Patients at the heart of research

At Kidney Research UK patients are at the heart of our research. Engaging with patients is a high priority for us as we know they can offer a unique insight using their experiences. This will ultimately make our research more effective and beneficial for patients. To help us achieve this we have an inclusive and progressive ethos, of working with patients, individuals and other organisations with the desired aim of achieving our charitable objectives.

To ensure our research is focused we also aim to fund research into specific areas of kidney disease especially where an evidence gap has been identified.

Patients’ survey 2013

In 2007 we wanted to involve patients and seek their views on our work. Therefore, working with Clinical Directors and kidney patients we successfully undertook a survey and using the results we identified priority areas for renal research for the next five years.

Building on the findings of the 2007 survey, in 2013 we conducted a further survey with the aim of finding out:

- if patients’ opinions have changed
- which areas of research are most important to patients at different levels of renal treatment
- the age distribution of patients who were willing to participate

Our Research

Kidney Research UK is the largest funder dedicated to kidney research and kidney problems in the UK. We continue to recognise the importance of research and allocate over 75% of our charitable income to support the highest quality research.

Our funding remit covers:

- research projects
- career development
- investing in future experts in the field of Nephrology
- capacity building and investing in people
- directed research to address evidence gaps
- sponsorship of scientific meetings in fields of interest
Who did we ask?
The survey was open to all kidney patients attending dialysis units across the UK, those on our database and we promoted the survey through Facebook and Twitter.

What the results told us
Patients’ opinions have remained largely the same since 2007, although the priority positions of some renal research areas have changed. The top five areas in 2007 were in the order of: early detection; making damaged kidneys last longer; improving quality of life on dialysis; causes of particular kidney diseases and stem cell research.

The 2013 survey found the research areas patients think are most important (in order of priority) to be:
- cure for kidney diseases
- prevention of kidney disease
- causes of specific kidney diseases
- early detection of kidney disease
- finding new sources of organs for transplants
- improving treatments to make damaged kidneys last longer
- improving quality of life of patients at any stage of renal disease/treatment level

Most important areas for future research into kidney disease
The result of the survey suggests that future research should focus on finding a cure for kidney diseases, its prevention, causes and early detection.

It is important to note the selfless view of patients on which areas future renal research should focus. Rather than looking for research to improve their present condition and quality of life, patients want to improve the outlook for future kidney patients by finding the cause of and a cure for kidney diseases.

The priority areas of research identified in this survey are in line with our vision – Lives free from kidney disease, and are research areas that we are already supporting.

These findings will help us shape much of our strategic research development activity and inform our future research strategy.

How was the survey carried out?
The survey was carried out in two phases.

In phase 1 we identified patients’ research priorities.
- 1,017 patients responded and selected 7 out of 25 suggested renal research areas which they thought were most important to future research.

In phase 2 we asked the patients to rank the 7 most popular research areas identified in phase 1.
- The ranking was in order of importance with 1 representing the most important and 7 being the least important.

In both phases of the survey 49% of the participants were male and 51% were female.
Future renal research priorities most important to patients at key treatment stages

- **17%** Causes of specific kidney diseases (undergoing dialysis)
- **57%** Cure for kidney diseases (transplant recipients)
- **22%** Early detection of kidney disease (transplant recipients)
- **15%** Finding new sources of organs for transplant (undergoing dialysis)
- **8%** Improving quality of life of patients at any stage of renal disease or treatment (undergoing dialysis & transplant recipients)
- **10%** Improving treatments to make damaged kidneys last longer (transplant recipients & undergoing dialysis)
- **35%** Prevention of kidney disease (transplant recipients)

**Age of participants**

- **Under 17** 0.3%
- **18-24** 22%
- **25-34** 7.6%
- **35-44** 13.8%
- **45-54** 20.3%
- **55-64** 18.3%
- **65-74** 13.5%
- **Over 75** 21.5%
- **Undisclosed** 2.3%

**Participants at different stages of treatment**

- **An early stage kidney patient** 4.4%
- **A person diagnosed with a different renal disease (not CKD)*** 5.9%
- **A person diagnosed with CKD*** 21%
- **Undergoing dialysis** 24.6%
- **A transplant recipient** 37.1%
- **Unspecified** 7.4%

* Chronic Kidney Disease
Making a difference

Our funding allowed Professor Mike Nicholson and his team at Leicester General Hospital to research and develop a pioneering technique called normothermic perfusion, which involves flushing a donated kidney with oxygenated blood prior to transplantation. This can repair damage caused by cold storage, and allows doctors to test the kidney’s function before its transplanted.

Deborah Bakewell from Lincolnshire is the first person ever to have received a transplant following this process.

“In December 2010, I got the call to say a kidney was available. When I arrived at the hospital, Professor Nicholson told me about the new procedure he had developed and I thought, ‘If he feels the time was right, I was keen to go ahead.’”

The same night I had my transplant; someone else received another organ from the same donor which didn’t undergo normothermic perfusion. Our results after the transplant showed that my kidney was functioning much better compared to a kidney which hadn’t undergone the new process.

The difference the transplant has made has been absolutely amazing. I’m free now and I’ve got a whole new chance at life thanks to Kidney Research UK and the vital research they fund.”

Get involved

We offer a range of opportunities to get involved in research. It is an excellent way to learn new skills and gain invaluable experience and you will also be helping us to deliver even better research into kidney disease. Opportunities include:

- becoming a member of a research project team to provide advice and support to both researchers and patients.
- becoming a community champion in your local area to help us to promote research.
- becoming a member of our Lay Advisory Committee where you will help to develop the charity’s strategy.

You do not need specialised knowledge or to be scientifically trained; your knowledge and experience of living with kidney disease is what we are looking for.

For more information, visit our website www.kidneyresearchuk.org/getinvolved or e-mail: patients@kidneyresearchuk.org

0845 070 7601
www.kidneyresearchuk.org