

Kidney Research UK Response to the Cooksey Review

Kidney Research UK is a medium-sized research charity with an annual research spend of approx £2.3M. Although this budget seems relatively modest, the Charity is the largest funder of research into kidney diseases in the UK. Dialysis and transplantation accounts for over 2% of NHS spending, renal disease is a major risk factor for developing cardiac disease and a predictor of mortality. Major aims of the charity are the development of improved treatments for preventing end stage renal failure, and to improved treatments for patients receiving renal replacement therapy.

We have framed our answers according to some of the Review Questions listed. Answers overlap with other questions though.

1. Strengths and weaknesses of existing MRC and NHS R&D programmes

Strength: Training doctors in research (MRC)

The MRC has been very good at supporting involvement of the most able specialist doctors in training in research. Most of this work has been basic science rather than close to clinic, but that is inevitable given the timescale and amount of funding available for each award. The role of the MRC in scientific training of medical graduates has been invaluable, and has contributed very substantially to the quality of medical research in the UK, and to the profile of British medicine internationally. The Wellcome Trust and many smaller charities, including Kidney Research UK, have supported the MRC by providing similar programmes. In a recent analysis of the long term outcomes of our research spending, we found that Clinical Training Fellowships, and even more so, higher level Clinical Research Fellowships, had the highest rate of productive outcome, and of keeping the awardees on an academic track. Most of our current academic leaders have held one or more junior, intermediate or senior fellowships at some point in their career.

Mixed: Supporting quality basic research programmes

Finding funding for high quality research has been extremely difficult over the last decade and longer. Renal research is an example of an area that has suffered from not being on a list of NHS priority areas, despite its expense to the NHS, and the tractability of several areas. Project funding available from Kidney Research UK has generally only been awarded in amounts sufficient to support small projects – the current maximum is £100,000 and this will usually only fund limited 2-year awards. Basic researchers are therefore dependent on MRC or Wellcome Trust Work programme funding for progressing their work on a larger scale and over a longer period. This is extremely hard to achieve and there are few such awards in the UK currently. Work supported by the MRC has usually been of high quality, but we are aware of numerous high quality projects that cannot be supported because of limited resources.

Weakness: Supporting clinical trials

Despite willingness and some pump-priming help from the MRC and Kidney Research UK, the renal community has had great difficulty launching and running clinical trials to compete with those in cardiovascular disease and cancer. During the last decade the regulatory climate and other pressures have become so fierce that few investigators now think that it is possible to launch further trials on the frameworks

used in the past. Essentially, only pharmaceutical trials with huge investment have much chance of being established at the moment, unless the infrastructure and administrative support for this type of work are substantially developed nationally, so that the costs and mechanisms are not duplicated on each new project.

A major gap in provision has been in funding for clinical trials that are not industry-sponsored. The funds required for this type of work are large, and the timescales long. Most is beyond the scope of this Charity, or of charities in similar positions outside kidney diseases. This seems to be an area where the DoH and/or R&D investment could be very productively invested. It is to be hoped that reorganisation might facilitate this.

Weakness: use and transparency of use of NHS R&D funds

In addition to supporting important clinical studies, research into methods for quality improvement in NHS service delivery seems to be an obvious place for NHS R&D investment. There has been very little coordinated activity in this area in the field of kidney diseases until some recent projects funded by the Department of Health on an ad hoc basis. However these funds were often awarded without a clear selection mechanism. Much locally funded work has been of low quality.

The major potential benefit from the proposals will come from the identification and refocusing of funding that is nominally assigned to R & D, but in fact deeply embedded in clinical service, to its original purpose. There are enormous opportunities for advancing patient treatment and care which could be taken up if this funding became available to areas that are difficult at present. It will be important that mechanisms for allocating such funding are put in place that ensure that top quality work is supported.

2. Key challenges

Objectives:

Excellence in fundamental medical research in order to provide the environment for invention, discovery, and generating skilled practitioners in research techniques for the pharmaceutical and biotechnology industries

Excellence in clinical research – including trials (enormous opportunities given the scale and inclusiveness of the NHS) and translational research

Excellence in healthcare improvement – but with real improvements in the processes for supporting this work

Exploiting the information explosion that will give the NHS unique power to answer questions in all of these areas in an unparalleled way (see Q11).

3, 4. Establishing priorities for research funding

We believe it to be essential to maintain separate funding streams for basic science versus clinical research. Whether research into service improvement should be third stream should be discussed.

An experimental extra stream for translational research might be timely, but this could be commenced as a special priority area for one of the first two streams in the first instance.

Fundamental biomedical research has been a UK strength, and the recent enormous progress in genomics and developing understanding resulting from this is an enormous opportunity. Keeping the UK at the forefront of these developments is likely to have substantial knock-on benefits for the pharmaceutical industry and biotech sector, in addition to the benefits to medicine directly. The scale of fundamental biomedical research should be increased; expansion in other areas should not be at its expense. Judging this balance is a political decision, but the need for very long timescales in building research strength makes it dangerous to make sudden downward changes as the consequences may be very long lasting.

A focus on prioritising areas is desirable from time to time, but political priority areas that do not match tractability are not a help to the disease area, or to the future clinical research capabilities of the UK. Indeed they are a hindrance if they divert funding from areas with greater chance of achieving important progress, and prevent the development of the most able groups. Priority areas for the research in the UK previously have probably led to the performance of some work of low quality and little long term benefit.

5. Applying the results

Our analysis of our own research suggested that uptake was good but the timescale even longer than previously anticipated. Developments in basic research are usually more than 10 years, and in many cases over 20 years, in advance of major clinical advances resulting from them.

6. Forging links between disciplines

If appropriate funding is available, top quality researchers will seek out these links because they desperately want to find the answers to their questions. It is not clear that special initiatives favour the collaborations that are most likely to be successful. Good investigators will choose the best collaborations.

7-9. (No comment)

10. Extent of merger

See Qs 3,4 and 12

11. Connecting for Health dependencies

Renal services have long been at the forefront of healthcare IT, and the development of renal IT systems in London in the early 1980s were possibly the first electronic healthcare records. Similar systems are still far ahead of systems promised through CfH, and renal units have been sharing data with the UK Renal Registry through a virtual network under the auspices of the Renal Association for many years.

The potential benefits from the information that is beginning to flow from CfH initiatives are therefore very apparent to us. It could be a huge asset in clinical, epidemiological, and patient investigational research. It will be essential to ensure that this potential is realised.

Many surveys have suggested that patients are overwhelmingly in favour of their information being used in this way. They are particularly unconcerned about the use of non-identifiable data. Our own experience shows that the majority of renal patients are keen to access their own information, with identifiers, across a secure Internet

connection (www.renalpatientview.org). This in itself will create a valuable research resource.

12. Centralisation/ devolvement

To use NHS R&D funds to greatest advantage, a large proportion should be administered centrally to support specific projects. Local R&D funding should be much more transparently assigned to local R&D resource, for instance staff and facilities to support trials and research.