

■ Good communication is key to encouraging patients to take part in research. Your healthcare team should be able to explain clearly to you why your participation in research would be valuable, and you shouldn't be afraid of asking any questions

# What I tell my patients about **clinical research**

**Healthcare professionals all have an interest in research. Whether actively designing studies, recruiting and following up patients or analysing data for publication, they all recognise the need for new knowledge and understanding to guide their practice.**

Without well-designed studies generating robust and relevant information, renal medicine – like all medical specialties – will be frozen in time. Research is essential for making advances in the field, and in order for you, the patient, to benefit, this research must be made an integral part of clinical practice.

So, we understand that research is important, but do you? With more than three million patients recruited to clinical research studies by the National Institute for Health Research (NIHR) Clinical Research Network in the last six years, and more than 600,000 in the past year alone, it is clear that a large number of patients do. These figures include more than 67,000 renal patients in the last six years, a quarter of whom were recruited in 2013/14. However, despite these encouraging numbers, successful recruitment into clinical trials remains the single biggest obstacle to clinical research. The majority of patients still know little about the opportunities such research presents and most are not actively involved in research. Many of you also don't realise that clinical research is core to the functioning of the NHS.

In this article, we will look at the four key things we believe you should know in order to show that research is an important part of modern medicine and to encourage your participation.

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## Communication

Good communication is at the heart of most successful endeavours. In clinical research, healthcare professionals need to share ideas with colleagues and effectively enlist their help to get projects off the ground and into print. In the same way, we need to be able to communicate with you, your family and your carers.

Research provides a great opportunity to have a discussion about how you can work together with us to find answers which could improve your life and the lives of other patients with renal disease. It has the potential to become a model for shared decision-making, as increasing anecdotal evidence indicates that people who get actively involved in helping researchers with the design and other parts of the research process have a much greater understanding of their health and well-being. In addition, taking part in research, helping researchers and making donations are all part of the same endeavour.

However, you may have a very vague notion of what research is and no idea at all about what it may mean for you personally. The concept that clinical research is an ongoing and essential search for new knowledge that will inform how you are treated is not an idea that is automatically familiar to most patients. Therefore, it is up to us, as healthcare professionals, to educate you.

It is important for us to integrate an awareness of clinical research into the overall care package we provide for you. Patient-centred websites can help do this, as can publications geared towards special patient groups, as well as national campaigns such as the NIHR's 'OK to ask' campaign (see Box 1). But, perhaps, building research awareness begins most effectively with day-to-day interactions with your healthcare providers – be they doctors, nurses or allied healthcare professionals. They can provide information in individual clinic consultations and group sessions, through posters, leaflets in outpatient clinics and websites.

In a research-centred healthcare system, such as the NHS, research is important both to you as an individual and to the wider patient community. Research has been successful in shaping modern medical practice, but there are also areas that need further work. Clinical research is not distinct from clinical care, but is integral to its success. As patients, you should be invited to be part of this activity and encouraged to ask about research studies that are open for recruitment in line with the NHS constitution.

Research is important to yourself and others like you, and you have an opportunity to help. Healthcare professionals should present information in an accessible way, to emphasise the importance of both the research questions being addressed and the significance of the contribution you can make. If you need more information, don't be afraid to ask!

### Teamwork

Just as the provision of high-quality clinical care relies on good teamwork, so does the delivery of high-

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### Box 1. Useful resources

- Kidney Information Network (KIN) <http://gmkin.org.uk>
- British Kidney Patient Association [www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk)
- NIHR 'OK to ask' campaign [www.facebook.com/NIHROKtoAsk](http://www.facebook.com/NIHROKtoAsk)

quality clinical research. A multidisciplinary approach is an essential part of the successful design and completion of any research project. Any significant piece of clinical research in renal medicine will involve renal specialists, but you will also see the involvement of physicians, research nurses, scientists, IT specialists and statisticians. However, the final – and perhaps most important – members of the team are the patients.

Study participants should be seen as members of the research team because they make an invaluable contribution. In the normal course of events, healthcare professionals are there to help you, but in a clinical research setting, that arrangement is turned on its head; suddenly, we find that you are there to help us. Without your free and unselfish participation in the research process, clinical research would quickly grind to a halt.

But, participation may mean more than being a research subject. You may become actively involved in the design of studies, helping to ensure that the protocol (the research plan) is practicable and not off-putting. You may also act as an ambassador of a study, helping to promote research awareness and increase recruitment and support. You could also have an important voice in helping researchers to focus on real-world research priorities. What you need from research may be very different from what we think you need, and we must use your experience as the major driver for NHS research.

As clinicians and researchers, we want you to join us, to work together to find the answers to important questions.

