

KIDNEY RESEARCH UK
(in association with the Renal Association)

Report Comparing Patient Opinions and Investigator Activities

**A comparison report across the findings from
Kidney Research UK's patient survey exercise assessing kidney patients' views on
research priorities
and the
Renal Association's survey on investigator activities**

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Executive summary

This comparison report reassuringly confirmed that research activity, both actual and researchers' interests, matched the areas considered as high priority by kidney patients.

Introduction

In common with all medical research fields, research into kidney disease is limited by the restricted availability of funding.

To inform the process of prioritising research for future funding:

- Kidney Research UK carried out a survey of patients affected by kidney disease to elicit their views on the aspects of renal disease most deserving of research support.
- The Renal Association Research Committee commissioned a survey of research interests of active UK researchers.

This report presents the comparison of the results from these two surveys to assess if the areas of research considered as high priority by patients were also areas of research activity and interest by researchers.

Comparison method

Kidney Research UK carried out a patient survey in 2007, using a Delphi style approach and reached 1193 respondents across 36 renal units throughout the UK, with 74% of participants identifying themselves as kidney patients.

The Renal Association web-based 'on-line' survey was carried out in 2006 and 2007 and results from both years were amalgamated to give 290 respondents, all actively involved as leading researchers in kidney-related research.

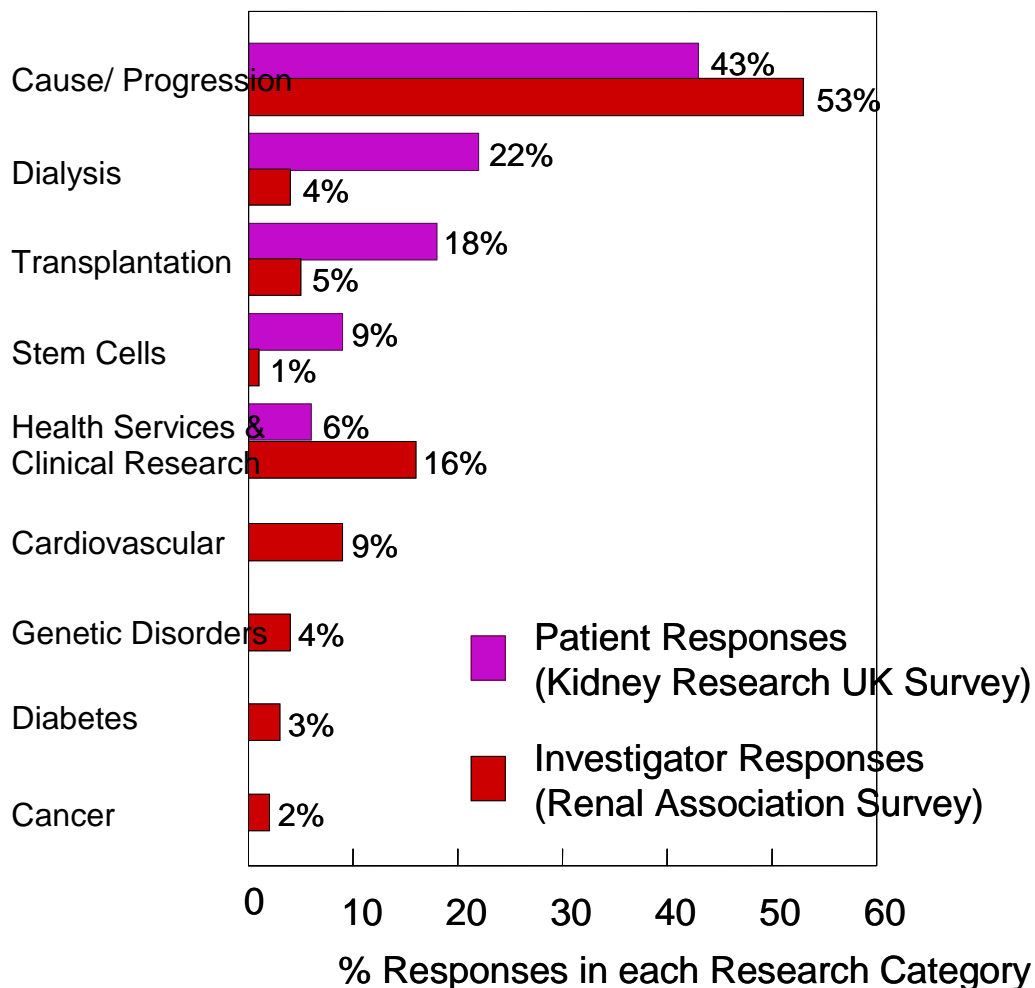
The results were analysed and compared across both surveys by dividing the two sets of survey results into broader categories. For example patient survey results for 'early detection of kidney disease, making kidneys last longer, causes of kidney disease and prevention of kidney disease' were matched with the research survey results for 'hormones, cytokines, signalling, cell biology, progression, ion channels' under a broader category entitled 'causes and progression - how the normal kidney works and what goes wrong in kidney disease'. Similarly, other broader category headings used were,

