogram revealed that he had developed endocarditis, an infection on his heart valve, spread from his previous central venous catheter. Due to a severe leak in one of his heart valves he was transferred to the cardiology unit for further assessment. After extensive investigations he underwent an operation to replace his aortic valve and bypass a blocked coronary artery.



Six months following his heart surgery his condition had stabilised and he was once again active although he had had to give up work and take early retirement. Abdul had to give up driving and required hospital ambulance transport to attend his dialysis sessions.

Patient transport

Accurate data on patient transport costs is very difficult to gather and commissioning arrangements and eligibility criteria vary across the UK.

Kidney Care UK (formerly BKPA) has recently undertaken a review of transport arrangements (awaiting publication) from which the figures below are drawn.

1. Typical/average costs per patient journey

Cost of journeys is circa £10-15 for 'walker' (this might for instance be a taxi) £50 for ambulance up to £300 for bariatric or patients with greater needs such as stretchers

The examples below highlight the significant variation in costs:

Trust A pays £13m pa for 300,000 journeys (average £43)

Trust B pays £17m pa for 235,000 journeys (average £72)

There may be a number of explanations for this variability e.g. location of dialysis units, local geography or average distance travelled but this is an area that merits further investigation.

2. Percentage and number of patients using Non Elective Patient Transport (NEPT)

Of 24,000 haemodialysis patients 65% use NEPT.

Renal patients account for 50% of NEPT journeys.

3. Average miles travelled

Estimated at somewhere between 5 and 10 miles per journey.

The Renal Association and NICE recommend that patients should be no further than 30 minutes travel time from home to dialysis but this is often not the case.

During the following six months Abdul had admissions with fluid overload and a chest infection but he was activated on the cadaveric deceased organ transplant list. This is the national transplant list for patients waiting for the donation of a suitable organ after the death of a donor. His wife came forward as a potential donor but was deemed unsuitable as she had an incompatible blood group. He struggled to cope psychologically and became depressed. He underwent a course of counselling with a renal psychologist. He also missed several dialysis sessions.

After two years on the waiting list he was offered a deceased donor transplant at the age of 53. The transplant functioned reasonably well and after a period of three weeks in hospital he was discharged. Sadly, at the age of 55 he suffered a stroke and two months later he died from a heart attack. He left behind his wife and two children who remember their father as someone who was unwell for the last 10 years of his life.

Questions for GPs and commissioners to consider

At the CCG population level, there are likely to be thousands of people living with CKD many of whose disease will not have been identified formally to the care system since the early stages of progressive CKD are usually asymptomatic⁷.

In the local population, who has overall responsibility for:

- Promoting CKD as a condition for which targeted interventions must be planned and delivered?
- Identifying individuals living with CKD at an early stage?
- Monitoring these individuals and planning interventions to retard the progression of their underlying disease?
- Ensuring individuals with CKD are educated in their condition and facilitated to appropriately self-manage?
- Planning care models to address key stages of CKD (diagnosis, progressive disease, pre-end stage disease and renal replacement therapy⁸)?
- Ensuring timely referral to secondary care services?
- Identifying and reporting on measurable positive and negative CKD associated outcomes?
- Quality assurance and value for money in CKD care?
- Evaluating any existing engagement activity that has already taken place with patients with regards to CKD care?
- Understanding if your health economy already has valuable local data around patient experience and outcomes for CKD care in your area?
- Understanding how this local data could be used to identify and drive improvements?⁹

The above questions are vital in understanding who manages which components of the whole system. Most importantly, it is impossible to effect optimal improvement if the system is not aware of the answers.

⁷ CKD Audit – Nitsch D, Caplin B, Hull S and Wheeler DC on behalf of the National CKD Audit and Quality Improvement Programme in Primary Care, First National CKD Audit Report 2017

⁸ Renal replacement therapy is The provision of either haemodialysis, peritoneal dialysis or transplantation after the native kidneys fail

⁹ If you require advice and resources around engagement please contact The Involvement Hub through this link: <https://www.england.nhs.uk/participation/>

Key learning from the sub-optimal journey:

Learning / Opportunity 1: BUPA health check red flags for asymptomatic CKD

At Abdul's first presentation there was evidence of abnormal findings in his urine with blood and protein both present. This was ascribed to a urinary tract infection although he did not really have typical symptoms. The finding of blood and protein in the urine combined with high blood pressure is highly significant if it persists. In retrospect we know that this man had progressive renal disease probably with IgA nephropathy. This is a disease with inflammation in the filtering units of the kidney resulting in the leakage of blood and protein in the urine. If his urine had been rechecked the abnormalities would have been identified as persistent with an increased urinary protein excretion manifested by a raised urinary albumin/creatinine ratio (ACR). The importance of this parameter is illustrated in the [NICE guidance for CKD 2014](#) below:

Figure 2: NICE guidance for CKD, 2014

Prognosis of CKD by GFR and Albuminuria Categories: KDIGO 2012				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30-300 mg/g 3-30 mg/mmol	>300 mg/g >30 mg/mmol
GFR categories (ml/min/ 1.73 m ²) Description and range	G1	Normal or high	≥90			
	G2	Mildly decreased	60-89			
	G3a	Mildly to moderately decreased	45-59			
	G3b	Moderately to severely decreased	30-44			
	G4	Severely decreased	15-29			
	G5	Kidney failure	<15			

Source: NICE guidance for CKD 2014

Essentially high levels of protein in the urine are associated with poor long term outcomes even when the renal function is in the normal range. His urine ACR was in fact 176 mg/mmol which is highly significant. From the NICE CKD guidelines:

- 1.1.19 For the initial detection of proteinuria, if the ACR is between 3mg/mmol and 70mg/mmol, this should be confirmed by a subsequent early morning sample. If the initial ACR is 70mg/mmol or more, a repeat sample need not be tested. [2008, amended 2014]
- 1.1.20 Regard a confirmed ACR of 3mg/mmol or more as clinical important proteinuria. [2008, amended 2014]

Mindful of these facts it would probably have been appropriate to refer Abdul to the local nephrology service as laid out in the guidelines below:

- 1.5.2 People with CKS in the following groups should normally be referred for specialist assessment:
 - GFR less than 30ml/min/1.73 m² (GFR category G4 or G5), with or without diabetes
 - ACR 70mg/mmol or more, unless known to be caused by diabetes and already appropriately treated
 - ACR 30mg/mmol or more (ACR category A3), together with haematuria
 - sustained decrease in GFR of 25% or more, and a change in GFR category or sustained decrease in GFR of 15ml/min/1.73 m² or more within 12 months

Had he been referred at that stage he would have undergone a renal biopsy which would have confirmed the diagnosis of IgA nephropathy. This would have enabled two management strategies:

- Treatment of the underlying inflammatory process
- Stringent control of his blood pressure and modification of his cardiovascular risk profile

Such interventions would probably have delayed the progression of his underlying disease and postponed or prevented the need for subsequent renal replacement therapy. This management may also have reduced his risk of an early death with stroke and myocardial infarction.

