

## **SIMPLIFYING THE CONSENT PROCESS: HOW ONE NHS TRUST MADE SMALL CHANGES TO MAKE A BIG DIFFERENCE**

### **Project Description**

Southern Health NHS Foundation Trust identified an opportunity to improve their service by establishing a simple consent system which increases the number of clinicians actively recruiting to studies and enables more patients to be approached to take part in clinical research.

This was part of a wider campaign to embed and develop a research culture amongst all staff working in older people's mental health.

The new process was hugely successfully and has so far led to:

- An increase in the number of clinicians actively and routinely offering all patients the opportunity to take part in clinical research as part of their normal care pathway
- A larger pool of potential participants for clinical studies, that includes a diverse range of cognitive impairments and varying severity
- A 23% increase in the number of patient referrals from health professionals following a research awareness day
- Implementation of a simple system for clinicians to record willingness of a patient to participate in research
- Southern Health NHS Foundation Trust setting research as a Trust priority, standardising research referrals and being one of the leaders in dementia research



The Memory Assessment and Research Centre (MARC) founded the first memory assessment service in the Southern Health NHS Foundation Trust area, and had been the primary source of recruits to clinical research trials. However, with eleven memory assessment services now established across the region, services have dramatically changed and a strategy was needed to support new research across the region and increase recruitment numbers.

Professor Clive Holmes, Clinical Director for MARC, explains, "It became evident that the traditional source of referrals to MARC had considerably diminished in size, and this was impacting on the number of patients recruited to trials on time and target. A major change in mindset and practice was needed to re-invigorate research into the region".

### **Challenges hit**

- Changing staff practice, ethos and behaviour towards research
- Getting buy-in from senior clinicians and executive members of the board to make research a priority
- Clinicians introducing the opportunities of research within patients' brief interactions with health care as an outpatient
- Establishing a simple system to record patients willingness to partake in research within the Trust's IT boundaries

## Changing research practices

The biggest challenge for the initiative was increasing the priority given by staff to research so that it became normal practice for all patients to be routinely offered research in their care pathway. Professor Holmes explains the challenge, "We needed to challenge people's mind set and change their behaviour. Our approach needed clear leadership, improvements in the consent processes and practices, clinical buy-in, and having the individuals to drive research".

A vital component of the initiative was engaging with the health professionals who came into direct contact with patients at their appointments. This began with an annual research awareness day to create an interest in research and to help embed the philosophy that research is as much a part of a patient's disease management than any other approach.



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## Leadership

Gaining senior level support from the chief executive board was just as crucial, and with the support of Jessamy Baird, the Trust's Director of Health Technology and Outcomes, this helped push research high up the Trust's agenda.

Professor Holmes explains, "It was instrumental to get clinicians on board. I attended case meetings to encourage other clinicians to refer patients to research and also help them understand that researchers are not so far disconnected from the practical concerns of everyday work in the Trust. Over time I began to build up a two-way relationship and provided advice and a second opinion on their patients".

## Self-referrals

To increase awareness of dementia research and encourage patients to self-refer to research, the team also tried and tested multiple ways of obtaining consent.

Christine Dean, research nurse, explains: "Patients and carers want to know the facts about research and have access to information so they can make a meaningful decision and choice about joining it. We know that patients find conversations with NHS staff more reassuring; however we wanted to also test out other channels. The most successful being sending consent letters to patients directly from their clinician, as they had built up rapport with them, were considered a trusted source".

## The vision

It is hoped that the initiative will continue to be rolled out across the region; increasing opportunities for people to be involved in research and contributing towards achieving the ambition for 10 per cent of people with dementia to participate in clinical research, as set out in the Prime Minister's Challenge on Dementia (2012, 2015).

## Bringing about change

Southern Health uses a patient record system called RiO, which is widely used across community and mental health Trusts. Unfortunately this system was unable to add new features for the benefit of recording a patient's interest in research.

The alternative was to build on an already existing Trust initiative that aimed to record consent from patients' mental health notes. The Trust were already developing a standalone consent utility to request patients' permissions to add their clinical information to a Hampshire wide electronic health record. And so, with the support of the Research and Development (R&D) team the network were able to add a simple tick box to record a patient's willingness to participate in research.

According to Professor Holmes, "It was extremely important this process be easy, straight forward and take a minimal amount of time for the clinician. It needed to be simple enough for clinicians to ask patients during their routine appointment and record it by ticking a box. By including in a second question to the existing consent form, it enabled us to access the patient's records in RiO and then use that for our research".

## Top Tips

- You need to get the executive board of the Trust involved
- It is important to engage all clinical staff in this process
- Keep it simple and minimise the amount of work that health professionals have to do
- Get patient/carer involvement early as they can tell you if a form is too difficult for patients to understand

For more information visit:

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



With Join Dementia Research, patients are able to register themselves to the service and find out about research studies they match to, without committing themselves to research. They can then express an interest in studies on a case-by-case basis.