- Dialysis
- Transplantation
- Stem cells
- Health Services Research
- Cardiovascular
- Genetic Disorders
- Diabetes
- Cancer

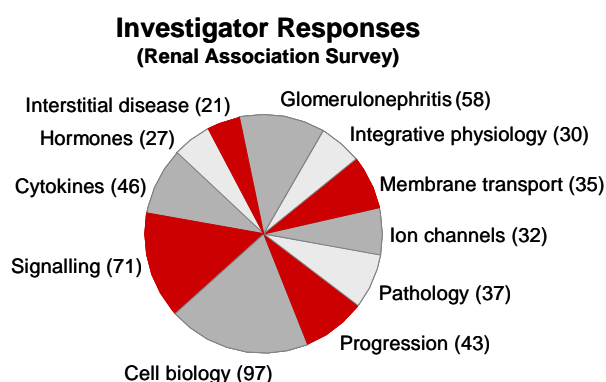
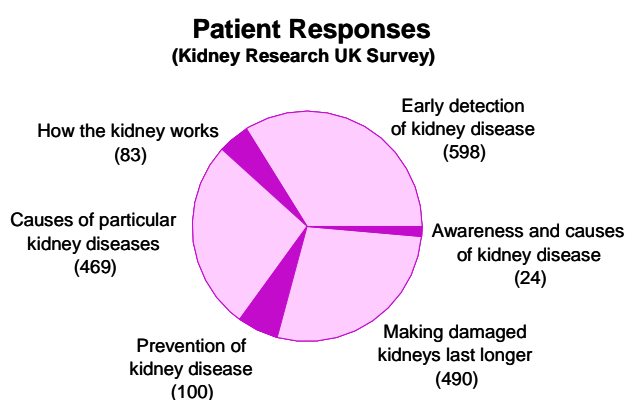
The original survey results grouped within these broader categories were also looked at in detail.

Results

The overall results of the analysis from both surveys are show in the picture below.

