Renal Research:

From a pioneering past, to a positive future for kidney patients.
Kidney disease is a silent killer. There are three million people in the UK with it right now and there is no cure. We are the leading kidney research charity committed to developing treatments, patient information and raising vital public awareness to help save lives.

The prevalence of kidney failure has continually increased in recent years. A proportion of kidney disease is genetic or due to malformations. However, cases of high blood pressure – which is controlled by the kidneys – continue to rise, as do the numbers with diabetes, obesity and cardiovascular disease, all risk factors for kidney disease. This makes our work today more essential than ever.

Kidney Research UK funds vital research into the causes of kidney disease, prevention and better treatments and is striving to make transplanted kidneys work better and last longer. We also raise awareness of kidney-related issues and organ donation amongst the general public. Our online kidney health information service provides advice and literature on how best to deal with each type of renal disease.

The lives of 3,000,000 people are at risk as a result of moderate to severe chronic kidney disease. We know that two million of these have been identified, resulting in a ‘missing million’ of undiagnosed patients. This ‘missing million’ is therefore at greater risk. As the number of people with kidney disease is set to increase over coming years, our work, which relies almost wholly on donations from the general public, becomes more essential than ever.

We are working hard to ensure that one day people’s lives will be free from kidney disease. Thanks to help from our supporters, we have achieved breakthroughs in the diagnosis, treatment and care of those affected by the disease as this report will show.

@Kidney_Research
www.kidneyresearchuk.org
This document brings together in one place the key available evidence on the current picture of kidney health in the UK. It celebrates breakthroughs in recent and ongoing research, tells the story of real people who have been affected by kidney disease, and sets out what is needed to enable more breakthroughs in generations to come.

With scientific research we know that some terms can be very technical, so with this document we aim to ensure that the information contained, the stories told, and the recommendations made are accessible to patients, the public, healthcare professionals and decision makers alike.

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1943

The first ‘artificial kidney’ is constructed by the Dutchman Dr Willem Kolff

1954

The first successful human kidney transplant takes place between between identical twins
We have made remarkable progress since Dr Willem Kolff’s first kidney dialysis machine was created in the 1940s. The resourceful doctor made use of sausage skins, orange juice cans and even a washing machine! Thankfully, extensive research and technological development has moved us forwards considerably. New and exciting research is taking place all over the UK, helping us to make ground breaking strides.

But we still have a long way to go if we are to truly tackle kidney disease and make every kidney count. Kidney disease in its many forms affects several million people in the UK, and has a devastating impact on the lives of patients, their families and carers. While there are over 5,200 people on the transplant list waiting for a kidney, less than 3,300 transplants take place each year2. Those requiring haemodialysis in the UK have to undergo treatment three times a week on average.

Research is essential if we are to better understand kidney disease and develop new and improved treatments. In developing this report our ambition is to shine a spotlight on the fantastic achievements that have been made in the fight against kidney disease and to look at what is on the horizon that demands our attention.

We are committed to driving forward research into kidney disease in the UK. The UK Renal Research Strategy, produced by the kidney sector and published in 2016, provides a direction for renal research, policy and funding communities. With your support, we want to help fulfil our obligations in ensuring that the vision of the strategy is realised.

In this document we outline to policy-makers the overarching priorities that support the future of renal research. It is essential that these are addressed in order to be successful in continuing to grow UK leadership in renal innovation. We examine the challenges still faced and put forward recommendations for how these can be overcome.

We know we must go further, continue to drive innovation and ensure that the UK maintains its position as a leader in renal research to deliver the best possible outcomes for patients. I hope that this report helps to shape the approaches we take to tackle kidney disease for the foreseeable future.
Research is the foundation of effective kidney healthcare. It plays a critical role in creating new, better and more innovative treatments for patients.

The UK is a world leader in research in numerous fields. While many renal research studies taking place in the UK set the bar globally, we know that there is still much we should do to grow our leadership in renal research.

