

HAVING THE LAST WORD: EMPOWERING PATIENTS TO ENQUIRE ABOUT RESEARCH PARTICIPATION

Project Description

When it comes to recruiting people into clinical trials and studies, the onus is often placed squarely with the consultant to ask their patients about involvement in research. However, in an environment where the consultation period is short, research can often slip off the agenda. This can be looked at from another angle - empowering the patient to take the responsibility for asking their consultant about getting involved in research. To do this, part of the Clinical Research Network worked closely with a number of managers and service leads across their host Trust to investigate the possibility of placing a simple sentence about research involvement at the bottom of every outpatient appointment letter.

The results, although impressive, were not due to patient empowerment as expected. Patient referrals during the pilot project did increase but this increase was not due to patients asking. Rather it was thanks to the consultants asking their patients. This appears to have been due to the approvals process of altering appointment letters, which had made the consultants more aware of the research going on locally.

Join Dementia Research supports putting the power in the patients' hands, as people can sign up to the service themselves and see which studies they may be eligible to take part in. The most important thing to come out of it is that we got people talking about research.



Within the time-stretched environment of the NHS, it is perhaps not surprising that there is often precious little opportunity to discuss participation in local research studies and trials with patients. The NHS Constitution confirms that research remains an important pillar of the NHS and that 'the NHS will do all it can to ensure that patients...are made aware of research that is of particular relevance to them'. But, despite this, research often slips off the bottom of any consultation process as it relies on the clinician or healthcare professional having the time to mention the topic.

With the Clinical Research Networks now embedded across England, recognition of trial participation is slowly seeping into the nation's psyche thanks in large part to the active Patient and Public Involvement (PPI) initiatives that the networks have catalysed. This project looked at taking this one step further and turning the consultant-patient relationship on its head by launching a new initiative aimed at encouraging patients to ask their clinician about trial participation rather than waiting to be asked. In order to do this, the feasibility of adding new wording to all outpatient appointment letters sent from the Old Age Psychiatry department within the host Trust in north east England was explored.

Adding a sentence

The cost-effective measure of adding one sentence about research at the foot of standard appointment letters was suggested, with a rationale of informing patients about the possibility of getting involved and providing a further prompt to discuss research, particularly when research is perhaps not the clinician's top priority.

The goal was to add the sentence 'If you are interested in finding out more about clinical research, please ask your doctor or nurse' to the bottom of every outpatient appointment letter.

Involvement of patients was a key ingredient. Not just in encouraging them to enquire about research but from the outset of the project. Getting their input into the language used in this one sentence was vital.

A member of a PPI group, Derek Forster, recalls being asked to comment on everything from the overall aim of the project to the actual wording used in this crucial sentence. "The time constraints on clinicians mean that we were tasked with finding something sufficiently eye-catching and appropriate to place on a patient's appointment letter. The group provided a lot of comments and suggestions on how the wording could be altered and, importantly, where the text could be most effectively placed".

Gaining approval

Once decided, and Trust approval was gained, the project was timetabled to roll out across the

department. To monitor the impact of the initiative, patients who signed up to find out more about trial involvement were asked some standardised questions about the addition of the sentence to the appointment letters.

Increasing referrals

The project demonstrated a significant increase in the number of referrals into studies running across the region. Post-implementation saw a 26% increase in the referral figure in just four months.

However, there was an interesting twist in the tale. Of the patients who signed up, not one of them said that they had done so because of the sentence at the bottom of their appointment letter. In fact, without exception, none of them had even noticed the sentence.

So, how did the project manage to encourage more patients to get involved in research? Dr Bob Barber, Director of the local research network for Dementias and Neurogenerative Diseases, thinks the implementation of the initiative helped to raise awareness of research in the minds of clinicians, which in turn increased referral rates. "The team spent some considerable time working across the Trust consulting with the various management levels to get approval for adding the sentence to the consultants' letters. This had a kind of 'halo' effect as it ended up stimulating the consultants to ask their patients about getting involved in research rather than the other way around.

"The most important thing to come out of it is that we got people talking about research. And, regardless of whether it is the patient asking the consultant or the consultant asking the patient, these conversations are now taking place, so we can expect more referrals with time".

Dr Andrew Byrne, the principal investigator of a project that was running in the North East, agrees that the initiative was surprisingly effective. He comments "The sentence was aimed at increasing patient awareness of research and this was definitely achieved. However, there were wider benefits gained from the project. The process also facilitated increased links with dementia service leads and managers to highlight the importance of making people aware of dementia research. In addition, through this project, we also recognised that sometimes simple strategies and not just complex or high-tech approaches, can be highly effective in highlighting research amongst patients and clinicians".



Learning Points

The planning and implementation stages of this project facilitated engagement with dementia service managers across the Trust that may not otherwise have occurred. Historically, common practice has been to focus efforts of communication with consultants and frontline staff who see patients on a daily basis with perhaps less effort made to forge links with managers.

It is important relationships with managers are cemented with on-going contact and that increased networking opportunities between the local research network and dementia service leads are sought.

Vicki Hetherington, Senior Clinical Trials Officer, explains that although on paper it looks like a simple solution, the project nevertheless generated some challenges. "The Trust where we are based is a large mental health Trust and there were many layers of approval that had to be sought in order to make any alterations, however minor, to the outpatient letter". She continues "Director-level agreement was obtained relatively swiftly, but service specific managerial agreement took longer than anticipated and, with over 30 consultants to engage with as well, this caused a bit of slippage to the project".

In hindsight, it seems that the wording or emphasis on the sentence at the foot of the outpatient appointment letters may not have sent a strong enough message. Further work involving a PPI group was exploring the possibility of altering the sentence to stress involvement in research into their condition, which may strike more of a chord with patients reading their appointment letters. Another common feature from the PPI feedback, is the suggestion of using bolder text and different coloured font, so the sentence stands out more on the 'busy' appointment letter.

Conclusions

This very simple initiative looks set to have a longstanding effect. By enabling outpatient appointment letters to include a specific mention of research, this created an opportunity to empower patients to ask consultants proactively about research. However, by working through the layers of management that needed to be consulted with and

to agree to changes to standard Trust documentation, there was an unexpected result in that awareness of research was actually raised with the very consultants whose letter had been altered rather than with the patients who received the letters.

Top Tips

- Identify the key stakeholders within the Trust who need to be consulted about any possible changes to standard outpatient appointment letters
- Manage the relationships with these key stakeholders on an ongoing basis
- Assess the time that will be taken to gain all of the necessary approvals and revise the timelines for any project implementation accordingly
- Change the wording used to: 'If you are interested in finding out more about clinical research into your condition please ask your doctor or nurse' and use bold/different coloured text to make the sentence more noticeable
- Recognise that any project involving a number of diverse stakeholders may result in a 'halo' effect in which the desired group may not demonstrate the most uptake or engagement and that the results may be witnessed in a different group

With appointment letters to patients with memory problems or dementia, an opportunity to add the following sentence could be explored: 'If you are interested in finding out more about clinical research into your condition please visit:

www.joindementiaresearch.nihr.ac.uk or call Alzheimer Scotland: 0808 808 3 000, Alzheimer's Research UK on 0300 111 5 111 or Alzheimer's Society on 0300 222 1122'.

For more information visit:

nhs.joindementiaresearch.nihr.ac.uk