

Hospitals should be at the heart of Britain's world-beating partnership with patients in research

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ABSTRACT

The Royal College of Physicians Future Hospital Commission report and recommendations highlighted the importance of clinical research to its definition of the hospital of tomorrow. But why should hospitals put research at the centre of what they do and how can they make it happen in practice? This opinion piece sets out a vision of a 'research hospital' from a patient and public perspective. It argues that patients will increasingly value those hospitals that: visibly focus on research to improve quality of care and treatment; actively enable their patients to contribute to this endeavour; and help to make the results of this research more accessible to its public.

KEYWORDS: Public involvement in health research, research hospital, future hospital, clinical research, NHS research

The British public and medical research make for excellent partners

This year, hundreds of thousands of us will take part in clinical trials.¹ Millions of us will donate money to medical research charities over and above what we give to science through our income tax.² Some of us will go one step further and work alongside researchers and clinicians in the name of research. The UK National Institute for Health Research (NIHR) has pioneered internationally leading work to involve patients and the public in research prioritisation, the design and delivery of studies and the dissemination of results to the public.³

In spite of the anxiety of scientists that the public don't or won't get it, people have consistently supported advances in medical research that have pushed ethical boundaries. Votes in parliament have unfailingly gone the way of medical research as MPs – spurred on by their constituents, many of whom have benefited directly from new treatments and therapies, which would not have been possible without research – have trooped through the voting lobbies to support the next great advance.

This is not a new phenomenon – in fact, it has been going on for decades – but it is an occurrence that has scaled new heights in recent years. You only have to see the numbers of people who turn up at their local park at the weekend to do a marathon or

other activity in aid of 'finding a cure' for this, that or other condition. It is as if medical research occupies a sweet spot between that peculiar British habit of giving generously (more than any other country apart from the Netherlands⁴) and the altruism encapsulated in our healthcare system. And we are all set to gain from it.

However, at that very moment when we might expect to benefit personally from this endeavour as a patient, the NHS can fall short.

In a survey commissioned by the NIHR Clinical Research Network, 95% of people said that it was important to them that the NHS conducted clinical research and 89% would be willing to take part in clinical research.⁵ However, most of us will be lucky to have a conversation with a consultant or doctor let alone have the chance to participate in a research study.

Only one in three patients surveyed as part of the annual Cancer Patient Experience Survey report having a discussion with their doctor about clinical research.⁶ In other conditions, such as type 1 diabetes, medical research charities report much lower rates.⁷ This in spite of the provisions in the Health and Social Care Act 2012, which place a duty on all NHS organisations to promote and advance research and the fact that, under the NHS Constitution, patients have a right to information about appropriate and relevant clinical trials.⁸

It is welcome that the Royal College of Physicians (RCP) Future Hospital inquiry and report emphasises the importance of research to the life of a hospital and to the lives of its patients.⁹ But I would go one step further. I would argue that the commitment to research shown by a hospital should be seen as a clear indicator of its ambition for year-on-year improvements in the quality of care received by its patients and local community.

In a recent talk to consultant physicians and the RCP Patient and Carer Network I attempted to articulate my definition of a 'research hospital' from a patient and public perspective. At that meeting I said that my aspiration was for patients to be able to say the following about their hospital:

- > What my hospital does in research is visible to me.
- > I can choose to contribute to research as part of my care.
- > My experience is valued as part of the research being done there.
- > Research is clearly viewed as a mark of quality by those who work there.
- > My contribution is acknowledged and the results of research are made available to me.

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What my hospital does in research is visible to me

Some months ago I was walking around central Toronto, Canada where many of the hospitals and associated institutes are clustered. It was not easy to miss them. Typically, each had large signs on the building façade or walls. Almost without exception these made much of the fact that ‘world-class research’ was performed there. While some may regard it as garish, I felt it was an important statement of what those hospitals felt was important to their local community. NHS trusts should similarly wear research visibly on their sleeve.

I can choose to contribute to research as part of my care

Hospitals should be hubs for encouraging patients and carers to participate in research. An increasing number now actively promote the NIHR’s annual ‘OK to Ask’ campaign, which is aimed at encouraging people to ask about clinical trials that might be relevant to them.¹⁰ But doctors and NHS staff also need to be supported by their trust board to feel that they have the time to have such conversations with patients and, at the very least, signpost them to other sources of information and help such as the UK Clinical Trials Gateway,¹¹ which gives details of all open and recruiting trials in the UK and will soon enable people to register to be a research volunteer.

My experience is valued as part of the research being done there

NHS trusts can also help to stimulate a wider discussion with people about what research should be prioritised and how best to do it. Many NHS trusts now have public involvement in research advisory groups or similar forums. These can have a vital role in helping researchers design appropriate research studies from refining their research question to devising the best method of recruitment. A growing number of hospitals are now also taking on ‘patient research ambassadors’ – volunteer patients, carers or members of the community – to be the face of research for other patients.¹²

Research is clearly viewed as a mark of quality by those who work there

Engendering a research culture within a hospital is no different to any other culture change. It requires attention to vision, leadership and the setting of clear performance targets. Staff need to be supported to do research and success should be recognised. Forward-thinking trusts like the Royal Devon and Exeter NHS Foundation Trust, a former winner of the *Health Service Journal* Clinical Research Award, publishes annual figures for the number of patients recruited to studies, the number of research grants won and other data to demonstrate their commitment to research.¹³ This also includes feedback from staff and patients on their experiences of being part of research.

My contribution is acknowledged and the results of research are made available to me

It has been the perennial bugbear of patients who have taken part in research that they are often not thanked for their contribution. Nor do they get to see the results of the studies

they have been involved in and how this work has made a difference. Funders and principal investigators must play the leading role here in ensuring this happens. But NHS trusts can also contribute by making sure the results of studies they have been part of are reported in newsletters, on their website and at patient open days.

Realising this vision of a future research hospital is not just a ‘nice to have’, it is about making a difference to the lives of patients and to the life of the surrounding community. The evidence shows that patients receiving care in NHS facilities that support research experience better outcomes.¹⁴ As this supporting data grow and become more widely publicly available, patients may well see research activity and achievement as an indicator of whether their hospital is a place where they or their family wishes to be cared for or not. I certainly hope so.

It will be important to the credibility of this research activity that it is seen to be addressing needs and priorities that matter to patients and their families. In fact, patients are now pushing research colleagues, their institutions and funders hard to work to an agenda that is more patient-focused than ever before. A recent analysis of James Lind Alliance Priority Setting Partnerships has highlighted that while patients and health professionals frequently prioritise non-drug treatment research, most research is focused on the evaluation of drugs.¹⁵ The NHS, its hospitals and workforce can be important allies in making sure this mismatch does not continue.

The good news is that as a country we are in a better shape to achieve this vision than ever before. Over the last 10 years, the NIHR has forged an ever-closer relationship with its colleagues in the NHS: 98% of NHS trusts now recruit patients to clinical research.¹⁶ Public confidence in health research, the way it is developed and the researchers and clinical research nurses continues to grow.¹⁷ Our challenge and our opportunity is to use this trust and the wider partnership that research has with the public to put research at the centre of hospital life and that of the local health system that it is part of. ■

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