

Handling enquiries from the public about taking part in research

SUMMARY OF THIS PAPER

- Patient representative groups/medical charities have asked for more clarity from DeNDRoN on how they should handle public enquiries about what studies are running where in DeNDRoN.
- They want the NIHR portfolio to tell them whether a study is running in each LRN
- They want a specific LRN and/or national contact to help with patient enquiries.

Patient representative groups/medical charities using the NIHR DeNDRoN portfolio

The portfolio: <https://portal.nihr.ac.uk/Pages/Portfolio.aspx> is used by some medical charities when handling calls. Patient representative groups/medical charities have asked for more clarity from DeNDRoN on how they should handle public enquiries about what studies are running where in DeNDRoN.

Some patient representative groups/medical charities want the NIHR portfolio to make it easy for them to see, when talking with a patient, if a particular DeNDRoN-supported study is recruiting in the area where the caller lives. Ideally they would like the website to show, next to study title, which Local Research Networks (LRNs) this study is running within. This would give them an idea whether to look in more detail or not to bother.

Question of whom to contact

- Some groups have said they would like to know whom to contact in each LRN.
- They have enquired whether a central DeNDRoN contact for enquiries could be useful to clarify the geographical boundaries for each LRN's recruitment area.
- It is worth noting that different LRNs work differently; some (I gather) don't want to have a system which encourages such enquiries to LRNs, whilst others are happy to.

Current national information from DeNDRoN

In practice, when calls are received at the DeNDRoN Coordinating Centre, the PPI Coordinator will often send people the document on the DeNDRoN website:

(Go to <http://www.dendron.org.uk/pp/index.html> then click on 'Research Registers and Patient Related Organisations')

but the PPI Coordinator usually doesn't refer calls on to LRNs. This is because most callers make clear that their interest is focussed on potential cures. If they are clearly relevant to refer on, the PPI Coordinator will do so. That document briefly covers:

- Information about possibilities for participation in research studies; What research participation means; Explains DeNDRoN and research databases, including the NIHR portfolio; Touches on inclusion and exclusion and the different phases of clinical research studies; lists medical charity websites; patient and public involvement in DeNDRoN, and groups such as INVOLVE and People in Research

Wider issues

Clearly this topic relates to the wider issue of the user-friendliness of the NIHR portfolio website, other local & national research information resources, and LRN-level 'Research Interest Registers' for interested patients and their carers.