

Developing new research sites and new patient populations

SUMMARY OF THIS PAPER

- It asks whether PPI in Local Research Networks can help to open up new research sites or patient populations.
- It asks whether patients and carers are really able to help LRNs to overcome what are largely internal NHS bureaucratic barriers.
- It aims to prompt a discussion about how, at a time when LRNs are very busy, links with local patient groups/charities can be made as effective as possible.

In practice, can PPI help LRNs with identifying and developing new research sites or patient populations in geographically distinct areas that are not currently involved in clinical research?

Local Research Networks (LRNs) sometimes want to run a study in a new setting (e.g. an NHS Trust) but find it difficult to gain agreement. Recruitment could potentially be quicker if they had more research sites to work with. Also, it may be that access to new 'sets' of patients could help. When the challenges are often NHS hurdles and bureaucratic delays, LRNs wonder whether PPI could help. Sometimes they are busy building links with existing sites/populations; workload doesn't allow for opening up new sites from scratch. LRNs do speak at local patient groups/charities, when time allows, but would like a steer on how to make local public links in a cost effective way.

For more background, here are some responses from LRNs to the above question:

- i. "I think we are still finding out what we can do, and haven't formulated aims so tightly, although developing new sites is high in our aspirations.
- ii. PPI as outreach, contacting, developing and nurturing new researchers - we are becoming active in this way, but the 'public' here is the clinicians."
- iii. "One of our main activities so far has been interacting with patient groups. Taking information to charity branches will likely result in some requests from patients to their usual caregivers, who may not currently be involved in research, but we wouldn't have any information about this. So to use PPI in the way you describe, a 'geographical area' should be in mind, to gauge any impact of the PPI activity, so there could be a target for new sites and PPI one of the means of bringing it about."
- iv. "... our experiences in linking with [*Primary Care*] and GP surgeries re DOMINO [*a dementia study*] means that we now have feelers for study recruits far and wide, ..., and I'm not sure how else PPI could support this."
- v. "I've been thinking that our PPI steering members and reference panel could have a greater role in providing information about access to and recruitment to studies via the local branches of medical charities and carers groups, to publicise new sites once they have been identified and set up. The question of 'how to do this consistently and effectively' remains - of course!"

- vi. “My gut response is that we will be aware of potential new sites/populations as far as medics as PIs [*Principal Investigators*]. However it may be that when we start to make greater use of Allied Health Professionals as PIs they may have useful input.”
- vii. “A good question and on the surface it feels like we should be able to work with our PPIs to open up new opportunities. However, any new opportunities being explored need to be considered in tandem with contacting the local NHS teams covering that area. If you raise the expectations of a patient group and then the local clinicians do not want to engage with us, you will be left with some very unhappy [*members of the public*].”
- viii. “... we have held two focus groups and both groups raised these kind of issues and wanted to contribute to growing new areas but I am not sure we have been successful and joined up in how we have then taken this enthusiasm forward.”