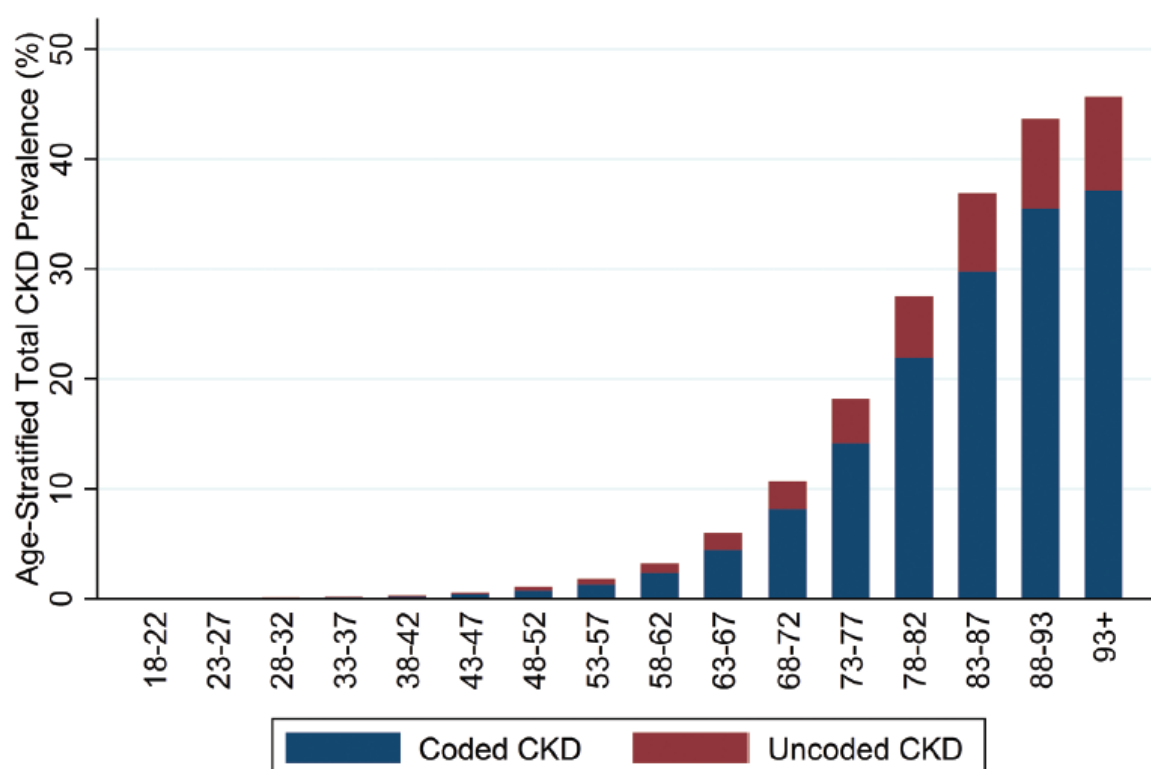
Abdul was clinically well for the next decade and this is typical of early CKD where it is unusual to have any symptoms. At his next presentation, he was noted to have high blood pressure. This may not be in itself unusual in a middle-aged man but further investigation with either 24 hour ambulatory monitoring or home blood pressure monitoring would have revealed a more permanent problem and not simply 'white coat hypertension'. In addition, further testing of his urine at this time would have revealed increased protein excretion with a raised ACR (165mg/mmol). By this time his renal function had also started to fall and his estimated GFR had fallen to 53mls/min/1.73m². He might have been treated with specific treatment for his underlying disease and amelioration of his cardiovascular risk profile. He would have been placed on his practice CKD register. He also would have been referred to the local nephrology service.

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Learning / Opportunity 2: Detecting asymptomatic CKD in the community

Nearly two million people in the UK have been diagnosed with moderate-severe CKD by their GP but it is estimated that a further one million people remain undiagnosed as people with CKD often have few or no symptoms until the later stages of the disease. This problem has been identified in the national CKD audit. It revealed significant numbers of patients in primary care with CKD are being incorrectly coded, as shown in Figure 3 below for a sample of 911 GP practices¹⁰:

Figure 3: Total CKD prevalence, by age group

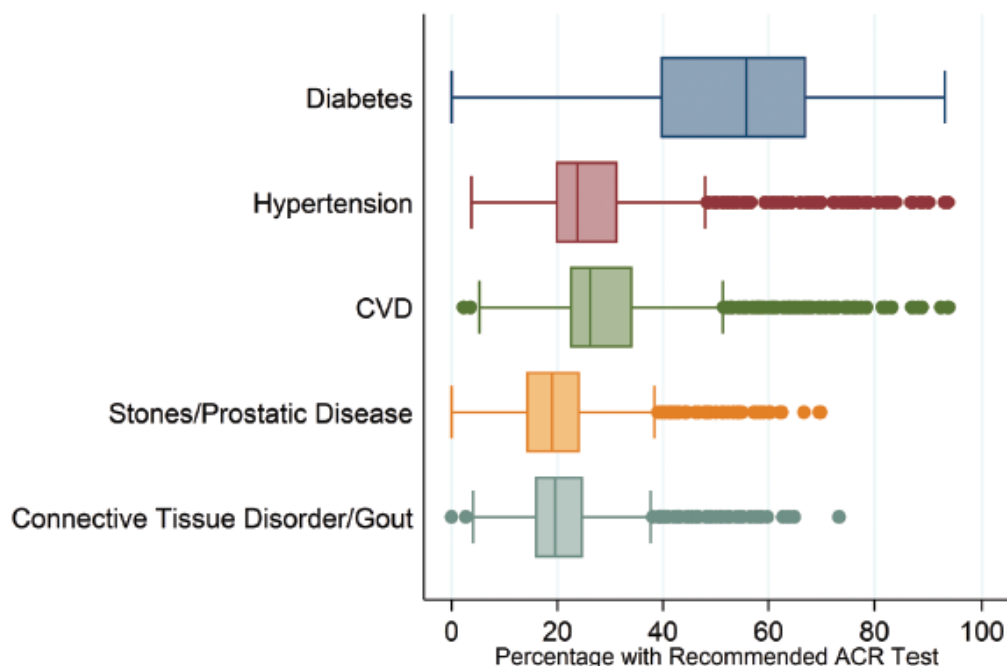


Source: National CKD Audit published January 2017

One particular area of concern was the number of patients with high risk diseases that may lead to chronic kidney disease who are not undergoing routine protein testing in their urine by ACR as shown below. This represents a missed opportunity in primary care since we know that patients with these diseases have higher rates of developing CKD and early intervention will probably lead to better (and less expensive) outcomes.

