

CLINICAL RESEARCH

SPECIAL REPORT

WHY TRIALS CAN BE A STRENGTH

Trusts must tell the public about their research so they can build support for this vital work and encourage people to get involved. By Alison Moore

What patients and the public know about clinical research – and where they get their information from – is likely to affect their views of it and whether or not they will get involved, given the chance.

But a recent “mystery shopper” study by the National Institute for Health Research’s clinical research network highlighted how difficult it is for people to get information about research. Of the 40 trusts and 81 sites visited, more than nine out of ten were not providing sufficient information to support patients or visitors who wanted to find out about the research they were doing.

The research looked at trusts’ websites, information boards and screens in hospital, and asked at reception and at Patient Advice and Liaison Services about what research the trusts were involved in and opportunities to get involved.

They found:

- 91 per cent did not have information in reception areas or waiting rooms, or on boards or screens;
- 55 per cent of sites were unable to provide useful

information through Patient Advice and Liaison Services;

- 45 per cent of staff asked at reception said the trust did not carry out research or could not offer help in finding out information;

- only 34 per cent of trust websites contained useful information for patients about research.

Joanna Eley, one of the patient volunteers who conducted the survey, says it is important to understand how ordinary people find out about research.

“I had to go to a particular hospital and look systematically, using a list of questions, to see if I could find out anything about research and how a patient or member of the public could become involved,” she explains. “I found very little. It took some persistence to get help.”

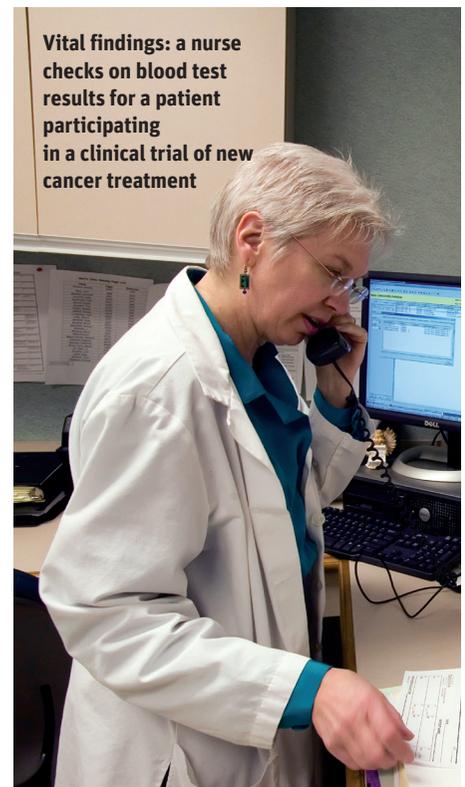
Eventually the PALS were able to put her through to the research department where someone sent her a link to useful information on the website. But she says an ordinary member of the public would have been unlikely to have persevered in their attempts to find the right person to speak to.

She suggests it would be worth making information available through GPs’ surgeries so people become more aware of research at an earlier stage. “It is about making research part of the way we think about medicine. Everyone who comes into contact with the health service should be given the message that great research is being done and it is making a difference to patients.”

So how do patients and carers find out about trials they could be involved in? For many, the answer is probably only after they are diagnosed and that will depend on the individual doctor they deal with. One concern is that, although nearly all acute trusts are involved in research, this can sometimes be because of a few very committed staff. Patients in other areas of the trust may not be told about opportunities, simply because their doctor is not involved.

And patients who have just been told they have a serious or even life-threatening disease may not be ready to absorb complex information or consider their options. Greater awareness of the importance and

Vital findings: a nurse checks on blood test results for a patient participating in a clinical trial of new cancer treatment

