

“ We have spent years existing with this condition but thanks to the research breakthroughs that have happened, thanks to doctors, nurses, friends and family, we can finally take the first tentative steps to live again. ”

Chloe Laurence – read her story on the back

Patient survey 2016

It is important that we regularly review the strategic direction of our research. By asking you for your views on research priorities we ensure that we are addressing the needs of the people we are working to help.

We undertook our first patient survey on research priorities in 2007. Then in 2013, our second survey provided evidence to inform the development of the UK Renal Research Strategy (UKRRS), which sets out key aims and recommendations for the research community. In line with one of the UKRRS recommendations ‘to increase engagement of patients with kidney research’ and Kidney Research UK’s commitment to patient engagement, our 2016 survey built on the learnings from our previous surveys. The results are presented in this flyer.



Call us on 0300 303 1100
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www.kidneyresearchuk.org

Our research

At any one time, our investment in research is in the range of £11 to £14 million, making us the leading national charity dedicated to the fight against kidney diseases. We’ve been at the forefront of pioneering kidney research for decades. We invest in the training and support of leading kidney scientists and doctors throughout the UK. Many of these individuals have gone on to make major advances in the understanding of the causes of kidney diseases, as well as the successful development of better approaches to treatment.

Chloe Laurence explains why research matters to her family

In November 2011 we fell pregnant with twins. A scan at 16 weeks revealed growth problems and that our twins were in trouble.

We were told of four possible reasons for the growth discrepancy between the babies and four possible outcomes. Only one of those was that our smallest baby would survive for a significant time after being born.

A one in four chance; a 25% chance of taking a breath. “Incompatible with life.” The enormity of those three little words is something I still struggle with today.

During the next few months, my husband Mike and I took the rough with the smooth and absorbed all the information that was thrown at us. Despite two premature labour scares, the boys held on until 37 weeks and were induced. Oscar was born first and Mike held him whilst Finlay was born.

Seeing your child being resuscitated at the end of your bed isn’t something you would ever want to see.

At 3 days old, Finlay was transferred to Great Ormond Street Hospital. Blood results showed the kidney failure was much worse than anticipated. Arriving at the hospital, we were met by the most wonderful people: Finlay’s consultant and the nurse looking after him. They told me my boy was beautiful...not poorly, not in pain, not dying, not untreatable, but beautiful.

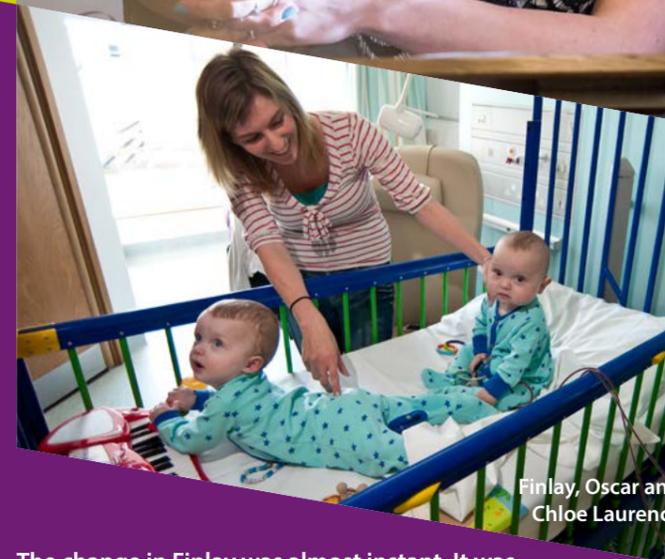
Over the next 6 weeks Finlay had six operations and didn’t improve. A turning point was starting haemodialysis.



Design, medical writing and data analysis support were provided by Oxford PharmaGenesis



Finlay and Chloe Laurence



Finlay, Oscar and Chloe Laurence

The change in Finlay was almost instant. It was working! Although not out of the woods, he started to respond. We existed on just a few hours’ sleep each night, and we still do. Life revolved around hospital appointments and blood results.

It wasn’t an easy journey, but at 23 months old, Finlay had his kidney transplant. By that point he had had 20 operations. We know there are more to come.

Knowing that Finlay will need more kidneys in his lifetime is a heartbreaking realisation that our family will never be free of this journey. However, I honestly believe that another 10 years of kidney research will push treatments so much further than anyone can imagine. Knowing that 10 years ago my baby probably wouldn’t have survived just proves the need to continue to fund research. We have spent the last years existing with this condition but, thanks to the research breakthroughs that have happened, thanks to doctors, nurses, friends and family we can finally take the first tentative steps to live again.

PATIENTS at the heart of research

Patients’ views and opinions are central to our work at Kidney Research UK. Patients are experts in their own condition and by listening to the patient and carer ‘voice’ we ensure we have input from the people who matter most: you. Patient engagement in research ultimately makes our research better and more effective.

