

## **BEING A TORCH-BEARER FOR RESEARCH: INTEGRATING RESEARCH CHAMPIONS WITHIN A TRUST**

### **Project Description**

In recent years, the Tees, Esk and Wear Valleys NHS Foundation Trust has developed a number of initiatives to increase research opportunities for their staff and their patients, particularly in the field of older people's mental health. These developments have increased the number and diversity of research studies taking place across the Trust, which has created more opportunities for staff to become principal investigators or local collaborators. In turn, this has led to a much-welcomed increase in the number of opportunities for patients and their families to take part in new drug trials and clinical studies.

One such initiative is the creation of Dementia Research Champions, members of the team in each of the Trust's memory clinics. Currently

thirteen in total, they include nurses, occupational therapists and psychiatrists. Their role is to inform their colleagues of new local research studies, to recruit their own patients and to encourage other staff to raise the topic of research in the clinic.

With the advent of Join Dementia Research, the Research Champions have been able to offer patients the chance to sign up to national dementia studies and to promote the service in their memory clinics. This helps to ensure that all patients with dementia can choose to express their interest in participating in research as a routine step along their patient journey.

### **Creating a high-quality research portfolio**

Five years ago, the Tees, Esk and Wear Valleys NHS Foundation Trust reviewed their research portfolio, and recognised that they needed to promote more research and to develop a more co-ordinated research strategy. The Trust's Senior Leadership Group therefore created a new role of Research Lead in older people's services. Dr Sarah Dexter-Smith, the Lead for Psychology in Mental Health Services for Older People, took on this role. She began by establishing a multi-disciplinary Steering Group to oversee the development and implementation of a number of new initiatives.

### **Introducing Research Champions**

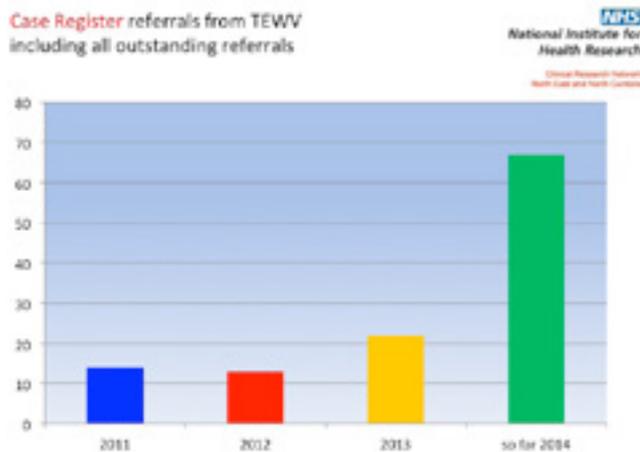
One such initiative was the creation of Research Champions - a dedicated individual within every memory clinic to provide a link with the Research Lead. The Research Champions inform their team about new local research opportunities, recruit their own patients to studies and support their colleagues with recruitment. They keep research high on everyone's agenda and troubleshoot when there are difficulties.

Some staff were initially resistant to the idea of Research Champions as they believed people with dementia would not want to take part in research. This concern has since been effectively challenged. Sarah and research and development (R&D) staff also helped to develop some of the first few Champions' confidence in talking about research by providing training and support.



Members of R&D staff and Dementia Research Champions

The first wave of Research Champions took part in an event with the aim of finding new staff members. The experienced Champions told their stories of recruitment, describing how patients report that taking part in research gives meaning to their life again. Sarah believes that “peer-to-peer communication was much more powerful than me or anyone else telling staff that being a Champion was a good thing to do. That’s what helped to bring the previously unconvinced on board”.



Number of referrals to the dementia research register in the Tees, Esk and Wear Valleys NHS Foundation Trust – August 2014.

Soon after the Research Champions got started, the Trust undertook a review of their dementia care pathway. With the Champions’ support, Sarah successfully introduced a discussion about participation in research into the early stages of the pathway. She points out, “The two initiatives went hand-in-hand, as the Research Champions were already there with the capacity to take on this new responsibility. The change to the pathway also gave validity to the Champion’s role. Research was no longer a nice extra, but a fundamental part of the patient journey”. In 2014, when these developments took place, the impact on recruitment was immediate and very striking.

### Introducing the Join Dementia Research service

At first, the Research Champions only recruited patients to local research projects, collecting patients’ details centrally on a local register. In 2015, the Trust became one of the first to use the nationwide Join Dementia Research service.

