Project Description

Challenging engrained behaviours and embedding new ways of thinking can be tough. And, when faced with a ‘it didn’t work then so it won’t work now’ attitude, it can be difficult to find a way through. In some situations, the best medicine is often simply to talk about the issues, to explore any barriers and to take a refreshingly new look at the future. With Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) previously posting lower than expected recruitment numbers to dementias and neurodegenerative diseases research studies, the local network decided to investigate what the obstacles to recruitment within the Trust were and held an open forum meeting where any issues could be voiced. The result was a small but significant increase in recruitment as well as a fuller portfolio of studies being established within the Trust. There was also a suggestion that the network acted upon support for clinical applications for funding to free up their time to undertake research and the unexpected offer of distributing research network literature via mobile libraries in the community.

AWP is a large Trust in the South West of England, covering a substantial tract of over 2,000 square miles and working with around 35,000 patients each year. Despite this, recruitment to dementias and neurodegenerative diseases research studies within AWP had remained low, contributing to just under 3% of the total South West recruits during the period April 2009 - March 2012.

In order for research opportunities to be offered to more people within the AWP region, barriers to recruitment needed to be identified and addressed. An ambitious project was embarked upon to consult with staff and other stakeholders, to create a plan of action and to implement specific actions to target enhanced recruitment.

Project Design and Implementation

In order to establish a baseline from which to grow a better understanding of and participation in research studies, the local research network devised a multipronged strategy for raising awareness. Kate Fuller, Clinical Studies Officer, explains, “We wanted to explore the barriers to recruitment so we held an innovative ‘thought shower’ session to which many of the key stakeholders in the Trust were invited. The outcomes from this were far-reaching and allowed us to begin to develop a plan about engaging more effectively with the host Trust”.

This involved finding better ways of working with clinicians, who often do not see research as a priority, and other members of the healthcare delivery teams and, of course, with patients and carers too.

Emily Gardner, another Clinical Studies Officer, agrees that contact with patients and carers is key. “The point of diagnosis for any disease or condition
can be a lonely time as a very different future is suddenly given to you rather than being chosen by you. At this time, most people start to ask questions about what treatments are available, what care they might expect to receive and what progress scientists and clinicians are making towards a cure so there is a very receptive audience just waiting for the correct information”.

The ideas from the meeting included ensuring ongoing consultation and the support of the Trust Board. Another suggestion was that presentations about how people can get involved with practical examples should be peppered with case studies of patients and carers with direct experience of trial involvement. One very practical suggestion was to support clinicians to apply for Research Capability Funding (RCF) for clinical backfill so that they can undertake research. RCF is allocated to research-active NHS organisations to help them to act flexibly and strategically to maintain research capacity and capability and to support the appointment, development and retention of staff to undertake research. In this instance, the local network was able to do this to fund a position for one day per week for six months to free up time for research. This was enhanced by offering relevant Good Clinical Practice training to allow the clinician to get actively involved in a locally recruiting study.

Impact of the Project

During the period of the project there was a significant increase in recruitment. Compared to the same time the previous year, almost a doubling in the number of people recruited into dementias and neurodegenerative diseases research studies by the AWP Trust was witnessed. The number of principal investigators responsible for running studies and trials within AWP increased by 50% and the number of portfolio studies open within the Trust increased accordingly. Although the timeline for the project was very short, the upswing in numbers bodes well for coming years.

This, in turn, led to better relationships with clinicians, particularly in memory services, collaborating with Clinical Research Network staff to recruit patients to studies. And this means more patients being given the opportunity to participate in research.

The Trust has regular induction days for new staff and Clinical Research Network staff were now invited to attend these meetings to present about research.

There was also a most unexpected outcome for the project which revolved around mobile libraries. Mary Griffin, local research network manager in the South West, says “During our initial ‘thought shower’ meeting, there were a number of new ideas that were thrown into the mix. Someone who had used mobile libraries in the past as a way of promoting services and of raising awareness, suggested this as a possible conduit for getting information to patients and carers. Although it was not part of our initial project plan, we decided to explore its feasibility and contacted all the libraries in the region to carry the network’s materials. Libraries in Bristol and Devon agreed to do so, so we ended up with a completely new mechanism for distributing literature and information to people who might be interested in getting involved”.

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Challenges

- It is often difficult to find the correct gatekeepers in the changing NHS landscape
- Open meetings generate many ideas that help catalyse new ways of thinking, but can be difficult to capture and act on
- Trust attitudes can be entrenched but the meeting helped move towards the adoption of new behaviours

Challenges and Learning points

Within the changing landscape of the NHS lie significant challenges around embedding new projects. As Trusts are reorganised and restructured and as funding moves from one area to the next, it is often difficult to find the correct gatekeepers.

Mary Griffin is also aware that open meetings where people are free to share their thoughts and ideas can be fraught with difficulties. “There were so many different ideas aired that it was difficult to capture all of them and it was certainly never going to be possible to act upon all of them. But there was a kind of ‘snowball effect’ which helped to catalyse some new ways of thinking.

“Part of the problem was that we were approaching a Trust where some behaviours and attitudes were quite entrenched. We wanted to encourage the adoption and adaption of new behaviours which would help us move towards our goal of increased recruitment and this first meeting helped us along that path”.

Top Tips

- Encourage open forums for discussion and debate to challenge well-established and deep-seated opinions and attitudes
- Don’t be afraid to explore. Appreciate that all ideas aired in such forums can have merit and that it may be some of the more unusual suggestions that will lead to previously untapped avenues being explored
- Attend Trust induction days and other meetings to raise awareness about the local Clinical Research Networks
- Develop a clear pathway for trainee doctors to access research opportunities and be supported to be a principal investigator or local collaborator
- Support clinical applications for Research Capability Funding to provide clinical backfill so that personnel can undertake research
- Explore possibility of mobile libraries carrying materials to promote research

For more information visit: nhs.joindementiaresearch.nihr.ac.uk