Get involved

WE NEED PATIENTS! Kidney Research UK relies on people like you to help us make a difference to those living with kidney disease. All you need is your own experience of living or caring for someone with kidney disease.

There are many ways in which you can get involved with Kidney Research UK and it can be as big or as small a commitment as you choose.

- Let us help you share your story and inspire other patients.
- Write a blog about your experiences.
- Become a member of a research project team, advising and supporting researchers and other patients.
- Become a member of our Lay Advisory Committee and guide us on our work.
- Become a patient representative on a group that develops research ideas and help innovation in kidney research.
- Take part in a challenge event or organise your own fundraising.
- Volunteer in our shops or office.
- Participate in a local research trial.



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Who did we ask?

The survey was open to all UK kidney patients. It was sent to renal units across the UK and additional patients were invited to complete the survey by email and through social media channels.

How was this survey carried out?

Respondents were asked to choose their top seven priorities out of 20 renal research topics and to rank them according to their importance, with '1' being most important and '7' being least important. Topics were then weighted according to their rank: '1' was assigned a weight of 7; '2' was assigned a weight of 6 and so on. Finally, all weighted scores for each research topic were totalled and ranked. The final rankings of the renal research topics are presented here.

Most important areas for future research into kidney diseases

The survey results suggest that future research should focus on discovering a cure for kidney diseases, prevention and early detection, and finding new sources of organ transplants. These findings are in line with our vision 'lives free from kidney disease' and will inform our future activities in research development and strategy.

What else the results told us

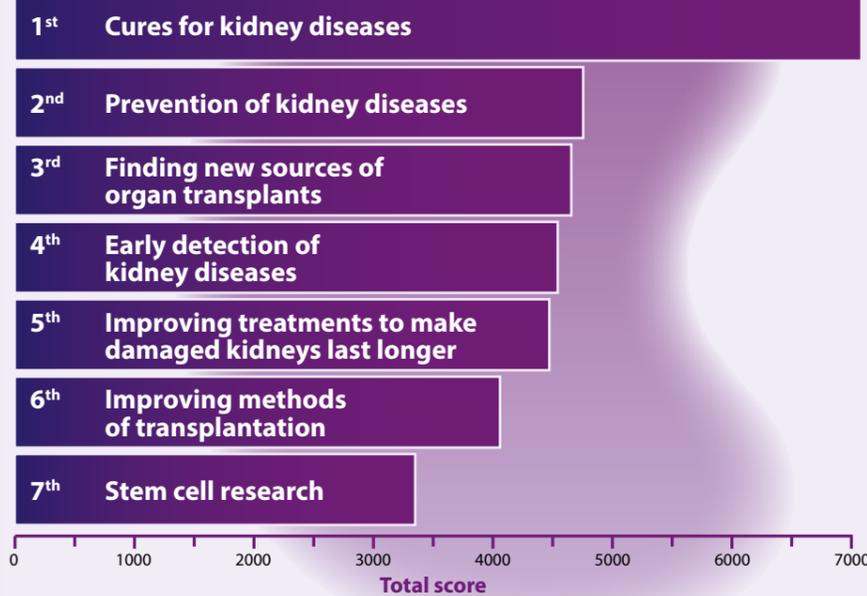
Compared with the patient survey in 2013, 'causes of specific kidney diseases' and 'improving the quality of life of patients' were replaced by 'improving methods of transplantation' and 'stem cell research' in the top seven research priorities.

Older patients prioritised 'prevention' and 'early detection of kidney diseases', whilst younger patients prioritised 'improving methods of transplantation'.

'Improving treatments to make damaged kidneys last longer' and 'causes of specific kidney diseases' were more important to patients with chronic kidney disease (CKD) stages 1–4 than those with more advanced disease and patients overall. Kidney transplant recipients prioritised 'finding new sources of organ transplants' and regarded 'improving methods of transplantation' as more important than patients in the other disease progression stages and patients overall. 'Early detection' was more important to patients with CKD stage 3 or 4 and those undergoing dialysis, than to patients overall, those with CKD stage 1 or 2, or recipients of a kidney transplant.

Of all respondents, around 8% were patients who described their ethnic group as other than white. Given that people from black and minority ethnic communities face a higher risk of kidney diseases, Kidney Research UK would like to encourage a bigger response from these communities in the next survey.

Renal research priorities of respondents



“ All I want is more counselling, for people of any age with kidney failure. ”

“ Please find something to help. ”

“ All of the research areas are important and they should all be improved. ”

What do these tables show?

The bigger the circle, the higher the priority. Numbers show how high each group ranked the research topic.

The biggest contrasts in renal research priorities across age groups

	≤24 years	25–44 years	45–64 years	≥65 years
Prevention of kidney diseases	6 th	5 th	2 nd	3 rd
Early detection of kidney diseases	7 th	6 th	5 th	2 nd
Improving methods of transplantation	4 th	3 rd	6 th	8 th

Younger patients prioritised improving methods of transplantation, whilst, as age increased, the focus changed to early detection and prevention.