¹⁰ National Chronic Kidney Disease Audit, National Report (Part 1), Jan 2017, p11
https://www.lshtm.ac.uk/files/ckd_audit_report.pdf

Figure 4: Practice variation in percentage of patients at risk of CKD but not on the CKD 3-5 Register, who are receiving recommended urinary ACR testing (past year for diabetes; past 5 years for others), by risk factor



Source: *National Chronic Kidney Disease Audit, National Report (Part 1)*, Jan 2017, p11
https://www.lshtm.ac.uk/files/ckd_audit_report.pdf

It remains a challenge to identify patients with potentially progressive CKD in the community. However, the rewards for identification are enormous because of the potential to offset the costly treatment of end stage renal failure. Renal replacement therapy, in particular dialysis, is extremely expensive and associated with profound quality of life and economic consequences for the patient and their family. Identification of these patients at an early stage could potentially prevent, or at least delay, the need for renal replacement therapy. Patients with CKD also have an increased risk of cardiovascular disease, premature death and hospitalisation as shown in a seminal study from the USA, see Figure 5 and 6 below.

Figure 5: The increased risk of death for patients with CKD from cardiovascular disease, premature death and hospitalisation

Table 2. Adjusted Hazard Ratio for Death from Any Cause, Cardiovascular Events, and Hospitalization among 1,120,295 Ambulatory Adults, According to the Estimated GFR.*			
Estimated GFR	Death from Any Cause	Any Cardiovascular Event	Any Hospitalization
	<i>adjusted hazard ratio (95 percent confidence interval)</i>		
≥60 ml/min/1.73 m ² †	1.00	1.00	1.00
45–59 ml/min/1.73 m ²	1.2 (1.1–1.2)	1.4 (1.4–1.5)	1.1 (1.1–1.1)
30–44 ml/min/1.73 m ²	1.8 (1.7–1.9)	2.0 (1.9–2.1)	1.5 (1.5–1.5)
15–29 ml/min/1.73 m ²	3.2 (3.1–3.4)	2.8 (2.6–2.9)	2.1 (2.0–2.2)
<15 ml/min/1.73 m ²	5.9 (5.4–6.5)	3.4 (3.1–3.8)	3.1 (3.0–3.3)

Source: Go et al. 2004 New England Journal of Medicine

There are several ongoing ventures looking at technological solutions to this problem which involve monitoring either hospital or primary care pathology systems. One such project is the [ASSIST-CKD](#) project, joint-funded by Kidney Research UK and the Health Foundation. It uses software to map data from routine blood tests (eGFR), creating graphs of kidney function over time. For patients with deteriorating kidney function, the participating laboratories send a report, including the graph, to the GP with a prompt that specialist advice may be needed. There is also the [IMPAKT™](#) tool specifically for use on GP practice IT systems. This programme of work is currently taking place in primary care to help identify people with CKD in several areas around the country.

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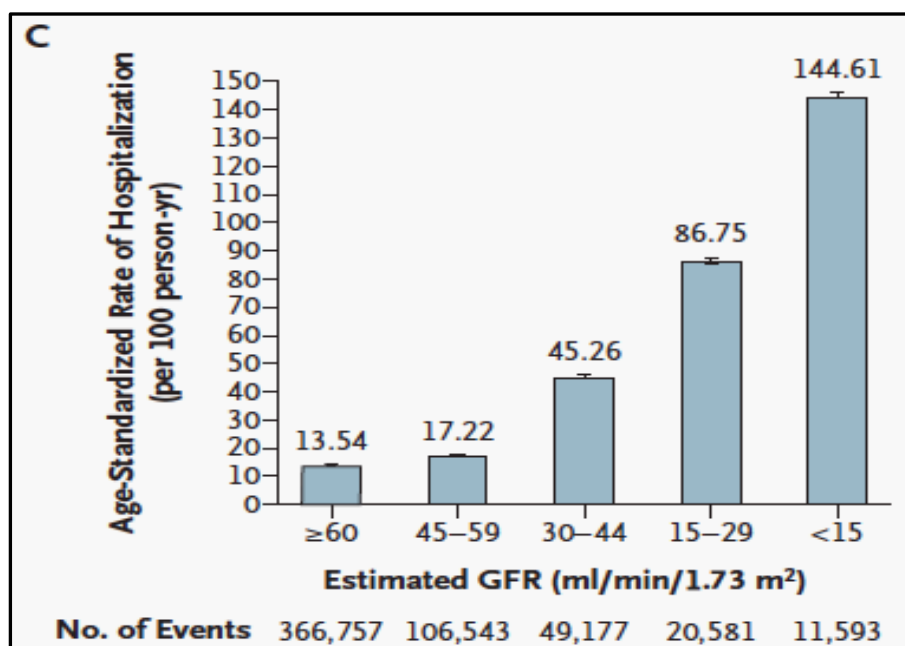
Learning / Opportunity 3: AKI (acute kidney injury) as a presentation of underlying CKD

Abdul was admitted with significant AKI at the age of 44. During this episode he was seriously unwell with a chest infection which resulted in severe acute kidney failure necessitating temporary dialysis. The precipitation of severe acute kidney injury by a community acquired chest infection - particularly in someone without obvious other risk factors such as blood pressure medication, diuretics or cardiovascular disease - should arouse suspicion that there might be underlying chronic kidney disease because it is unusual. The increased risk of AKI is reflected by the increased risks of hospitalisation for patients with worsening renal function in the study by Go. The National CKD audit report (part 2) (<https://www.lshtm.ac.uk/media/9951>) confirms that people with uncoded CKD are at increased risk of hospitalisation and AKI,

presenting opportunities to improve awareness. The AKI Think Kidneys programme has published information on CCG reporting and rates of AKI (www.thinkkidneys.nhs.uk) highlighting variation in mandated reporting of AKI and of rates by CCG.

NICE guidelines on AKI [Acute kidney injury: prevention, detection and management](#).

Figure 6: The increased risk of death for patients with CKD from cardiovascular disease, premature death and hospitalisation



Source: Go et al. 2004 *New England Journal of Medicine*

Abdul subsequently underwent a period of temporary dialysis during his stay on the intensive care unit. After his recovery, his kidney function had improved with an eGFR of 35mls/min/1.73m² at discharge. This may have seemed reassuring but the incomplete recovery reflects his underlying chronic kidney disease. His low blood pressure at the time was probably due to the infective process and masked his underlying hypertension. On discharge he should have been referred to the local nephrology unit for follow up. It would have been clear that his renal disease was progressive and assuming that he still had normal sized kidneys he would have undergone a renal biopsy which would have revealed the diagnosis of IgA nephropathy. At this point it may not have been possible to treat the underlying disease successfully, but it would still have been beneficial to treat his blood pressure and other cardiovascular risk factors. The aim would have been to slow the progression of his disease and retard the onset of the need for renal replacement therapy. Despite these measures it would have been likely that his native renal function would have slowly deteriorated even under the care of the local nephrology services.