The urgency for driving forward research into kidney disease is abundantly clear. Kidney disease has a drastic impact on people’s lives and takes a devastating toll; over 3,7007 people a year die while on dialysis and more than five people die every week while waiting for a kidney transplant2. It is only through a commitment to research and innovation that we can ensure that patients receive the best treatments, and therefore the best possible outcomes.

As the Chair of the Association of Medical Research Charities, I am therefore delighted to welcome this report by Kidney Research UK. This not only celebrates the pioneering past of renal research and the great strides that have been made, but also sets out the necessary steps to securing its continued innovation in the future.

It helps to set the groundwork for the UK Renal Research Strategy, developed by the kidney sector, published in 2016 and will provide a direction for renal research, policy and funding communities. Kidney Research UK, as a contributor to the strategy, will help to drive forward its core aims, in alliance with the wider kidney community, and touches upon some of the key issues in this report.

It is truly exciting to think of the huge progress that would be made if every kidney patient were provided the opportunity to take part in research; if NHS healthcare professionals were given dedicated time for training on renal research; if a greater focus were placed on research related to minority groups with kidney disorders. These are not unattainable goals and I hope this report helps to pave the way for significant changes that will benefit generations to come.

Lord Sharkey
Chair, Association of Medical Research Charities

1964
Teams in Seattle, Boston and London train and begin to send patients home to run their own dialysis

1976
Brain death guidelines in the UK start to facilitate the retrieval of organs from heart-beating donors after brain death – an important step towards the establishment of a national donor register
Kidney health in the UK

The lives of more than **3 million** people are at risk as a result of moderate to severe chronic kidney disease (CKD). Two million are on the CKD register, meaning that there is a missing million of undiagnosed patients.

**Around 6–8%** of the UK population are estimated to have moderate to severe CKD.

**Every year**, **64,000** people in the UK are being treated for end stage kidney failure. The prevalence of patients presenting with kidney failure is increasing at 4% each year.

The estimated annual cost of chronic kidney disease to the NHS in England is **£1.45 bn**.

It is estimated that there are **60,000 premature deaths each year in people with CKD**.

Over **5,200** people are waiting for a kidney, yet only around 3,300 transplants are carried out each year.

Dialysis treatment costs approximately **£25,000** per patient per year.
A person on dialysis aged 25 years has the same cardiac prognosis as the average 75-year-old.  

The median waiting time for a kidney on the transplant list is about 1,000 days; it is about 250 days for a lung transplant.

Over 3,700 people a year die while on dialysis and around 250 people a year die while waiting for a kidney transplant, which is more than 5 people a week.

A kidney transplant only lasts between 10 and 15 years on average.

1 in 5 emergency admissions into hospital are associated with acute kidney injury.

On average:
- Asian people wait 188 days longer and Black people wait 252 days longer for a transplant than White people.

Kidney failure is up to 5x more common in people from Black, Asian and Minority Ethnic (BAME) communities.

Kidney Research UK has to turn away around half of the excellent research proposals that we want to support – what possible breakthroughs might be in those we cannot fund?
Kidneys and kidney health

Kidneys are essential for life and perform a vital role in keeping the blood clean and chemically balanced. They are two organs located in the middle of your back, just above the waist.

What do kidneys do?
Kidneys perform many functions, but principally they have three main roles:

1) Cleansing the blood of toxins and transforming waste into urine, so they can be passed safely from the body

2) Helping to maintain a constant level of essential electrolytes such as sodium and potassium, and water content

3) Producing a number of essential hormones that play a vital role in blood pressure control and the formation of red blood cells

Without these functions a person would die within a few days, as a result of the build-up of waste products and fluids.

Renal research is vital because:

• Up to a million people in the UK may have undiagnosed chronic kidney disease (CKD)

• 3,770 people a year die while on dialysis and five people die every week while waiting for a kidney transplant

• The average waiting time for a kidney on the transplant list is about 1,000 days; this is compared to 250 for a lung transplant

What are the causes of kidney disease?
Kidney disease can take a number of different forms, from complete failure to produce urine to disturbances in the balance of one or more substances in the body for which the kidneys are responsible.

