Increasing staff engagement and patient participation in research

Patients can face many barriers to participating in research. It often involves long, costly journeys and takes place at inconvenient times - and if staff engagement is low, patients may never get the chance to participate.

Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH) serves a diverse population, including some of the UK's most vulnerable people, over a large geographical area. In 2014, we formed a research team, Grounded Research, which aims to conduct innovative research relevant to our community. Working with a network of nurses, research physicians, allied health professionals, clinical research professionals, and academic and commercial research partners, our priorities are:

- Supporting recruitment to current National Institute for Health Research (NIHR) portfolio studies;
- Running the UK's first dedicated community clinical research facility;
- Continuing the work of the RDaSH Grounded Research Centre for Nutrition and Behaviour;
- Increasing research in primary care;
- Expanding research activity in offender and ex-offender health;
- Using research to improve substance misuse services;
- Increasing research into dementia;
- Trialling pioneering wound care solutions in the community;
- Improving end-of-life care;
- Developing and implementing personalised mental healthcare;
- Preventing occupational burnout in the healthcare workforce.

What were our aims?
We identified that, across RDaSH, staff engagement and patient participation in research have been low: in 2012, we had just 49 recruits to research studies. We wanted to resolve this by increasing the scope of studies and patient access to them. Our aims were to:

- Build research capacity and capability trust-wide, with a focus on nurses;
- Develop and launch a community research hub, which would bring the research to our community and reduce the need for patients to travel to other sites to participate;
- Achieve excellent, measured research recruitment and delivery across a range of study types and specialties;

Key points
- There are barriers to research participation, and a trust had low staff and patient engagement
- Staff training, a community hub and a network of patient ambassadors increased participation
- Regular update events maintain the patient network and have embedded a research culture in the trust

Keywords
Clinical research/Community engagement/Training and CPD

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Abstract
To address low engagement with research, Rotherham Doncaster and South Humber NHS Foundation Trust formed a research team. The team supported nurses to improve their research skills, opened a community research hub and created a nurse-led network of patient research ambassadors to recruit patients to studies. The trust now participates in more studies and has embedded a culture of research, running regular events to recruit and thank patients, and to support and encourage staff.

Citation
How did we go about it?

Research capacity

We developed the trust’s research capacity by helping student and qualified nurses in clinical roles to improve their research skills by:

- Shadowing the trust’s research team;
- Attending the NIHR good clinical practice training course;
- Acting as principal investigators on NIHR portfolio studies;
- Joining our clinical trial research team.

Patient ambassadors

Nurses introduced a PRA network across the trust in 2017 and we now have 15 people taking on the role (once renamed ‘research champions by the NIHR’). A nurse in the research team led on this, with other team members supporting. To recruit PRAs, they worked with the trust’s engagement team and attended patient and carer support groups, trust consultation forums and meetings of the trust’s council of governors.

The PRAs have used word of mouth to raise the profile of research in the trust and their communities. As well as helping to recruit patients to specific studies and research experience questionnaires that we are conducting or sponsoring, they have participated in studies themselves. They have been involved in developing research studies by writing lay reviews, sat on the interview panels for new staff, and met new team members as part of their induction. After acting as case studies for the local Clinical Research Network (CRN), PRAs’ stories have been told by regional and local media. By working with us, the PRAs have given patients a voice in research and ensured the research we deliver is what our patients want.

To maintain the PRA network, we hold quarterly thank-you events where we share current research and seek patients’ views on our plans and strategies.

Community hub

We opened the UK’s first community research hub, with a specific focus on engaging communities. This offers specialist advice on research design, conduct, regulation and implementation. It has a clinical treatment room with specialist equipment, office space, IT facilities and meeting rooms for partnership working.

What have we achieved?

RDaSH now participates in more studies than ever: in 2019 we have recruited 1,865 patients. We opened the UK’s first community research hub, which has given us a chance to showcase our achievements to a wider audience, thereby raising the profile of our team and the trust;

- Nurses’ greater involvement in research as part of their clinical role;
- Around 300 staff have attended the NIHR good clinical practice training course – this has also increased our capacity for principal investigators on NIHR portfolio studies;
- Improved public and patient involvement, and more PRAs – their support and insight are vital to our continued development.

We have developed and embedded a research culture at RDaSH, welcoming staff of all research abilities to learn and enhance their skills. We invite all staff to regular ‘research cafes’, where we discuss current research projects and the results of recent studies, and ask staff to share their experiences of participating in research and academic studies with a research element. We hope this culture will bring a host of benefits for patients, clinicians and the NHS, including access to better and more cost-effective treatments, and opportunities for staff development.

We were also asked, for the first time, to participate in a clinical trial for an investigational medicinal product. This has been challenging, but has been achieved.

What are our future plans?

We want to give our community the chance to participate in a variety of research studies. We plan to increase PRA diversity; create an infrastructure to support involvement at all research levels; retain PRAs by developing a quarterly newsletter and hosting thank-you events across the region; involve them in RDaSH’s research conference; and co-author peer-reviewed articles with them.

We plan to develop links with universities by developing our own nurse-led research studies. We also want to give nurses an opportunity to learn research-development skills, as well as how to write research proposals, collect and analyse data, and report the study. To help them disseminate their findings and add to the body of nursing knowledge, we want to arrange presentations at conferences and produce publications – the ultimate goal being to have a nurse-led study adopted into the NIHR portfolio.

Having participated in a recent clinical trial, we now hope to be seen as capable of running trials on commercial products and be internationally recognised. We also want to continue to develop our profile and branding, increase RDaSH’s capabilities and add to our portfolio of studies. NT

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