

The Renal Association



KIDNEY RESEARCH UK
(In association with the Renal Association)

‘Future Priorities for Renal Research’ Survey Report

**A report on the findings from a patient survey exercise assessing
kidney patients’ views on research priorities**

28th September 2007

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Foreword

Back in 2001, I was one of four people who formed an independent committee to review the past 15 years of research funding undertaken by the charity (at that time called The National Kidney Research Fund) and subsequently in 2005 I chaired the reforming of that committee to revisit our previous review. The purpose of both the original and the follow-up review was to satisfy the Board of Trustees that appropriate and effective governance was in place for awarding research funding and to confirm that there were clear outcomes and benefits from the research funded over the years.

The results of our first review were reported to the charity's Trustees in September 2002 and confirmed that the charity had provided a consistently positive influence on renal research funding in the UK and that the fellowship schemes had also been extremely successful with the cadre of clinical nephrologists and renal scientists supported by these fellowship schemes being impressive. The report also included some recommendations and our subsequent review in 2005 revisited this original report and looked at the responses to those recommendations made, resulting in a supplementary report being presented to the Trustees in September 2005.

One of the key recommendations from our reviews was that the charity should consult Clinical Directors and patients for their views on the priorities for kidney research in the future. This work has been carried out and the following report details this process and the findings from this survey.

Our thanks go to everyone who took part in this survey, both individual patients and carers who completed the survey and ranking forms and also to all Clinical Directors of the UK Renal Units without whom we could not have achieved the success of this survey exercise.



*Professor Neil Turner
Chair, Kidney Research UK (appointed 2007)*

Executive summary

Overall 1193 people, representing 36 renal units across the UK, participated through all phases of the survey, initially starting with eliciting their views on research priorities and then subsequent ranking of the five most popular themes.

The results were as follows, stating highest priority first,

- Early detection of kidney disease
- Making damaged kidneys last longer
- Improving quality of life on dialysis
- Causes of particular kidney diseases
- Stem cell research

Participants represented a cross-section of experiences of kidney disease and related conditions as summarised below,

- 33% Dialysis patients
- 25% Transplant patients
- 16% People with Chronic Kidney Disease
- 2% Family and carers
- 1% Professionals (clinical directors and doctors)
- 23% Status non-disclosed

Introduction

Kidney Research UK has traditionally been a reactive organisation in its approach to funding research responding to applications from curiosity-driven researchers for project and fellowship support. However over the last few years, the charity has begun to be proactive in setting research priorities through a small number of more specific calls for applications in particular areas of kidney research whilst continuing to predominantly allocated the majority of its funding through its main core grants rounds held every year and open to all areas of kidney research.

As a member of the AMRC (Association of Medical Research Charities), Kidney Research UK abides by the conditions of membership, awarding all its research funding through a robust and transparent external peer review process, supporting only high quality applications and has in place a Research Strategy statement publicly viewable on its website. <http://www.kidneyresearchuk.org/content/view/24/47/>

The charity recognises that the priorities for areas of research are dependent on both the funds available and the expertise existing within the research community and academia. Additionally the charity has an inclusive and progressive ethos, working where possible with partner organisations to achieve its charitable objectives.

The charity accepts that it does not hold a unique place allowing it to identify research priorities nor does it conclude that its research portfolio, whilst consisting of vital high quality kidney research, will reflect the priorities perceived by those affected by or those treating the disease.

Therefore, the charity undertook this simple and inexpensive 9-month survey exercise, to consult with Clinical Directors and patients attending renal units in the UK and identify what they considered should be the priorities in kidney research for the next five years.

Objective

To collect and summarise the views of Clinical Directors and patients on research priorities associated with kidney disease and aspects of living with kidney disease.

Method

An internal team from the charity was established to undertake the development and production of the survey materials and carry out the survey exercise.