People with low levels of damage to their kidneys can often carry out their day-to-day lives normally and find no significant impact on their wellbeing. However, although people can live with poorly functioning kidneys, it may come at the expense of chronic ill health including high blood pressure, anaemia, bone disease and a much higher likelihood of suffering from heart attacks and strokes.

Kidneys can be affected by many different diseases. Young children with kidney failure are commonly born with abnormal kidneys, caused by irregular genes. In contrast, older children and adult kidney disease is usually caused by damage to previously normal kidneys, which can occur for a number of reasons such as immunological factors, infections or diabetes.

Kidneys may also be damaged by issues such as the side-effects of drugs used to treat other disorders, or by circulatory failure triggered by disease. Some kidney diseases are so rare that very little is known about them. Further research is needed to get to the root causes of these.

1980
Continuous ambulatory peritoneal dialysis (CAPD) is developed; a better option for patients to administer themselves

1983
Immunosuppressant drug called cyclosporine is approved for organ transplantation
Dr Stephen Reeders at Oxford Renal Unit undertakes initial gene mapping for polycystic kidney disease (PKD), NKRF then fund the next stage gene sequencing to establish how mutations led to the development of PKD in patients.

What is chronic kidney disease?
Chronic kidney disease (CKD) describes a wide variety of kidney disorders that cause damage to the kidneys over a period of months or years.

In addition to the risk of progressive kidney damage, CKD is associated with an increased risk of diseases affecting the heart and arteries. Management is focussed on treating the specific cause of the kidney disorder as well as general measures to protect kidney function, including blood pressure treatment, weight loss, exercise and smoking cessation.

It frequently goes unrecognised and it is estimated that up to a million people in the UK have undiagnosed CKD. In fact, CKD is quite often found by accident when a doctor carries out tests to investigate something else, for example during routine employment medical screening, where signs of kidney disease are discovered at an early or moderate stage.

CKD commonly goes hand in hand with diabetes and cardiovascular disease. If the problem is not discovered, eventually your body will let you know – as well as being ill, the lifestyle you and your family enjoy changes, your life could even be at risk. By this stage it is often too late for any effective preventative measures and some people with CKD will progress to end stage renal disease, where regular dialysis treatment or a kidney transplant is needed to keep them alive. In the UK, about 900 children and 64,000 adults are in this situation.

Kidney disease does not affect all populations equally. Black and South Asian patients are over-represented, particularly in the most severe stages of disease. CKD is associated with lower socio-economic status, and people from more socially deprived areas have poorer access to the transplant waiting list.

What is acute kidney injury?
Acute kidney injury (AKI) is a sudden reduction in kidney function. It is not a physical injury to the kidney and usually occurs without symptoms. In England over half a million people sustain AKI every year with AKI affecting 5-15% of all emergency hospital admissions. As well as being common, AKI is harmful and often preventable, and is a major patient safety challenge for health care.

Can’t you go on dialysis?
- Dialysis is often described by patients as “life support with no life”
- Every time you dialyse it places additional strain on the heart
- Dialysis is not a cure

Can’t you have a transplant?
- Transplants don’t last for life – they currently last an average of 10-15 years
- Over 5,200 people on the list are waiting for a kidney in the UK, but there are only around 3,300 kidney transplants carried out each year
- A complex mix of drugs is needed to stop the body rejecting your donated kidney

1985
Dr Stephen Reeders at Oxford Renal Unit undertakes initial gene mapping for polycystic kidney disease (PKD), NKRF then fund the next stage gene sequencing to establish how mutations led to the development of PKD in patients.

1990
A team at Newcastle University funded by NKRF demonstrates that abnormalities in genes within the immune system may be predisposed to disease in around 60% of cases of patients with aHUS.
Research in practice

Kidney Research UK is funding a wide range of research projects, which are helping to save people’s lives. Below is the story of a little boy who, without the significant achievements made in renal research, would not be with his family today.