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Learning / Opportunity 4: Optimal management through shared decision making under a multidisciplinary renal team

One of the most critical interventions that might have taken place would have been a referral into the low clearance clinic. This is a multi-disciplinary team clinic which has access to a number of specialised nurses, pharmacists, dieticians, social workers and other associated healthcare professionals. Access to this clinic would have enabled the following:

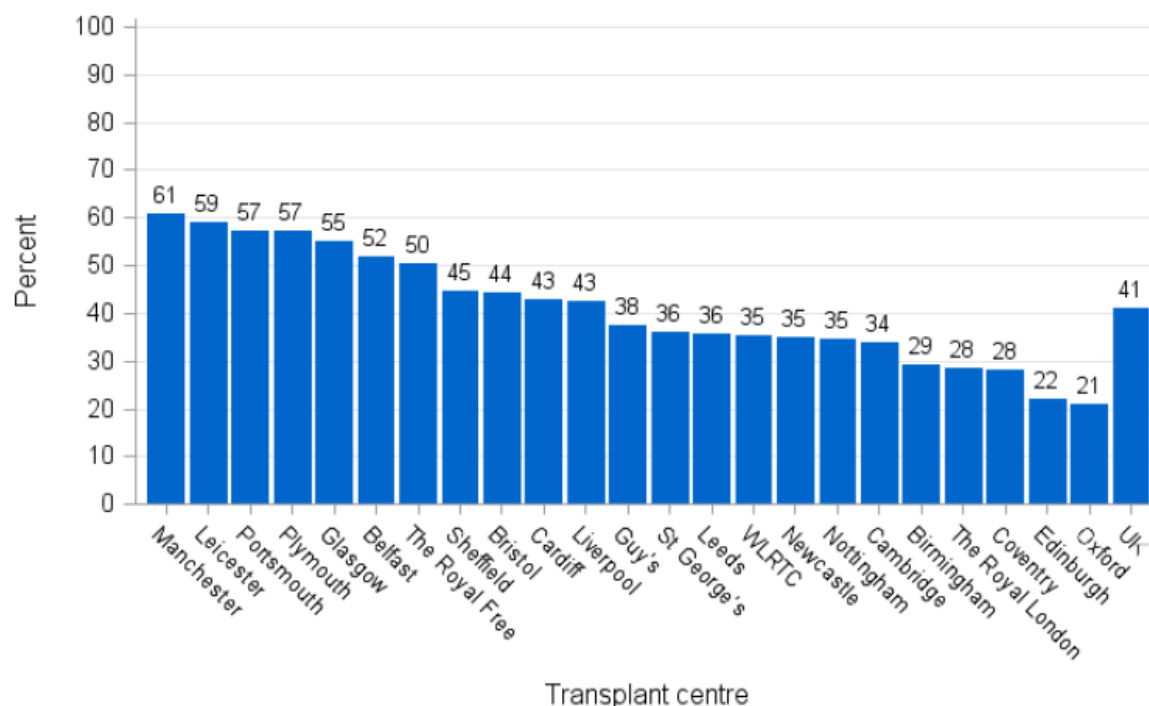
- Education regarding renal replacement therapy with shared decision making to enable an informed choice regarding options
Examples of such tools can be found at [Yorkshire Dialysis Decision Aid](#) or [Kidney Research UK. Dialysis Decision Aid: making the right choices for you](#)
- A home visit to discuss options one to one with his family in his home environment
- Management of anaemia and other complications of advanced CKD
[NICE Chronic Kidney Disease: Managing Anaemia](#)
- Assessment and early access to the renal transplant waiting list
See KQUIP [Transplant First Initiative](#)
- Comprehensive assessment of possibilities for [living donation](#)
- Timely assessment and placement of vascular access
[Renal Association Vascular Access guidelines 2015](#)
- Access to home based renal replacement therapy
[NICE Guidance Renal replacement therapy for adults](#)
- Improved patient experience with increased likelihood of becoming an [activated patient](#)
- The [Think Kidneys](#) programme

Timely access to the low clearance clinic is pivotal to the optimal management of patients with progressive CKD. It ensures that patients are able to make a well-informed decision with sufficient time for consideration with their family and friends. Such an approach forms the cornerstone of shared decision making. Centre specific reports from the UK regional registry and NHSBT (National Blood and Transplant) reveal that there are important variations in some of these outcomes (UK Research Registry Report and NHSBT Kidney specific report).

https://www.renalreg.org/wp-content/uploads/2017/09/19th-Annual-Report_web_book.pdf; <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/4607/kidney-annual-report-2016-17.pdf>

Early access to the renal transplant waiting list is important to maximise the number of pre-emptive renal transplants performed. This is important since there is a survival advantage to early transplantation. National variation is illustrated in Figure 7 below.

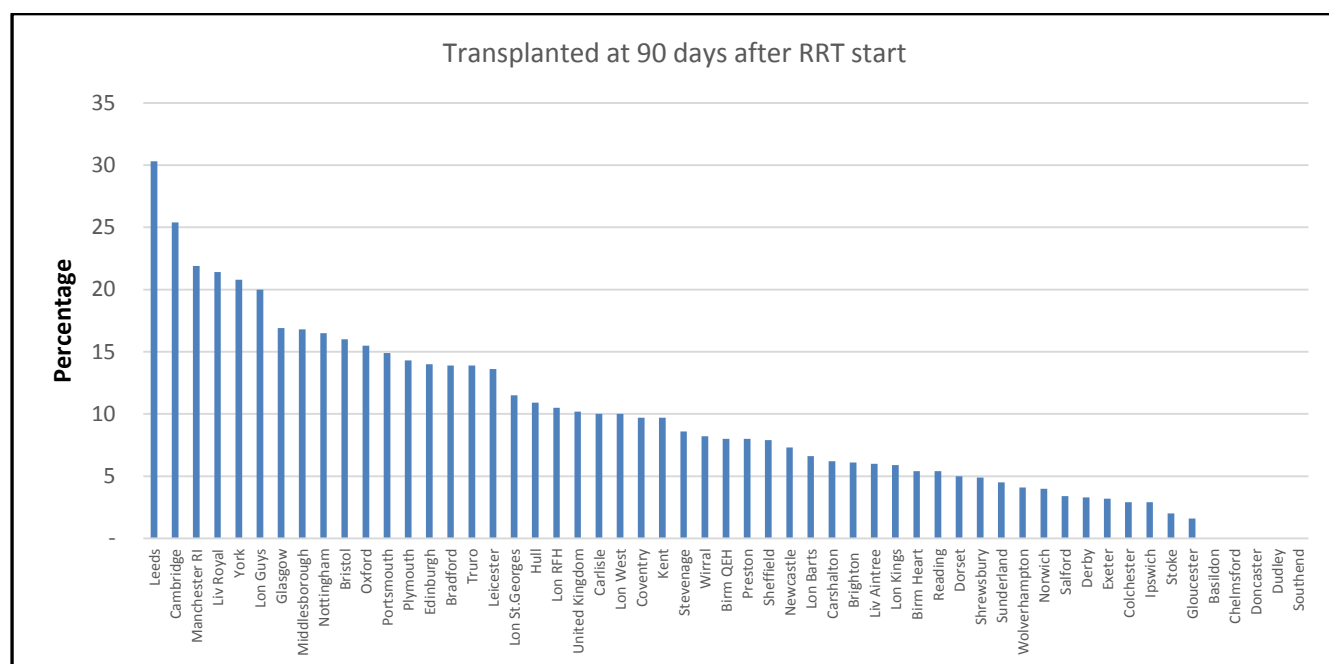
Figure 7: Adult pre-emptive listing rates by centre, registrations between 1 April 2015 and 31 March 2016



Source: NHSBT Kidney Specific Report for 2016/7

Access to living kidney donation is also highly variable across England. This was illustrated in the [NHSBT Annual Report on Living Donor Kidney Transplantation for 2016/7](#). Areas with successful programmes approach 20 live donors per annum per million population whereas other areas have rates around six. Centres across England that provide early access in to the renal transplant system, whether deceased or living donor, have higher rates of patients with functioning renal transplants 90 days after starting renal replacement therapy, as detailed in the most recent Renal Registry report and shown in Figure 8 on the following page.