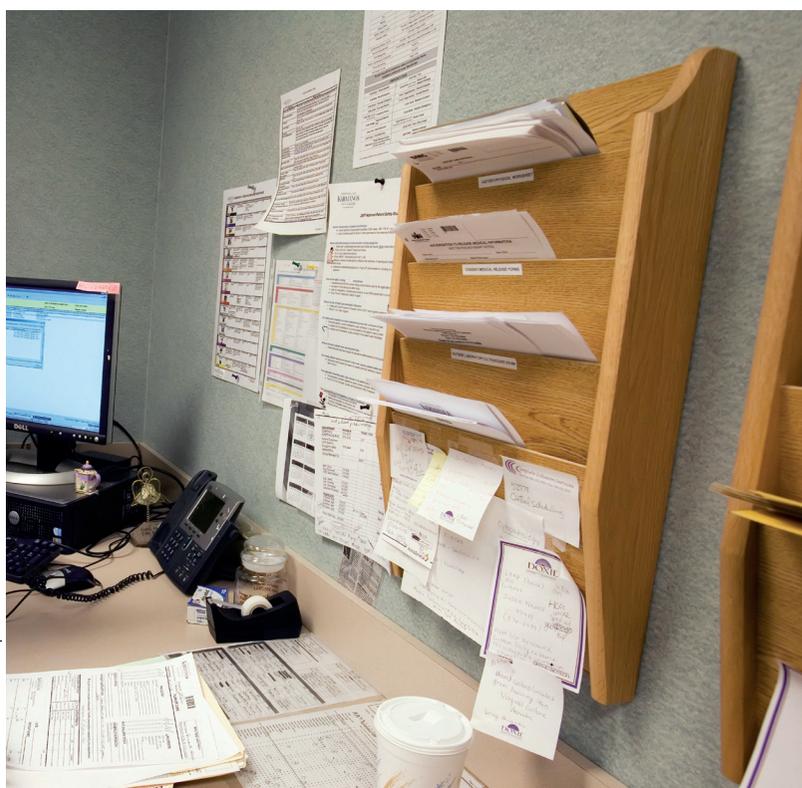


‘Everyone should be given the message that great research is being done and is making a difference’

opportunities of research at an earlier stage may help.

NIHR clinical research network chief executive Dr Jonathan Sheffield says he was not surprised by the outcomes of the mystery shopper project and it mirrors his own experience that more could be done to raise awareness of research in trusts.

“All trusts are committed to research,” he says. “If you look at their strategic statements it is quite clear that they have a commitment to research. But what you don’t see is that being very visible to patients as they walk around a hospital.



“If you are serious about embedding research in the NHS you need to get that patient engagement. We want this to be more visible to people. When people visit hospitals – perhaps as visitors or as patients – it is a really good time to get the message across.

“It is clear that patients do have an appetite for getting that information. They are interested in knowing what research is available in their own locality. We have to make certain that organisations present research to them in an accessible way.”

And he adds that there is evidence that the public supports research and expects hospitals to be doing it. More than four fifths believe it is important for the NHS to offer patients an opportunity to take part in research and 53 per cent of cancer patients who were not asked to take part in trials wished that they had been asked.

There are many benefits to patients and the public

understanding better how research works, Dr Sheffield says, and that it generally leads to systematic, serial improvement in care rather than to miracle cures. But over time these are significant – such as rises in cancer survival rates.

“The idea that research is carried out by boffins in a back room hidden away from the rest of the hospital is an old style image,” he adds.

NIHR clinical research network has produced an information pack to help trusts develop public and patient awareness, which includes examples of signs that can be used to promote research plus examples of good practice (see link below).

Some trusts have responded positively to the mystery shopper initiative and want to drive forward working with patients and public on understanding of research. Leeds Teaching Hospitals Foundation Trust has approached West Yorkshire

WHO WANTS TO BE A CITIZEN SCIENTIST?

Helping the public become informed and involved in research requires a multifaceted approach such as the one being adopted by the Citizen Scientist project in Salford.

The importance of research and the opportunities to get involved are being promoted through a website, an open day at the Salford Royal Hospital focusing on research, and a host of other events. The scheme is being run by the Salford Royal Foundation Trust on behalf of partners in the Manchester Academic Health Science Centre.

Francine Jury, project manager on the Citizen Scientist scheme, says other plans include pop-up events across Salford and contacts with colleges and universities – and even at the local rugby club. “It is wherever people go in their spare time,” she says. Local advertising is also planned.

So far about 100 people a month are signing up to express an interest in getting involved in clinical trials and the aim is to have 1,000 registered by the end of the year. By 2017, the hope is that 10 per cent of the area’s population – about 20,000 people – will have signed up.

As well as helping trials find participants, the scheme should raise awareness of research being

done locally, how clinical research works and what the benefits are.

The scheme was started because of difficulties in signing up enough people to trials within the tight timescales of much research. Focus groups revealed that many people knew little about clinical research or how to get involved.

The website allows potential subjects to register an interest and find out about planned research. But, as the numbers registered grow, researchers should be able to request matches with patients who have a particular condition – from a ready made group who have already said they are interested in being involved.

“People will engage with research if it is delivered to them in a way they can understand – that is the whole point of this project,” Ms Jury says, adding they can also provide feedback to researchers about the patient experience.

But it is important that research is done in a way that is acceptable to patients and encourages participation – and in many cases that means making it sure it is done with local people. “We have found that people in Salford are not even prepared to go to the other side of Manchester to take part in research,” Ms Jury says. “People feel comfortable in their own surroundings.”

Comprehensive Local Research Network to work with it on this.

The network’s patient and public involvement development officer Isla Dowds says it is important to get staff on board so they are happy and competent to talk about research and will signpost patients to sources of information.

Her work ranges from setting up a “speed dating” system to link patient groups with researchers, to encouraging patient information leaflets to be handed out to those interested in trials, to running workshops bringing together patients, the

public and researchers.

“It starts from the premise that in this partnership both parties need to learn. Health professionals and researchers need to learn about doing good involvement and many lay people don’t know much about research. They can learn most effectively from each other,” she says. ●

FIND OUT MORE

→ www.crnc.nihr.ac.uk/profilepack

How to promote research in trusts

→ www.hsj.co.uk/hsj-local/

For the latest information on research in your region