Kidney transplantation in children

Although kidney transplants usually only last for around 10-15 years, having a kidney transplant remains the best treatment available for irreversible kidney disease in children. There is no minimum age for a transplantation, but the child has to be big enough to receive the kidney, and so transplants usually take place when children are over two years of age.

Finlay’s story

Chloe was delighted when she was told she was pregnant with twin boys, Oscar and Finlay. However, it became clear from scans that Finlay was much smaller than his brother and there were serious complications with his bladder and kidneys that were a significant risk to his chances of survival. “At 16 weeks pregnant I was told by doctors that there were four possible outcomes; only one gave Finlay a chance of surviving,” Chloe said.

When the twins were born, Finlay had severe loss of kidney function. He was rushed to a neonatal unit to be resuscitated and just three days later, he was moved to Great Ormond Street Hospital to undergo an operation on his kidneys. Following this operation, his first of many, Finlay was started on peritoneal dialysis. He was just four days old.

By the time he was eight weeks old, Finlay had undergone eight operations. With his health still not improving, Finlay was switched to haemodialysis. It was the lifeline that Finlay needed, and meant that he was strong enough to undergo further critical operations. Chloe said: “It worked straight away, I saw the change in him immediately.”

With the haemodialysis making Finlay stronger, just one month before his second birthday Finlay was able to undergo a transplant operation; he received an adult kidney, from his father.

Now three years old, Finlay is a cheeky, cheerful and happy boy!

1992
Professor Giovanna Lombardi discovered that regulatory T cells (Tregs), were potentially capable of preventing transplant rejection in patients with lupus. Funded by NKRF
There are many examples of how research has saved lives, and the case studies that follow provide just a small snapshot of some of the innovation being carried out today. We hope these demonstrate what incredible research is underway throughout the UK, and the impact it is having on the lives of patients.

New study to improve life expectancy of children on dialysis

There are currently more than 120 children in the UK on conventional haemodialysis (HD). This means that they receive treatment around three times a week, each time taking between three to four hours. Sadly, some children on HD go on to die of heart disease in their 20s and 30s as a result of complications of the treatment.

To improve the quality of life and life expectancy for children on HD, we are funding an international study to try and find an alternative treatment. This will look at a newer form of dialysis, called haemodiafiltration (HDF), which works by removing more toxins from the body. We are hopeful, as there is evidence that adults on HDF have increased survival rates by more than 35%.

In this study we are monitoring a number of factors to see just how HDF is making a difference. We will be looking at growth and nutrition, heart and blood vessel scans, blood tests and quality of life.

The research project will take around three years and cost £200,000. Dr Rukshana Shroff at Great Ormond Street Hospital is leading the work.

Children with severe CKD can face severe problems that may affect their nutrition, cause bone problems and damage the heart and blood vessels.

My research is looking into ways of reducing the risks of heart disease in our patients.

If we find that this new type of dialysis leads to improved results in these areas, then it may become the preferred type of dialysis for children in the UK, which could have a huge impact on their lives.

Pranav’s story

Pranav first became unwell on Christmas Eve 2002, just before his fourth birthday. His parents took him to the local A&E, and he then had to stay in hospital for one month. He went to Great Ormond Street for a kidney biopsy, which revealed that his kidneys had a severe disease called Focal Segmental Glomerulosclerosis (FSGS). This meant that Pranav’s kidneys were unable to work properly and he was very unwell as a result – he was vomiting a lot, unable to eat and experienced a lot of swelling.

Following this, one of Pranav’s kidneys failed and he was started on haemodialysis. Unfortunately this made him feel very tired and he had no energy at all to concentrate in school or be able to take part in sport. The dialysis also made him feel quite dizzy and gave him headaches.

In September 2005, when he was six, Pranav received his first kidney transplant. It failed immediately due to recurrence of FSGS, and the kidney was removed in September 2007. He went on to receive a second kidney transplant in February 2012, but sadly this also failed within just 48 hours due to recurrence of FSGS.