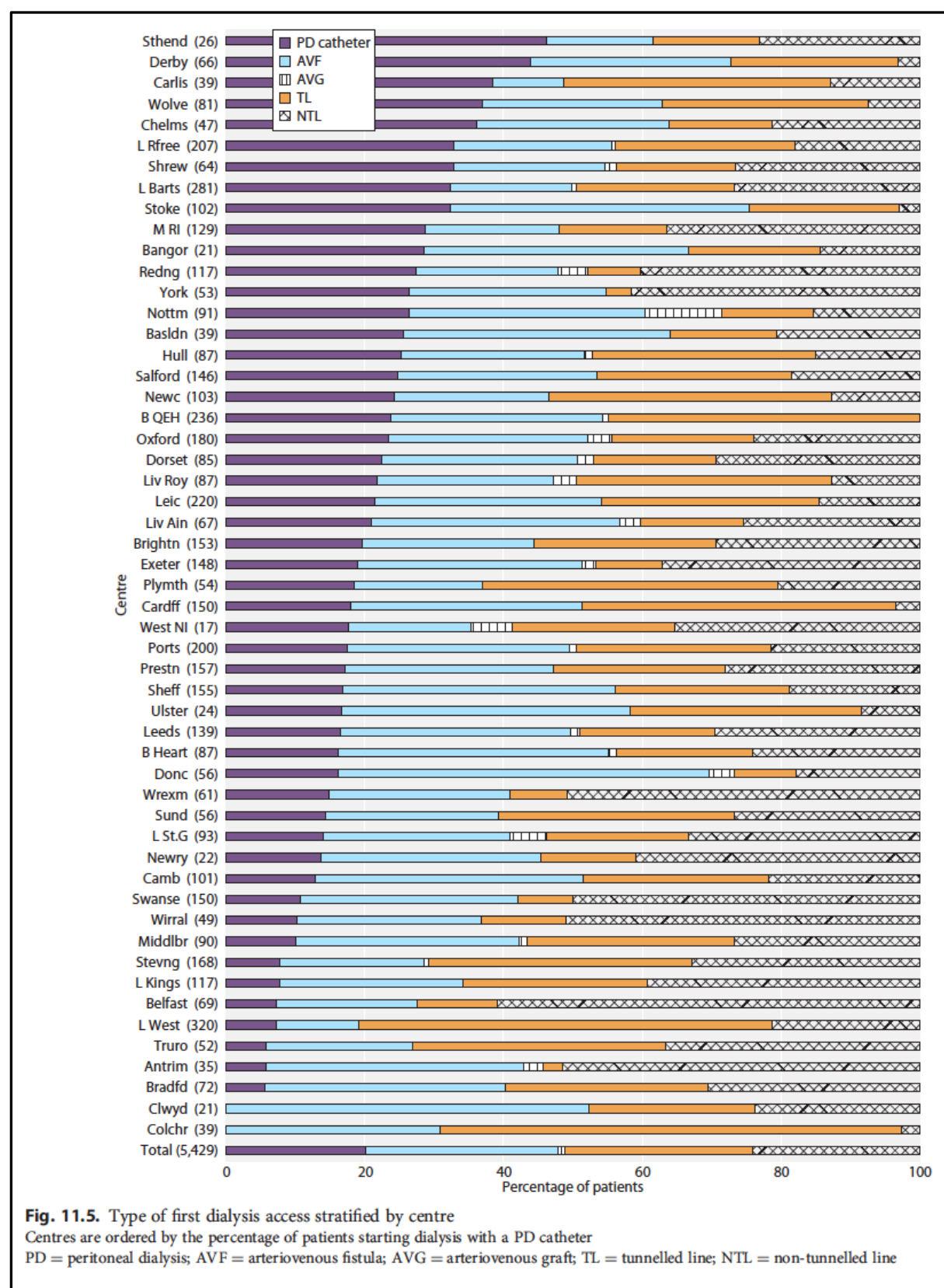
Figure 8: The percentage of patients at English renal units who are transplanted within 90 days of starting renal replacement therapy



Source: UK Renal Registry Annual 18th Annual Report

Another important function of the low clearance clinic is to provide education and information regarding other forms of renal replacement therapy apart from transplantation. Through a process of shared decision making it is essential that a patient has a chance to make a fully informed choice regarding their type of dialysis or conservative care. It is particularly important that they have dialysis access ready to use at the time when the symptoms indicate the need to start treatment. If access is not in place, then the only option is to start emergency haemodialysis through a temporary central venous catheter. There is evidence that starting dialysis under these circumstances is detrimental to the long-term outcome. It can be seen on the following page that there is considerable variation across the UK in the type of dialysis access at the point when dialysis starts.

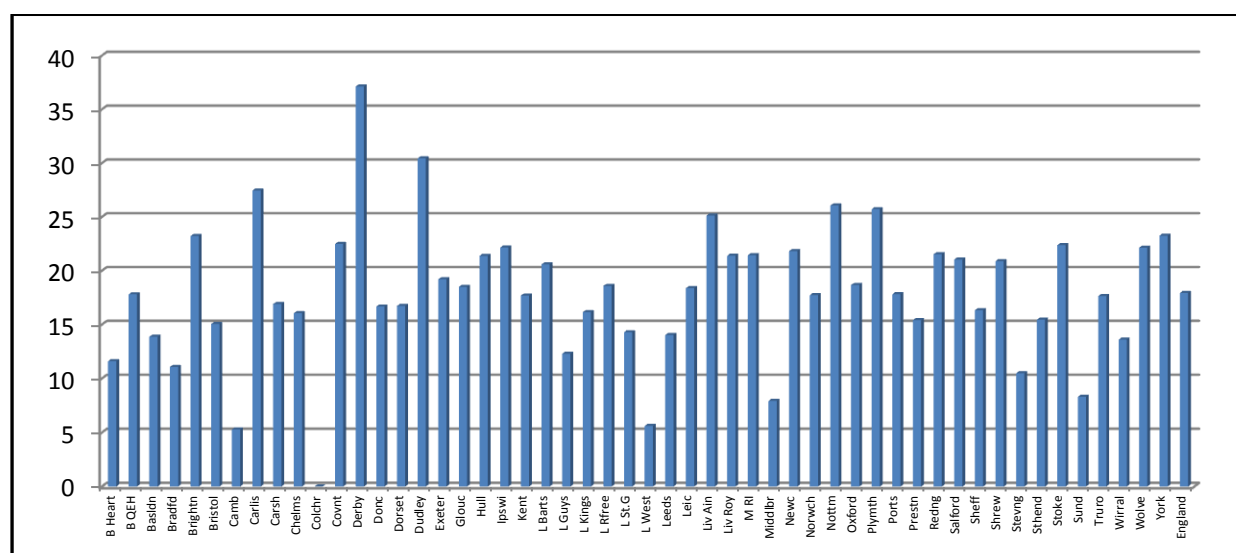
Figure 9: Type of first dialysis access stratified by centre