The biggest contrasts in renal research priorities across disease stages

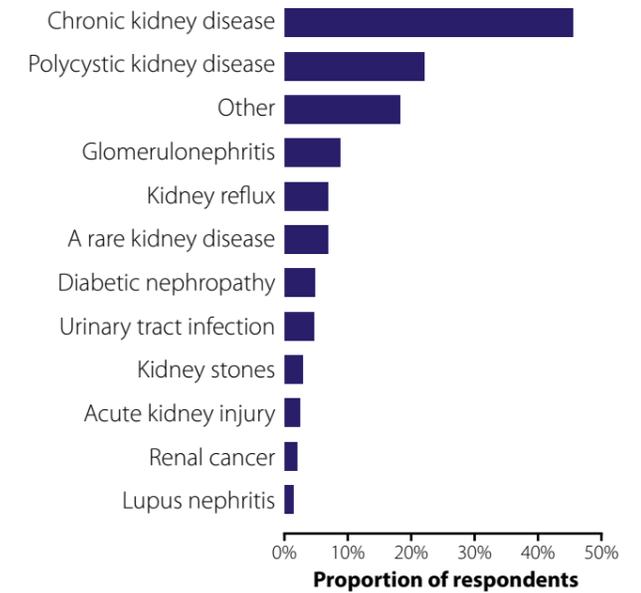
	CKD stages 1 or 2	CKD stages 3 or 4	Undergoing peritoneal dialysis or haemodialysis	Kidney transplant recipient
Improving treatments to make damaged kidneys last longer	2 nd	2 nd	8 th	8 th
Causes of specific kidney diseases	3 rd	6 th	11 th	9 th
Finding new sources of organ transplants	6 th	5 th	2 nd	2 nd
Improving methods of transplantation	7 th	8 th	5 th	3 rd
Early detection of kidney diseases	5 th	3 rd	3 rd	6 th

Early stage kidney patients prioritised causes of kidney diseases and postponing the need for renal replacement therapy, whilst transplant patients prioritised improving transplantation.

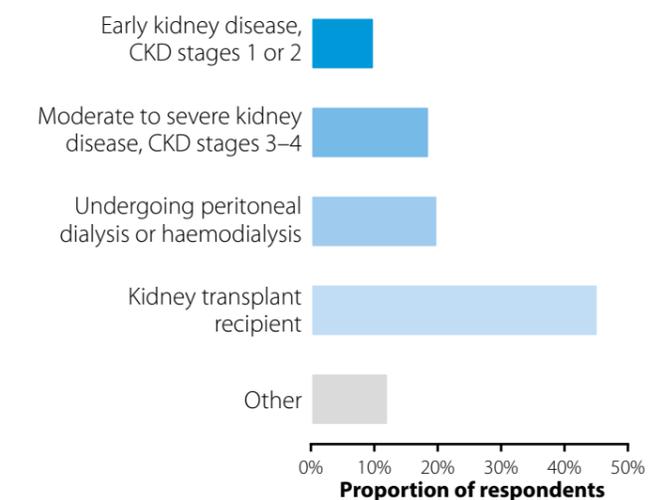
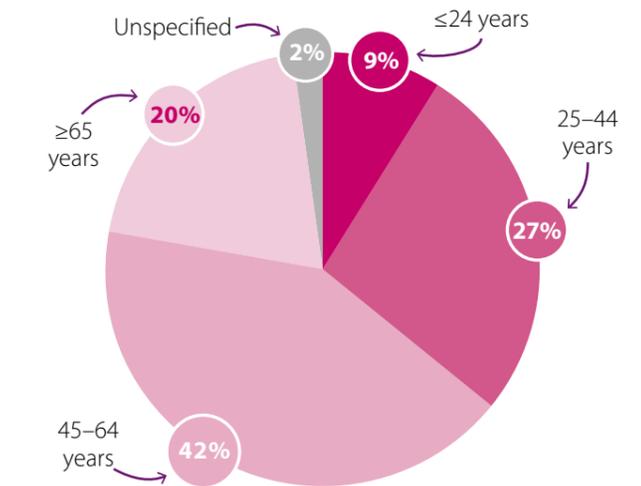
CKD, chronic kidney disease

Who responded?

Total number of survey respondents: 2158



Please note that the percentages do not add up to 100%, because respondents could select multiple options. 'Other' includes conditions such as IgA nephropathy, nephritis, nephrotic syndrome and focal segmental glomerulosclerosis.



Please note that the percentages do not add up to 100%, because respondents could select multiple options. 'Other' includes respondents who had CKD stage 5, those who did not specify the progression stage or had another condition.