However, his doctors told him that there was a new type of dialysis machine that would clean his blood in a better way: HDF. After he started this treatment he started to feel a lot better, with more energy and a big appetite!

Pranav is now excited for the future. He enjoys playing the drums with an orchestra and he hopes that with this new treatment he will continue to improve his drumming and be able to do new things, like learn to drive. This would not have been possible before.
Urinary tract infections (UTIs) affect approximately 50% of all women in the UK. Kidney infections can occur if the UTI spreads to the upper urinary tract, which can lead to permanent kidney damage. In rare cases the infection can even become life-threatening. Worryingly, these infections are becoming increasingly resistant to antibiotics, meaning they are more difficult to treat and treatment options for UTIs are running out.

As a result, Dr Rachel Floyd at Liverpool University has undertaken a three year research project for Kidney Research UK, which has advanced our knowledge towards finding new treatments for UTIs. She has done this by looking at the bacteria E. coli, which causes 85% of UTIs, to see how this bacteria moves to the kidneys and causes damage.

Dr Floyd hopes that her research will identify specific processes that drug companies could explore when developing new treatments for UTIs.

She said: “We hope to be able to say ‘these are the factors that we think are responsible for causing UTIs. Can you develop something specific that will stop this happening?’”

Kelly’s story
Kelly experiences from recurring UTIs and almost lost her life after an antibiotic-resistant strain of the infection spread to her kidneys. The infection moved from there into her bloodstream, causing a potentially fatal condition called urosepsis. Kelly was rushed to intensive care and spent ten days in hospital.

“My pulse was racing, I felt faint and had severe pain in my abdomen. It was the worst pain I’d ever had. I thought I was going to die. Having been through what I’ve been through, I really think we need to use antibiotics responsibly – or we will all be paying the price.”

A new ground breaking study battling superbugs

2004
NKRF research discovers a cell that causes kidney scarring which can lead to kidney disease

2005
NKRF becomes Kidney Research UK

2005
NKRF launches its Peer Educator model to raise awareness of kidney disease amongst ‘at risk’ communities
PIVOTAL – a world-leading trial to address iron deficiency and anaemia in kidney patients on dialysis

Kidney patients on dialysis treatment commonly have an iron deficiency and become anaemic. This can lead to fewer red blood cells being produced than normal, which in turn leads to less oxygen to tissues and organs – particularly the heart and brain. With less oxygen, those tissues and organs may not work as well as they should.

Iron can be given to kidney patients intravenously through their dialysis machine. However, no one knows if it is better for patients to receive a little or a lot of iron through this method, so we are helping to find this out by funding a trial that will answer this question.

The PIVOTAL trial, led by Professor Iain Macdougall, Professor of Clinical Nephrology at King’s College Hospital, London, and Chair of the Anaemia Clinical Study Group is the first of its kind in the world and is the largest clinical trial that has ever been conducted in renal units in the UK.

The trial will take four years and involves over 2,000 patients as well as clinicians from 50 renal units across the UK. It has received interest from countries worldwide, and it has the potential to have an impact on thousands of patients.

Professor Macdougall said: “The results of the PIVOTAL trial will have widespread impact, and will likely influence iron management in dialysis patients around the world.

This study has not only shown that the UK can conduct large randomised controlled trials in patients with chronic kidney disease, but has allowed a network of research nurses to collaborate, share experiences and learn from each other.”

Derek King’s story

Derek King from Kent is one of the patients taking part in the PIVOTAL trial. It forms part of his regular four-hour haemodialysis sessions which are held three times a week in his local renal unit.

Derek had always enjoyed good health but in late December 2012 his kidneys suddenly failed and turned his retirement into a rigid regime of haemodialysis. He now looks upon his treatment as a job that he must do to stay alive. But he hopes his involvement in PIVOTAL will help to make a real difference to the lives of future haemodialysis patients.

“This is the first clinical trial I’ve been involved in and I would definitely recommend it to others. These trials mean that we can gradually learn more and more and that’s the name of the game. It might not benefit me but if I can help someone in the future it’s all for the good.”