Source: UK Renal Registry Annual 18th Annual Report

There is a consensus that home-based therapies, for example peritoneal dialysis or home based haemodialysis, are often preferable for an engaged patient who has made an informed choice through shared decision making. Again there is variation across England in the take-up of these modalities:

Figure 10: Percentage of patients on home dialysis modality stratified by centre



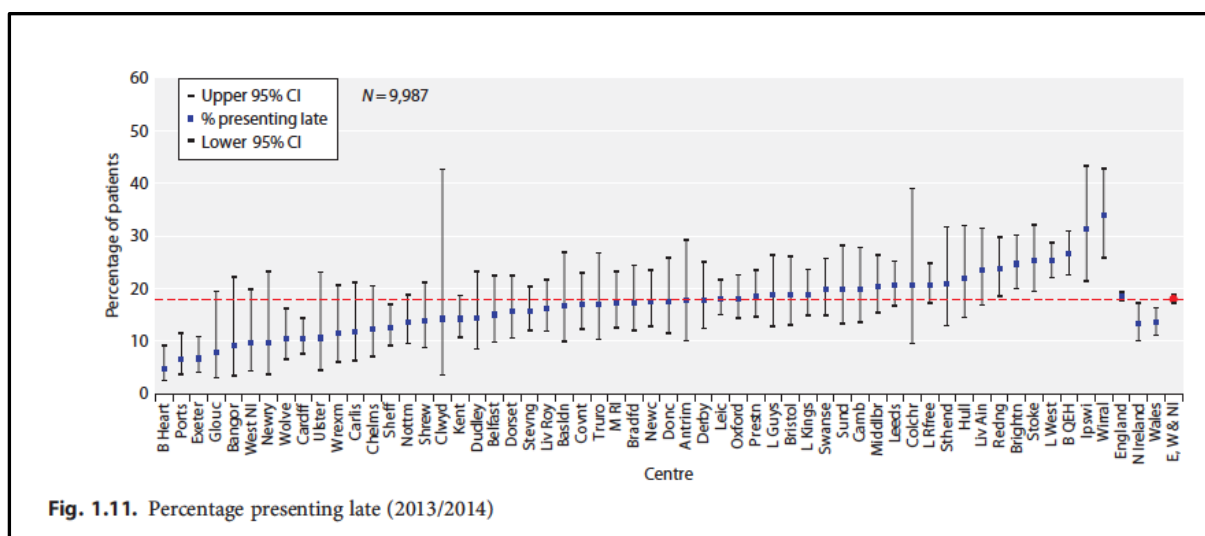
Source: UK Renal Registry Annual 18th Annual Report

[Return to Abdul's story.](#)

Learning / Opportunity 5: Unplanned starters

If patients with progressive CKD do not pass through the crucial low clearance clinic because they remain unidentified then they will often present at a very late stage and require urgent dialysis treatment to save their life. This has been called 'crash landing' although the term 'unplanned start' is preferable. As the result of several campaigns these numbers are falling across England and this is important since such patients have significantly worse outcomes. It is hoped that the new IT-based screening programmes may lead to further reductions in these numbers. Figures from the Renal Registry report (<https://www.renalreg.org/reports/2015-eighteenth-annual-report/>) show significant regional variations in these numbers. Despite improvement over time rates still remain high in some areas and the data highlights the importance of early identification, management of risk factors and the need for timely referral when indicated.

Figure 11: Percentage of patients presenting late to renal unit



Source: UK Renal Registry 18th Annual Report

[Return to Abdul's story.](#)

The final outcome

As a result of missed opportunities and poor patient activation Abdul's condition was diagnosed very late in its course. He was thus denied the chance to treat the underlying IgA nephropathy and also the prospect of retarding the progression of his CKD. Since he never passed through the low clearance clinic he was unable to make an educated and considered choice regarding renal replacement therapy through shared decision making. In effect he was denied access to early pre-emptive deceased or living donor transplantation. Through his late emergency presentation, he was forced to start on haemodialysis at the main hospital unit as an inpatient, initially in the intensive care unit. His chaotic early course meant that he was denied early elective access to home therapies and the delay in establishing definitive access resulted in a life-threatening complication from his temporary vascular access which ultimately delayed his transplant.

What could have happened differently? Abdul's optimal journey



Abdul was a healthy young man who did not suffer from any major illnesses in his childhood. He was always interested in cars and after school he joined a local Ford Motor dealership in the sales department.

He married his wife at the age of 26 and they had two children in his late twenties. Abdul played football for a local team and played 5-a-side with some friends once a week. He also took his children swimming at the weekend and he and his wife would enjoy taking the children to the local park where they would often meet friends who also had young children.

BUPA Well Man Check

When he was promoted at the age of 30 Abdul underwent a BUPA Well Man health check as part of his company medical insurance. The examination was all normal except his urine dipstick examination revealed that he had 'blood and protein' present and as a result his GP was notified. He attended his GP practice a week later but the urinary abnormalities persisted. A conversation took place between Abdul and the GP about what options were now available. The GP outlined the tests that he would recommend, and why. Abdul was keen to know what was wrong as soon as possible and so his GP checked his renal function and blood pressure and sent his urine off for formal protein quantification (Albumin/creatinine ratio). The results were as follows:

- Creatinine 92 $\mu\text{mol/L}$
- eGFR 83.1 mls/min/1.73m^2 (Normal $>90 \text{mls/min/1.73m}^2$)
- Albumin/creatinine ratio 176 mg/mmol (Normal $<2.5\text{mg/mmol}$)
- Blood pressure 135/88 mmHg

These results reflect normal kidney function in terms of filtering blood but reveal a leak of protein (albumin) into the urine. This finding is significant as it may be an indication of early renal disease as demonstrated in the [NICE guidelines for Chronic Kidney Disease](#) shown on the following page.

Figure 12: Prognosis of CKD by GFR and Albuminuria categories (NICE)

Prognosis of CKD by GFR and Albuminuria Categories: KDIGO 2012				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30-300 mg/g 3-30 mg/mmol	>300 mg/g >30 mg/mmol
GFR categories (ml/min/1.73 m ²) Description and range	G1	Normal or high	≥90			
	G2	Mildly decreased	60-89			X
	G3a	Mildly to moderately decreased	45-59			
	G3b	Moderately to severely decreased	30-44			
	G4	Severely decreased	15-29			
	G5	Kidney failure	<15			

Source: NICE guidance for CKD 2014

Referral to nephrology

His GP was concerned by these results, particularly because of the increased albuminuria, and so he had a conversation with Abdul about the possible implications, including the potential diagnosis of CKD, and what in his clinical judgement he would recommend. The GP used a technique called [Teach-back](#) to ensure that he had explained himself clearly.