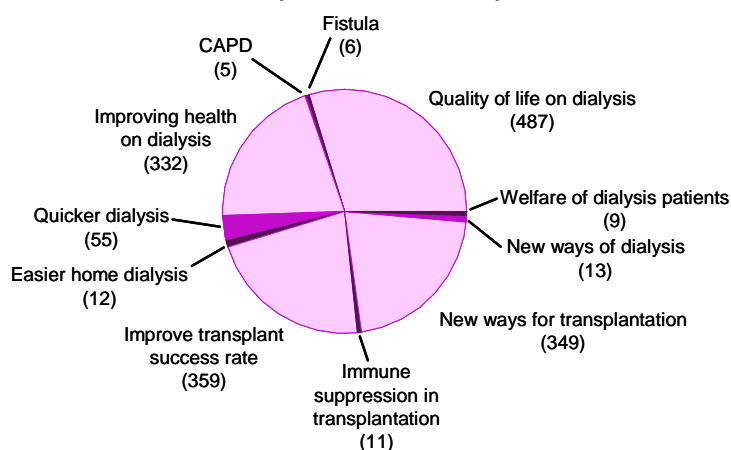


Both patient and researchers consider that 'causes and progression - understanding the mechanisms of how the normal kidney works and what goes wrong in disease' are of the highest priority for research activity and funding. The ranges of results from both surveys in this broad category are shown in more detail in the picture below.

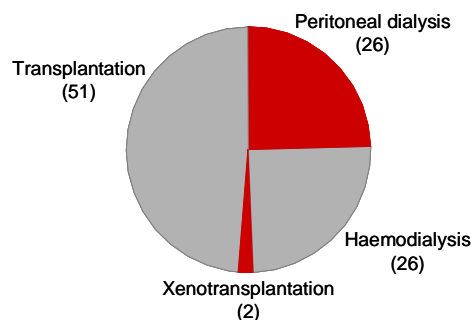


'Dialysis and transplantation' were rated as high priority areas by patients as one might predict since these areas have direct relevance to the lives of kidney patients, however researchers were less attracted to these areas. Again, the breakdown of this broader category is shown in the picture below.

**Patient Responses
Kidney Research UK Survey**

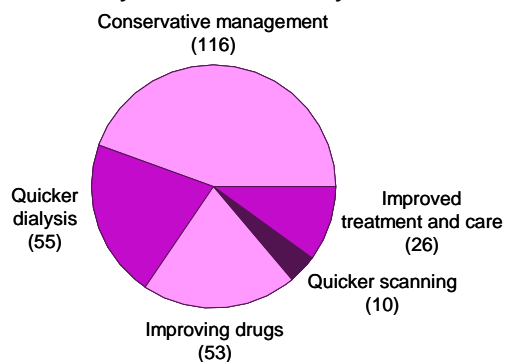


**Investigator Responses
Renal Association Survey**

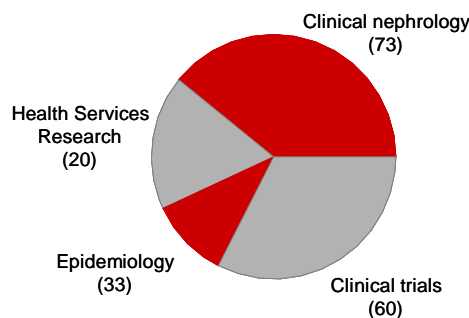


'Clinical and Health Services' was more popular with researchers than with patients. The most highly rated areas within this category are shown in the picture below.

**Patient Responses
Kidney Research UK Survey**



**Patient Responses
Kidney Research UK Survey**



Other areas with more researcher than patient interest included 'conditions associated with kidney disease' (such as diabetes, high blood pressure, malignancy, blood vessels) and it was thought that this was possibly due to patients not appreciating their relevance to kidney disease.

Patients expressed a high interest in stem cells which was thought to be due to it being both topical, whilst also controversial, and its potential to offer future possibilities for treating kidney disease.

Conclusion

The majority of Kidney Research UK's income comes from cause-related supporters, either those directly affected by kidney disease or their families. Therefore it is necessary and important that consideration is given to the views and opinions of kidney patients when allocating funding.

Reassurance has been provided by these surveys, and the comparison thereof, that researchers are both active and interested in the areas that are considered by patients to be important. We hope that this shared view will be beneficial in enabling the advancement of research into prevention and treatment of kidney disease both now and in the future.

It is hoped that these surveys will be repeated in the future to continue to understand research priorities of both kidney patients and the wider research community. It will also be interesting to survey the younger researchers who will be the future 'experts' influencing the future direction of medical research efforts.