2007
Dr Michael Stechman at the University of Oxford discovers genes responsible for kidney stones. This work was funded by Kidney Research UK

2010
Dr John Bradley and his team in Cambridge discover that a protein called tumour necrosis factor (TNF) may one day make it possible to instruct cells in a kidney tumour to die. This would stop the growth of the cancerous tumour
Making kidney transplants last longer

Up to 10% of patients who receive a kidney transplant are affected by a disease (polyomavirus-associated nephropathy (PVAN)) that attacks the transplanted kidney, and causes massive destruction. As more people receive organ transplants, the numbers who experience this are expected to grow.

There is currently no effective treatment available. The only option is to reduce the immunosuppressive drugs that a person is on, giving their immune system a chance to battle the virus. However, these drugs are given to try and stop the body rejecting the transplanted kidney, so coming off the drugs presently is very risky.

Dr Andrew Macdonald has completed a two year study at the University of Leeds that has identified a possible way to prevent infection and therefore in the future treat patients with PVAN.

PVAN is one of the leading causes for the loss of a recent kidney transplant in both adults and children and is caused by infection with the BK polyomavirus.

Our research aims to find treatments that attack certain parts of the virus. By attacking the PVAN, we hope that more patients can have kidney transplants that last longer.

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When Janice was about three years old she kept getting bad bouts of cystitis. After suffering a number of kidney infections aged 14-15, doctors realised her right kidney had stopped growing. Her left kidney was struggling through working harder and so Janice had repeated infections and scarring on the kidneys, which just made them deteriorate further.

She was started on peritoneal dialysis in 2009 but this was largely unsuccessful and in October 2010 Janice became very ill – she developed peritonitis, which led to sepsis. This led to total organ failure and put Janice in a coma for almost two weeks. After that she couldn’t have any more peritoneal dialysis and was switched to haemodialysis.

Janice said: “I just kept getting infections all the time in my lines, I had four or five lines in 18 months. So I spent a lot of time in hospital through that as well.”

When Janice’s health improved, her sister was tested to see if she could donate a kidney; it was positive and a live transplant was carried out successfully in November 2011. But, just a few months later, in February 2012, Janice’s kidneys were failing due to BK virus. Janice was given antibiotics which eradicated the virus, but the donated kidney was too damaged to survive. After her kidney was removed, she had to return to haemodialysis.

In 2013 two of Janice’s friends were tested to donate their kidneys. One came over from South Africa, and one from Australia. Against the odds, they were both a positive tissue match. However, ahead of any decision of which of her friends would donate, Janice got a phone call from the hospital saying a kidney from a deceased male was available immediately. Janice had a second transplant operation, but unfortunately the kidney never worked.

“That was such a massive blow, a disappointment for everybody really, for my sister because she’d given me her kidney, for my parents, my husband and all my friends to see me going through all that again, and spending a considerable amount of time in hospital.”

In 2014 two of Janice’s friends were tested to donate their kidneys. One came over from South Africa, and one from Australia. Against the odds, they were both a positive tissue match. However, ahead of any decision of which of her friends would donate, Janice got a phone call from the hospital saying a kidney from a deceased male was available immediately. Janice had a second transplant operation, but unfortunately the kidney never worked.

“I remained on dialysis and unfortunately I developed cytomegalovirus infection (CMV) and double pneumonia and lost my kidney. So I haven’t had a lot of luck really. Now, because I’ve had two failed kidneys and a lot of blood transfusions, I can’t go ahead with my friends’ donor kidney any more as I’m growing so many other people’s antibodies that it’s difficult for me to get a donor match.”

But Janice is resolute. She is not going to give up and hopes that Dr Macdonald’s research will provide the breakthrough that she needs.
Atypical Haemolytic Uremic Syndrome, which is also known as aHUS, is a rare form of kidney disease that has no cure and causes irreversible kidney failure. Research funded by Kidney Research UK has been central to understanding aHUS and ultimately to finding an effective treatment for the disease. One of the people behind it is Professor Tim Goodship, who works at Newcastle University. With his team, he was the first to recognise genetic abnormalities associated with aHUS. He has spent more than 20 years studying the disease, and his work has clearly made a dramatic difference to patients.