Following this conversation the GP provided Abdul with some patient information on CKD and explained that he would be referring him to his local nephrology department. He was seen in the renal outpatient department at the hospital three weeks later, where these results were confirmed and he underwent an ultrasound of his kidneys, which was normal.

His consultant explained to him that his kidneys were still filtering normal amounts of blood but that they were leaking protein into his urine. He explained that the most likely cause for this was some form of inflammation involving the filtering area of the kidney which is called the glomerulus. He suggested considering a kidney biopsy because of the strong link between high levels of proteinuria in the urine and progressive kidney disease leading to end stage renal failure. He explored the benefits and risks of this course of action and Abdul's preferences. Both Abdul and

his wife were concerned about the proposal for a biopsy but after careful consideration and discussion, Abdul consented and a kidney biopsy was carried out as a day case without complications.

Diagnosis

Abdul returned to see his consultant two weeks later and was told that examination of his kidney sample under a microscope had confirmed the diagnosis of IgA nephropathy, one of the most common types of glomerular inflammation. The consultant was careful to explain in lay language, with the aid of patient information leaflets, what this meant. The consultant regularly checked that he was explaining himself in a way that Abdul could understand. This diagnosis came as something of a shock to Abdul since he had led a healthy active life and had not felt unwell. After discussing his anxieties with his consultant Abdul was offered an appointment with one of the renal specialist nurses for counselling and provided with information about the charities and local groups providing advice and guidance to patients with renal disease.

- Kidney Care UK (formerly British Kidney Patient Association) <http://www.kidneycareuk.org>
- National Kidney Federation <http://www.kidney.org.uk/>
- Polycystic Kidney Disease <http://www.pkdcharity.org.uk/>

He had been counselled regarding the risk of CKD by the specialist nurse at the renal clinic. Specifically, he had been advised regarding:

- The increased risk of developing end stage renal disease
- An increased risk of developing acute kidney injury
- An increased risk of hospitalisation
- An increased risk of cardiovascular disease
- Precautions to be taken with medications

It was explained that the best form of treatment at this stage would involve stringent blood pressure control and attention to his cardiovascular risk profile (i.e. cholesterol, weight loss, regular exercise, low sodium diet etc.). He was also advised to monitor his home blood pressure.

Ongoing treatment and monitoring

He was referred back to his GP who took on the management of his cardiac risk factors. He continued to attend the renal clinic on a six monthly basis and he was placed on the CKD Register at his GP practice. He was started on losartan 50mg once daily which was then further increased to 100mg daily after three months. He required amlodipine 5mg daily to obtain satisfactory blood pressure control aiming for less than 125/80 mmHg. He was also started on atorvastatin 10mg daily to

control his cholesterol. Abdul was seen on a regular basis by the GP practice nurse and he continued to be reviewed every six months in the nephrology clinic with satisfactory blood pressure control.

A return to daily living



Over the next ten years, with the support of his family, Abdul managed to maintain a healthy lifestyle, continuing to participate in his children's sporting activities

He continued to walk regularly with his wife as well as managing his weight and diet. However, his renal function continued to deteriorate despite good blood pressure control.

By the age of 44 his renal function had deteriorated to an eGFR of 45 mls/min/1.73m² although he remained asymptomatic. This level of renal function reflects continuing decline in function. In general patients with chronic kidney disease start to experience symptoms at around 20 mls/min/1.73m² and renal replacement therapy is usually required at around 8 mls/min/1.73m². He required the addition of indapamide MR 1.5mg to keep his blood pressure under satisfactory control. At work he had been promoted and was now the manager of his local Ford franchise. His children had grown up and were starting to look at options for further education.

Admission to hospital and acute kidney injury (AKI)

At this point Abdul became unwell with a chest infection and went to see his GP. He was treated at home initially with oral antibiotics. Because of his underlying renal disease his GP recognised the risk of developing AKI. As a result, having explained the risks to Abdul, he suspended his indapamide and losartan. He checked his blood tests and arranged for a review in 48 hours. On the next day his blood tests came back and showed significant deterioration with his creatinine rising to 280µmol/L (eGFR 21 mls/min/1.73m²). His GP explained to Abdul that this was a medical emergency and then contacted the renal unit and arranged for an admission to hospital that evening where he was treated with intravenous antibiotics and intravenous fluids to maintain his blood pressure. This is often required during a

serious infection as the blood vessels dilate and become leaky, thus requiring more volume of fluid to fill them and maintain the blood pressure.

Despite receiving timely referral and treatment Abdul developed a severe episode of AKI but he did not require any dialysis and he recovered to be discharged after a seven day stay on a medical ward. On discharge, he was told that he had suffered from acute kidney injury secondary to the underlying pneumonia. He was given an early review in the renal clinic where his function had improved to 226 $\mu\text{mol/L}$ (eGFR 27 mls/min/1.73m^2). His general condition was much improved but he had raised blood pressure so his indapamide and losartan were re-introduced. His discharge summary informed his GP of this diagnosis and advised follow up blood tests after four weeks.

<https://www.kidneycareuk.org/about-kidney-health/conditions/acute-kidney-injury-aki/>

Deteriorating kidney function: Preparing for renal replacement therapy

Abdul continued to be reviewed by the renal clinic and by the practice nurse and, whilst remaining in generally good health, his renal function slowly deteriorated over the next six years. By this time both of his children had left home to pursue further education.

At the age of 52, his renal function had deteriorated to a creatinine of 322 $\mu\text{mol/L}$ (eGFR 18 mls/min/1.73m^2). Patients with an eGFR of between 15-29 are considered to have severely reduced kidney function and treatment should focus on planning for established renal failure.

Abdul's care was therefore transferred by the renal unit to the low clearance clinic so that he could receive formal education regarding the options for renal replacement therapy. This involved several educational sessions with both doctors and specialist nurses to make a shared decision over the three main options:

- Renal transplantation
- Haemodialysis
- Peritoneal dialysis

Abdul's wife attended these appointments with him so that they could consider together the best option in terms of both his home and social life along with his work commitments. A specialist nurse also visited Abdul and his wife at home to discuss possible home based options for dialysis.

The frequency of his visits to the renal unit was increased to three monthly and he was reviewed in a multidisciplinary clinic where he had access to the following:

- Renal doctors
- Specialist renal nurses
- Specialist transplant nurses

- Pharmacists
- Dietitians
- Social workers

He was treated for the complications of advanced renal disease including the following:

- Anaemia treated with intravenous iron infusions and regular monthly injections of Darbopoeitin
- Acidosis treated with oral sodium bicarbonate
- Renal mineral bone disease treated with phosphate binders and vitamin D analogues

Treatment decisions

After careful consideration with his wife and the rest of his family Abdul decided that he would like to receive a renal transplant with a preference for pre-emptive living donation. This was not an easy conversation because of the sensitive matters under consideration and Abdul did this by arranging a meeting of his close relatives at home where they all watched an information film provided by the renal unit. He also provided copies of the living transplant leaflet available from the hospital to all family members and requested them to consider the information carefully. He elected to consider haemodialysis as a backup, if transplantation was either unsuccessful or not possible. He preferred for dialysis to be carried out at home if possible.