Sarah had to iron out a few teething problems at the start as she describes, “We went round all the clinics to introduce all staff to the new system, and to ensure that the Research Champions felt confident using it. However, our recruitment figures went down, we think because patients were required to contact the service themselves, and for various reasons this didn’t happen”.

Exploring resolving this issue, Sarah explains “We’ve recently agreed with the Alzheimer’s Society that their staff will follow up interested patients, and help them to get registered”.

Join Dementia Research has become a much welcomed development as it expands the research opportunities for patients to national projects as well as local ones. It also means the Champions only have to recruit patients onto the service, rather than having to remember details of specific studies.

### Keeping up the momentum

With the aim of keeping the Research Champions enthused and motivated, Sarah meets with them as a group about twice a year. “We’re trying to keep them together as a network, so they can support each other, learn from each other’s experiences and benefit from hearing the stories of the patients they’ve helped”, Sarah discloses. She believes this is essential because the Champion’s role is not formally



Joanne Fenwick, Community Mental Health Nurse, Tees, Esk and Wear Valleys NHS Foundation Trust

recognised with a job title or extra pay. The rewards therefore come from seeing and hearing about the difference made to patients.

Being a Research Champion potentially brings career benefits too. All the Champions become part of a research network and are therefore the first to hear about job opportunities, courses and conferences. Sarah is keen to help the Research Champions develop their research skills as she describes, "One of our Champions got through to the finals of the Nursing Times awards in the research nurse category. So although they might start out simply by talking about research within their teams, I can now say to them, 'Look where else it can take you'".

### **Joanne Fenwick's experience of being a Research Champion**

**Joanne Fenwick is a community mental health nurse, working in the rural community of Ryedale, North Yorkshire. She was one of the first nurses to become a Research Champion in the Tees, Esk and Wear Valleys NHS Foundation Trust.**

#### **What interested you in becoming a Research Champion?**

I've got patients who are very courageous and want to make a difference by taking part in drug trial and studies. They know they can't do much for themselves, but they're thinking about their family and future generations. I wanted to help them but didn't know how. I've been nursing for 30 years, but I wasn't sure how people access research. So it was my patients that motivated me.

#### **Why were you chosen to be one of the first recruits?**

They wanted a Research Champion in each area and they thought about me because I'm passionate about older people. I used to run a medication-monitoring nurse-led clinic, which provided the ideal opportunity to

talk to people with an established diagnosis of dementia. I wasn't seeing them at the crisis point of a diagnosis, which can be very emotional for everyone involved. I saw them routinely, once they've accepted their diagnosis and life was moving on. That may be a better time to talk about research.

#### **What have you achieved in your role?**

Initially I helped to recruit patients to local research projects, but then because we were one of the first Trusts to use the Join Dementia Research service, I've been able to recruit patients to national studies. I recruited the first volunteer after the pilot scheme, and ended up also recruiting the 1000th patient, which got a lot of media coverage. I've been very enthusiastic about getting people signed up, not just the patients but their family members as well, for the studies that need healthy volunteers.

#### **What difference has it made to you?**

It's made a big difference personally and professionally. Last year I was asked to speak at an international nurses' conference in London, and I hadn't spoken in public before. It has opened up opportunities for me that I wouldn't have otherwise had, for example I've been to the university hospitals to watch the drug trials taking place and learnt a lot more about how research works. And I've been recognised for my work, by being nominated for awards, which I feel proud of. So I've gained new skills and greater confidence and a passion for promoting research.

#### **What difference has it made to others?**

As a Champion, you're not just doing it yourself, you share your experience with your colleagues. So it has a ripple effect. If others are interested, I tell them that knowing about research is key – the more you know, the more you can explain it to patients. If you have that commitment and dedication, you can easily do it. You can make that difference and get more people recruited to research.

## Top Tips

- A multi-disciplinary oversight group provides a range of valuable insights and promotes buy-in from the different groups of professionals
- Senior level support for the initiative is essential, to give the lead the authority to ask each clinical team to put forward a candidate for the Research Champion role
- A motivated and supportive leader is essential to hold the vision, and encourage staff to sign-up and stay engaged
- Research Champions need training at the start to build their confidence in talking about research and ongoing support to manage any changes and maintain their commitment
- Peer-to-peer communication is an effective way to recruit Research Champions and provide informal support
- Becoming a Research Champion can be the first step on a new career path, particularly for nurses - it is important to find ways to nurture and develop their research skills

For more information visit:

[nhs.joindementiaresearch.nihr.ac.uk](https://nhs.joindementiaresearch.nihr.ac.uk)