The National Institute for Health and Care Excellence (NICE) issued final guidance in January 2015 recommending eculizumab for use by the NHS in England. This means more patients like Shaun can go on to receive treatment, and aHUS no longer has to be seen as a death sentence.

Professor Goodship said: “This breakthrough in the treatment of aHUS would not have been possible without the genetic studies funded by Kidney Research UK that identified faults in the complement regulators (a biological process that regulates the immune system’s response to foreign bodies).”

2015
BBC Lifeline Appeal is launched in July – the most high profile fundraising campaign for Kidney Research UK yet

2015
The European Medicines Agency (EMA) recommends tolvaptan for approval. It is the first ever pharmaceutical treatment available in Europe for ADPKD patients

2015
Kidney Research UK invests £5.1 million into research

2015
Professor Lombardi begins a clinical trial into the Tregs’ potential to prevent transplant rejection in patients with lupus, as part of an international consortium

Shaun’s story

When he was 29, Shaun McCowie was diagnosed with aHUS. Shaun was familiar with this disease, as he had already seen his two brothers, two sisters, uncle, nephew and dad die from it. He thought that this was a possibility for him, or that he would probably spend the rest of his life on dialysis.

However, after spending 25 years on dialysis, Shaun was given a new treatment called eculizumab and underwent a successful kidney transplant. Life is now looking great for Shaun. He still has monthly check-ups to make sure everything is ok, and he also has one dose of eculizumab every fortnight which is administered by a drip.

“Now I’ve had my transplant, my family aren’t worrying about me having a heart attack because of the strain dialysis puts on your body. To be honest, I wasn’t sure how much longer I’d last on dialysis.”
Tackling the kidney shortage

When doctors receive a donated kidney, they have to check it to see whether it can be transplanted into another person. If a donor kidney does not outwardly appear healthy, it may be discarded as the surgeon does not have enough information to know it is viable, or too damaged for transplant. Professor Mike Nicholson at the University of Cambridge was given funding by Kidney Research UK, to look into whether there was a way to save these kidneys. He found out that by using a technique called normothermic (warm) perfusion, donor kidneys previously considered unsuitable for transplant could be tested, repaired and revived in a way that would otherwise be impossible.

Warm perfusion involves flushing donor kidneys with warm, oxygenated blood for about an hour prior to transplantation, allowing the gradual, controlled reintroduction of blood flow to the kidneys outside the body. This reverses much of the damage caused by storing them in ice and provides the opportunity to treat the organs with anti-inflammatory agents and other drugs before completing the transplant.

While Deborah was the first person to benefit from this new transplantation technique (see her story to the right), she hopefully won’t be the last. Up to 81% of the kidneys that are thrown away every year could be suitable for transplantation. This would mean 171 extra transplants for people who really need them. With so many people waiting for a kidney, Professor Nicholson’s work has the potential to save many more lives and tackle the shortage of kidneys.

With a Making EVERY Kidney Count grant of £740,000 from Kidney Research UK, this research has now moved ahead with a clinical trial involving 400 patients across several centres. This vital next stage is another step forward in helping more people like Deborah.

Professor Nicholson said: “I think the future will be that donor kidneys will be preserved using warm preservation techniques, and that will increase the quality of the kidneys. It might give us more kidneys to transplant, and the really exciting thing for the future is being able to give treatments to the kidney before it is transplanted. You may be able to dramatically reduce the chances of it having a rejection episode once it’s been transplanted – and that will improve the long term survival of transplanted kidneys, compared to what we currently have.

We simply would not have been able to do the research without the grant moneys that we have been given by Kidney Research UK.”