It was explained to Abdul and his wife that Black Asian and Minority Ethnic (BAME) patients face a number of challenges with receiving a kidney transplant. Members of the BAME population are less likely to be on the organ donor register, have increased risk factors of developing end-stage renal disease so are more likely to be on the transplant list and there are fewer compatible deceased donors. As a consequence BAME patients wait longer on average for a kidney transplant than the white population. Also, there are numerous cultural and religious barriers to organ donation among BAME communities and Abdul was informed of the work the [National BAME Transplant Alliance](#) in promoting organ donation. In light of this information Abdul's wife was very keen to be considered as a potential live donor and she was referred to the living donation specialist nurses who arranged for her to spend an hour with a [peer educator](#) who was part of a local programme to promote live donation in the BAME population. It was explained to Abdul and his wife that, although they are not related by blood, it was common for a wife or husband to donate a live kidney to their partner.

Unfortunately, following screening, it was discovered that Abdul's wife was not a compatible donor. She was very upset that she could not donate to her husband and she and Abdul arranged to meet with the Live Donor Co-ordinator to discuss their options. They had already discussed live donation with their family so were advised that they could, in the first instance, approach other family members to see if a suitable donor could be identified, or they might consider registering in the UK Living Kidney Sharing Scheme (Paired/Pooled Donation).

Paired / Pooled Donation Scheme

The 'Paired/Pooled' scheme provides the opportunity to find a compatible matched donor from across the UK. If you are in need of a kidney and have someone close to you who is willing to donate but you are incompatible with each other, because of your blood group or tissue type (HLA type), it may be possible for you to be matched with another donor and recipient pair in the same situation and for the donor kidneys to be 'exchanged' or 'swapped'.

<https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1432/27514-uk-living-kidney-sharing-schemes.pdf>

Abdul and his wife decided that they would discuss the matter with their family and if no suitable donor was identified they would register in the sharing scheme.



A number of family members came forward and were screened for compatibility. One of those who was screened was Abdul's older brother who turned out to be compatible.

Over the following three months Abdul's brother underwent a complete evaluation to confirm if he was a compatible donor and that he was deemed medically fit to donate by the transplant multi-disciplinary team. During this time he received counselling and support from the Live Donor Co-ordinator to ensure that he fully understood the medical implications of becoming a donor along with the potential emotional and psychological impacts.

Transplant

At the age of 54, when his renal function had deteriorated to a creatinine of 493 μ mol/L (eGFR 11 mls/min/1.73m²), he underwent an elective living donor renal transplant. His operation went smoothly with immediate transplant function and he was discharged after seven days. His brother was an inpatient for three days and recovered well. Two years later he remains well with excellent transplant function creatinine (108 μ mol/L (eGFR 62 mls/min/1.73m²). He is taking immunosuppression with tacrolimus and mycophenolate mofetil and he also takes amlodipine for his blood pressure. He has become a grandparent and continues to work as the manager of his local Ford garage.

The 'bills' and how they compare

For the financial evaluation we performed detailed analysis through mapping the lifecycle of the pathways. Through this process we were able to identify the cost drivers that would be incurred in primary, community and hospital care, using NHS reference costs and, where there is a hospital stay, average cost per bed day¹¹. We have included the wider social and economic impacts but we have not attempted to cost financially outside of the health remit or the social, emotional, physical and financial costs to the patient and family members.

This scenario is using a fictional patient, Abdul. It is intended to help commissioners and providers understand the implications (both in terms of quality of life and financial costs) of shifting the care pathway of people living with CKD from a reactive to a proactive approach. The financial costs are indicative and calculated on a cost per patient basis. Local decisions to transform care pathways would need to take a population view of costs and improvement.

¹¹ £400 has been used as a proxy measure to calculate the approximate costs of a single day's treatment in a ward in a hospital setting. This value has been derived from 2015/16 SUS data using the weighted bed-day cost with Market Forces Factor applied for age ranges between 40-74. This age range is typical for the suite of Long Term Conditions scenarios produced.

Edbrooke and colleagues estimated the average cost per patient day in 11 ICUs was £1,000 www.ics.ac.uk/EasySiteWeb/GatewayLink.aspx?allId=441 (please note that you will need to register to view the weblink). Reference costs applied are at 2015/16 prices. The excel spreadsheet designed to cost these scenarios includes full details of cost data sources and is available upon request. Please contact NHS RightCare at rightcare@nhs.net if you would like further details about the methodology.

Table 1: Analysis by provider

Analysis by provider	Sub-optimal	Optimal	Optimal %
Acute	£281,921	£50,063	17.8%
Ambulance service	£816	£0	0%
Primary care	£171	£3,622	2120.9%
Private sector	£135	£135	100%
Grand total	£283,043	£53,820	19%

The key difference between the standard and optimal pathways is a shift from costly unplanned reactive care to more proactive care and treatment.

This more proactive approach leads to a very significant reduction both in overall cost and a shift from expensive and avoidable secondary care management to less expensive early identification and monitoring in primary care. This shift represents improved value for money, better use of healthcare resources and most importantly a significant improvement in Abdul's clinical outcome and quality of life.

Table 2: Analysis by cost category

Analysis by cost category	Sub-optimal	Optimal	Optimal %
Self care	£135	£135	100%
Primary care management	£127	£3,622	2855.9%
Urgent and emergency care	£962	£0	0%
Secondary care management	£281,819	£50,063	17.8%
Grand total	£283,043	£53,820	19%

Note The two scenarios end at the same point in time and the costs are comparable over this timeframe. However, note that in the optimal scenario Abdul goes on living longer and these additional support and treatment costs are not included within these figures.

Much of the secondary care cost incurred in the standard pathway is the consequence of dealing reactively to problems associated with the undiagnosed, and therefore untreated, progression of Abdul's kidney disease.

Secondary care costs in the optimal pathway are focussed on the appropriate management of Abdul's disease as it progresses resulting in his planned transplant.

In addition to those savings modelled above Abdul's planned transplant also avoids the long term ongoing costs of dialysis.

As well as the healthcare costs summarised in the tables on the previous page the optimal pathway also enables Abdul to remain in good health and to continue to work thus avoiding additional social care costs.

Think change, Think NHS RightCare

This optimal pathway was understood, tested and created using the proven NHS RightCare approach.

NHS RightCare is a methodology that focuses relentlessly on increasing value in healthcare and tackling unwarranted variation. It is underpinned by intelligence and robust evidence, showing commissioners and local health economies 'Where to Look' i.e. where variation and low value exists. The approach then goes on to support health economies through 'what to change' and 'how to change'. The diagram showing all three key phases is shown below.



NHS RightCare offers facilitation and support to all CCGs and their health economies in implementing the RightCare approach and the developmental thinking, tools and data that enhance population healthcare improvement.

NHS RightCare is a proven approach that delivers better outcomes and frees up funds for further innovation. Please explore our latest [publications](#) and for more details about our programme visit www.england.nhs.uk/rightcare.

You can also contact the NHS RightCare team via email at rightcare@nhs.net

For more information about the Long Term Conditions work at NHS England please contact england.longtermconditions@nhs.net.