### Respect

Clinical research is, by necessity, a highly regulated affair. The modern researcher is subject to a level of oversight and governance that can, at times, seem burdensome. That is, until one remembers why these checks are in place – to protect you and to ensure the quality of our work. We have only to glance back into the recent past to see how research participants have been taken for granted and, as clinical researchers today, we must acknowledge that without proper controls such things can easily happen again.

Thus, clinical research is built on the foundation of informed consent, ensuring that you fully understand what is being asked of you. You should also

## Key points

- It is important to understand that good clinical research is essential for the improved future care of patients with renal disease.
- Your healthcare professionals should be able to communicate this effectively to you, as well as providing the key information and research findings required for you to make an informed shared decision about your care.
- Teamwork is essential for the successful design and delivery of clinical research and, as the patient, you should be regarded as the most important member of the team.
- Ethical clinical research must not only be built upon informed consent, but also upon respect, and when considering participation in clinical research you should be in no doubt that this is how you will be treated.
- Your contribution to research, whether this is by taking part, sharing data or raising funds, is greater than that of every other team member combined and you should always feel valued and acknowledged.

understand that you are free to make your own decision about starting or continuing in a study.

However, beyond the bare regulatory requirements of consent is the more nebulous notion of respect. How would we wish to be treated if we, or our loved ones, were research participants? How, in turn, should we treat those who participate in our studies? Unless our research is built on a framework of respect, it is likely to become an activity that is, at best, discourteous and, at worst, contemptible.

We will always treat you and your informed decisions with respect as we work together.

## Value

As research participants, you deserve not only our respect, but also our gratitude. It is difficult, if not impossible, to put a price on the collective participation of our patients in clinical research in the UK. Our study participants are volunteers, freely giving their time and their efforts to research, most often without the expectation of personal gain and usually for altruistic reasons. But, how often do we say, 'thank you'?

It is important that you feel valued and that your efforts are properly acknowledged. By first placing significant value on a patient's contribution and then communicating that to you, often with a simple 'thank you', we ensure that we are putting some of that respect into practice.

We value your participation in our research. Without you there would be no research and no new answers, and we thank you.

## Conclusion

Clinical research is, therefore, everybody's business. For healthcare to move forward and to improve, we need to implement the findings of new research. This research can only be done with your help. The best healthcare system is the one that is both research active and research aware. Healthcare professionals should, therefore, be celebrating research and working with the public to raise their understanding and build their research literacy: we should work towards creating a research active nation.

In this short article, we have highlighted the four areas which we believe are key to successful clinical research. These are that:

- Your participation in research is highly valued
- You deserve our respect at all times
- Research patients should be viewed as key members of the research team and, indeed, can be valuable contributors to study design and assessing delivery
- Communication between the researcher and the participant is where it begins ■

### Declaration of interest

The authors declare that there is no conflict of interest.

**I**t has been widely reported that a review of specialised services by NHS England is under way, and that there is a proposal to move the responsibility for commissioning renal dialysis to clinical commissioning groups (CCGs).

Renal patients have seen this proposal to 'declassify' dialysis as a specialised service on at least two previous occasions and have opposed such a move each time. The following are just some of the reasons why they believe such a move would be damaging and some of the questions that need answering.

- The renal patient journey is not one way. Dialysis and transplantation are inextricably linked, with patients moving backwards and forwards between the two therapies during their entire renal life. Transplantation remains a specialised service and it has to make sense for dialysis to remain where it is.
- There were experiments in providing dialysis in primary care some years ago at the Ashfurlong Medical Centre, Sutton Coldfield, but this was not well received, or considered a success, at the time.
- GPs are renowned in renal patient circles as knowing little about dialysis or the many and varied complications surrounding this treatment – renal patients only consult specialist clinicians. The complexities of renal disease are myriad, and GPs themselves always refer upwards on any renal matter. There is a major lack of expertise in primary care.
- Could smaller CCGs possibly run haemodialysis units, in financial and staffing terms, and have they ever expressed any wish to do so?
- What will happen regarding the issues surrounding dialysis; for instance, the specialist surgeons needed for 'fistulae' surgery, home dialysis training and transplant work-up?
- Dialysis away from base is an essential requirement for any renal patient trying to live their life – how will this ever be possible if dialysis is spread thinly within CCGs?
- How will CCGs provide the transport service (already a mess) to and from dialysis units?
- Patients are looking for a high-quality service that is transparent and has patient ownership. This proposal is the very opposite and patients fear their life-saving treatment will be moved to GPs, who are not sufficiently qualified and who normally refer decisions to nephrologists.

Patients ask that any review assists in making the already highly stressful clinical journey into one that places patients' needs at the forefront ■

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