Deborah Bakewell’s story

Deborah Bakewell was the first person to receive a kidney treated with this new method. For years she had suffered from cysts in her kidneys but by the time she reached her early fifties, her kidneys began to fail. She became very tired and had no energy at all. She was told by her doctor that her kidneys wouldn’t last until she was 55, and that without dialysis, she would die. The dialysis she had to have was intensive. For seven nights a week and nine hours every single night, Deborah was hooked up to a machine. Any quality of life she had was gone.

One day Deborah received a phone call saying a kidney had become available for her, but when it was examined the doctors said it was damaged. However, Professor Mike Nicholson stepped in and said that he could use his new technique to try and save it. She would be the very first patient to try this technique, but she jumped at the chance.

Once the kidney was transplanted into Deborah, it became pink – a good sign that it was healthy and would work. Now Deborah is enjoying life and has got back her independence. She even got to meet her step-grandchildren and loves spending time with them, which is something she never thought she would do when she was on dialysis.

“I was always a very independent lady but I gradually lost that independence and I became very reliant on other people. Dialysis is not a cure, it’s just a way of getting through the day. Looking back on it now I do wonder how I did it, because the frustration of being held to ransom by a dialysis machine.

On a daily basis I thank my lucky stars, I’ve been lucky enough to have a transplant, I’ve been lucky enough that my life has returned to normal. In my case I feel as if I’ve not just won the lottery, I’ve won the jackpot. But I feel so sorry that there are so many people in effect buying their ticket and they haven’t had anywhere near the opportunities that I have had. The research needs to go on and be funded, of course, to ensure that people like me can also feel like they have won the lottery.”
Putting research first

Research is the engine of improvement to human health, generating a better understanding of disease and improving care; developing ways to identify, prevent, halt progression or reverse disease.

To ensure the future of renal research and, ultimately, to provide the best possible outcomes for kidney patients and those at risk of kidney disease, investment and collaborative efforts are needed.

We welcome the fantastic level of progress that has been made to date in fighting and treating kidney disease. But we urge that this progress is built upon in order to provide the best possible outcomes for kidney patients and prevent lives being affected by kidney disease in the future.

In line with the strategy, policy-makers can take action to support renal research by acting on the recommendations below:

**Access for all**
Give every patient the chance to take part in all types of research

Too often, hearing about research opportunities depends on chance, and the ability to participate depends on where you live.

**What you can do:**
- Support steps that encourage anyone working in the NHS to inform patients about trials that may be relevant to them
- Ask your Clinical Commissioning Group how many patients are participating in research, and how they encourage participation

**Time to innovate**
Ensure that caring for patients and conducting research can both be part of a career for anyone working in the NHS

For many people working in the NHS, combining care and research is challenging and study leave is difficult to obtain.

**What you can do:**
- Meet with researchers in your area and ask your local NHS trusts what they do to support their healthcare professionals to undertake research, and what else they might need to enable them to provide more support

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Closing the gaps
Support research into the needs of minority populations

Research into issues affecting young people or minority populations is challenging as these populations are hard to reach at scale.

What you can do:
• Support programmes that increase understanding of kidney health and related issues among those from Black, Asian and Minority Ethnic (BAME) backgrounds
• Ask your local authority what they are doing to communicate about kidney health with BAME populations

We hope that policymakers will be enthused by the potential that lies ahead in renal research, and will engage with these recommendations. By taking action on these recommendations, all of which are within our reach, we can ensure a positive future for patients.

References:
5. Kidney Research UK, QI-CKD study

12. Kidney Research UK

Strongening the foundations
Establish biobanks and support the pre-clinical laboratory research that lies at the beginning of the path of discovery

The renal community needs to engage with Government and regulators on a range of issues to ensure research can progress swiftly to deliver early patient benefit, within a robust and appropriate regulatory framework. More broadly, medical research depends on new researchers emerging and being supported.

What you can do:
• Act as a champion for science in your local area, celebrating the work of those working in laboratories, academic institutions and in clinical practice up and down the country
• Support the renal community to engage with Government on key issues regarding funding, regulation of research and establishment of centres of excellence