The survey exercise consisted on three main parts:

- (i) The initial pilot for the questionnaire in three designated renal units.
- (ii) The expansion of the exercise in a further 4 renal units
- (iii) Nationwide expansion of the exercise across all UK renal units.

The pilot was undertaken over three and a half months (mid-October 2006 – end of January 2007) in Peterborough, Bristol and Edinburgh renal units and was followed by the wider roll-out across a further four renal units, namely Coventry, Derby, Leicester and Nottingham, between mid-November 2006 and early February 2007.

The full nationwide survey across all UK renal units, excluding those participating in part (i) or (ii), was carried out over four months (mid-January 2006 – mid-May 2007).

All parts of the survey exercise undertaken were consistent and included the provision of 100-200 printed survey packs to the respective Clinical Director(s). Each pack contained an introduction letter from the charity, a 3-page survey form and an SAE for the return of the completed form to Kidney Research UK. Clinical Directors, following their agreement, provided a pack to patients when they attended a normal clinical appointment at the renal or transplant unit. No obligation was placed upon any person to complete the survey form, nor any benefit provided to participants in the survey. Clinical Directors and colleagues were invited to participate under the same

terms. Kidney Research UK also made the survey forms freely available on line via its website for anyone to participate.

The survey methodology followed a 2-stage process. The first stage being the distribution, completion and return of the survey forms. The second stage being the analysis of all returns, assessing the five most common themes before re-contacting all participants to complete and return a further form ranking these five most popular themes in order with '1' representing the highest priority to '5' being the lowest priority. This survey method is typically known as a Delphi style approach.

The initial results were notified to all participants prior to the distribution of this report.

Results

For parts (i-iii) of the survey exercise, 12,327 forms were sent out:

7,200 via Clinical Directors and renal units (representing 36 of the 70 renal units) and 5,127 to contacts via the charity's Kidney Health Information line contacts database.

The total number of completed survey forms returned was 1093, giving a response rate of 8.8%. These 1093 respondents were then re-contacted to request that they rank the top five themes, in priority order.

The gender spread of those taking part was roughly 62% male and 38% female.

Results from the initial three pilot site (Peterborough, Bristol, Edinburgh):

Participant Category	%
Dialysis	56
Transplantation	25
Chronic kidney disease	9
Researcher	6
Other	2
Dialysis & transplantation	1
Clinical Director	1

Research Priority
Improving quality of life on dialysis
Early detection of kidney disease
Stem cell research

Funding new ways to do transplants
Improving transplant success rates

Overall Results from the survey exercise (1093 participants), (including parts (i - iii))

Participant Category	Actual number	%
Dialysis	350	33
Transplantation	272	25
Chronic kidney disease	178	16
Family and carers	23	2
Professionals (clinical directors & doctors)	7	1
Status not disclosed	263	23
TOTAL	1093	100%

Research Priority - TOP 5
Early detection of kidney disease
Making damaged kidneys last longer
Improving quality of life on dialysis
Causes of particular kidney diseases
Stem cell research

Research Priority - ranking 6-20
Improve transplant success (6)
New ways for transplantation
Improving health on dialysis
Conservative management
Prevention of kidney disease
How the kidney works
Quicker dialysis
Improving drugs
Animal research
Awareness and causes of kidney disease
Artificial kidneys
PKD
Hereditary aspects of kidney disease
All research is important (=19)
New ways of dialysis (=19)

In total there were 57 different priorities considered or suggested by participants in the survey. (see appendix A)

Conclusion

The survey succeeded in achieving its main aim of discovering what patients and clinicians consider to be the most important research priorities that will result in improvements in prevention, diagnosis and treatment of kidney diseases.

Engaging with these groups of interested, informed individuals will allow the charity to assess its research priorities for the future and has initiated a long term engagement with patients and their carers to help shape the development of research. This will ultimately benefit patients by addressing the problems faced by them in living with kidney disease.

The findings in this report will be reviewed and discussed by the charity's Lay Advisory Committee, Research Strategy Committee and the Board of Trustees, to help inform the decisions of the charity for future research funding.

