

## ASKING THE RIGHT QUESTIONS: EMBEDDING RESEARCH CONSULTATION

### Project Description

Broaching the subject of involvement in a research study or clinical trial can be tricky. Who is the best person to do this? And how should a patient be asked? Conventionally the onus to do this has rested with the consultant looking after the patient but, as our expectation of experiencing the very best that our National Health Service can offer, more and more people are becoming aware about getting involved in research, raising the possibility of recruiting greater numbers into trials. A wide ranging consultation was conducted in the South West of England with some of the area's leading charities and local patient groups to ask what they thought would be the best way to inform patients and carers about current research and opportunities to become involved. In addition, to gaining valuable insights into the kinds of questions to ask and the best communication tools to use, this unique opportunity was used to create a Patient Advisory Panel to help ensure the patient voice is heard locally.



Encouraging people to take an interest in research and in participation in research studies and clinical trials relies on being asked to take part. The 'ask' can take several different forms but has, until recently, relied almost exclusively on the healthcare professional raising the issue during a consultation.

This tends to get done on a very ad hoc basis, 'right place, right time', not systematic and often at a very stressful time for the patient, perhaps at the point of diagnosis or when attending a memory clinic.

Spurred on by newspaper and magazine articles and television programmes, a greater understanding of health and disease is, however, slowly drip-feeding into the public psyche. The clinical research networks have capitalised on this by launching a number of different initiatives aimed at raising awareness about research studies and clinical trials. However, questions remain about how people actually want to be approached about research and what the best mechanisms for getting this information across actually are. The team in the South West decided to approach this problem by asking patients and carers what worked for them.

### Project Design and Implementation

In order to establish a baseline and to get some initial feedback, a short 'listening exercise' was conducted to engage with patients, third sector organisations and NHS services. This was designed to gain valuable input as to how alternative patient engagement approaches could be conducted and ensure that all patients are given opportunities to participate in a current study or to join a 'consent for contact' register.

A small team led by a project lead and the local research network manager along with two patient representatives and two senior research nurses was assembled to take the project forward. Alison Fowler was the project lead; she comments, "The first part of this project was to devise a short questionnaire asking things like 'How would you like to find out about opportunities for being involved in research?' and 'What would encourage you to be involved in research?'. We deliberately kept the questionnaire short and focused to encourage as many people as possible to respond to it".

The questionnaire was then sent to about 100 patients, carers and healthcare professionals in two areas – Exeter and Plymouth and Bath and Bristol. However, the response, particularly from the consultants and nurses, was particularly low so the project team regrouped.

“We recognised that actually the best way to approach patients and carers and to get greater involvement was through the charities. The charities working in the diseases that dementia and neurodegenerative diseases covers too are absolutely brilliant at keeping in touch with their membership and, by working with them, we realised that we could cover the whole geographical area in the South West” continues Alison.

So, with Alzheimer’s Society, Parkinson’s UK, the Motor Neurone Disease Association and the Huntington’s Disease Association, a region-wide consultation was conducted. The aim of this was to help future communication plans and to work to embed research and, importantly, to understand how patients prefer to be approached. However, this wider consultation also wanted to be used to act as a catalyst to launch a new Patient Advisory Panel.

The questionnaire was distributed to a larger group and a launch event was held to which over a dozen research-friendly patients and carers enthusiastic to be part of the Patient Advisory Panel came along.

Jean Waters was one of them. “I was very keen to be involved. Patient and public involvement has been

shown to improve recruitment into studies and I knew that, if the group could get input into research studies at an earlier point, we could really help to shape the research with practical advice and guidance from those of us who live with the disease”.

### Impact of the Project

It is estimated that, with the help of local charities and support groups, the questionnaire was sent to more than 1000 people via e-mail. There was additional dissemination through charity support groups meetings and at memory cafés.

The majority of respondents reported that their preferred way to receive information about local research projects and clinical trials open for recruitment are through the person’s GP or consultant or via support groups. Over 40% of people said that they would be happy to start the discussion about research opportunities with their healthcare team at any time, with just a quarter saying that as soon as possible after a diagnosis had been made would be the best time. And almost 90% of respondents said that they wanted to know how to get involved in research for reasons ranging from an increased knowledge about the disease to the very personal reason of ‘doing something positive in a negative situation’.

The biggest impact of the project has undoubtedly been the creation of a Patient Advisory Panel. Mary Griffin, local research network manager for dementias and neurodegenerative diseases in the South West says, “Because we widened out the scope of the original consultation, we’ve managed to engage with a much greater number of patients and carers across our patch which is a huge benefit for us. Our Patient Advisory Panel has attracted people who are all very interested in helping us and who are really engaged with research. Going forward, this is going to allow us to have a much more patient-focused input to research studies opening in the area and, of course, invaluable advice on the communication that we have with patients on everything from newsletters to our website”.

### Challenges and Learning Points

It is also important to consider the growing number of outlets where messages about research and participation in research studies and clinical trials can be placed. Geoff King, Influence and Service Development Officer with Parkinson’s UK in the South West, thinks that one of the biggest challenges in a project like this is finding the right person to speak



to. He comments, “The sluggish response rate in this project was, in large part, simply mechanical. It was about identifying and speaking to the right people”.

Adam Smith, programme manager, is acutely aware of the need to use these channels appropriately. “Whilst we recognise that not everyone has access to or wants to use computers, we know that a growing number of people do so we need to make information available to people this way. However, for me, the main takeaway from this survey was the need for us to look at the wider healthcare team to promote research, we cannot rely solely on recruitment being as a result of the short consultation patients have with consultants. Receptionists, nurses, junior doctors and everyone who engages with the patient could be playing a role in supporting research”.

### Top Tips

- Identify the correct contact person or key gatekeeper in every organisation or voluntary group
- Compare and contrast the best communication tools for use across a given geographical area taking into account people’s preferences
- Understand that considerable time can be needed to agree wording on communication tools like leaflets or for questions in a questionnaire
- Keep the design and appearance of a questionnaire simple and ensure that the wording is clear and formulated in such a way as to engage the respondent
- Ensure that translated versions of the questionnaire are available for the most commonly used languages amongst your target population

For more information visit:

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

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