Three of the top five priorities reflect a general theme that research should be focused on 'causes of specific kidney diseases' and 'their early detection'. Interestingly, the 'stem cell research' result indicates that people are supportive of controversial research, presumably as it holds hope and potential for the future.

Not surprisingly there was a low interest in the more obscure areas such as 'understanding the structural changes in kidney disease' and 'the regulation of kidney function'; however both of these are currently key research themes relating to work addressing the causes and detection of the disease.

Therefore, it should be noted that those who took part, indicated their support for research priorities that, by their nature, may not see any short-term patient benefit. However, one might have predicted that more immediate areas such as improvement in dialysis, better diagnostic treatments would have been higher priorities in the kidney patients' view.

The second highest ranked priority relates to the overall theme of early detection, as unless we understand how the kidney functions and what goes wrong in early kidney disease, we will be limited in what we can address to 'make damaged kidneys last longer'.

The final priority area of 'improving quality of life on dialysis', relates to a different method of research, called qualitative research. This could bring benefits to patients more quickly than more 'blue sky' or

'basic' research methodologies mentioned above in the other priority themes.

Some priorities identified are areas that the charity is keen to develop in partnership and it has shown some success to date working with other funding bodies. For example in the areas of diabetes, blood pressure and cardiovascular diseases where there is a clear overlap with kidney disease.

Other areas highlighted by the survey, such as the treatment of kidney disease, improving drugs therapies and new methods of dialysis also fall within the remit of the charity. Our research could increase the understanding of the targets for new drug therapy and this area of drug development is also of particular interest to the pharmaceutical industry. Other areas where research can improve treatment include vein access and the use of fistulae, earlier referral and the overall improvement in patient care. Issues that we share with the NHS, DH and other kidney focussed organisations.

Appendix A

Rank order	Research Priority - all results	Vote
1	Early detection of kidney disease	598
2	Making damaged kidneys last longer	490
3	Improving quality of life on dialysis	487
4	Causes of particular kidney diseases	469
5	Stem cell research	372
6	Improve transplant success	359
7	New ways for transplantation	349
8	Improving health on dialysis	332
9	Conservative management	116
10	Prevention of kidney disease	100
11	How the kidney works	83
12	Quicker dialysis	55
13	Improving drugs	53
14	Animal research	46
15	Awareness and causes of kidney disease	24
16	Artificial kidneys	21
17	PKD	16
18	Hereditary aspects of kidney disease	15
=19	All research is important	13
=19	New ways of dialysis	13
21	Dialysis machine for easier use at home	12
22	Immune suppression in transplantation	11
23	Quicker scanning	10
24	Welfare of dialysis patients	9
25	Awareness funding research	7
=26	Cure	6
=26	Fistula	6
=26	Diabetes cure	6
=29	Less painful analysis	5
=29	CAPD	5
=31	Treatment of kidney disease	4
=31	Improve patient care	4
=31	Improve treatment of common kidney diseases	4
=34	Increase number of transplant surgeons	3
=34	Improving GP knowledge	3
=34	Cardiovascular disease	3
=34	Glomerular disease	3
=38	All research is important	2
=38	New ways to find organ transplants	2

=38	Improving dialysis fluids	2
=38	Blood pressure	2
=38	New kidney analysing technology	2
=38	Education to young diabetics	2
=38	Improving understanding of hypertension	2
=38	Slowing disease	2
=38	Finding suitable vitamins for dialysis	2
=38	Understanding link to other disease	2
=48	Diabetic nephropathy	1
=48	BP testing over 60s	1
=48	Counselling support	1
=51	Progressive chronic kidney disease	0
=51	Unknown causes of kidney failure	0
=51	Dialysis shifts	0
=51	Kidney cancer	0
=51	Effect of myeloma on the kidney	0
=51	How kidney function is regulated	0
=51	Structural changes in kidney disease	0