

**DeNDRoN FOCUS GROUPS
REGISTRATION RECORD FOR USE WITH TELEPHONE ENQUIRIES**

Title / Name	
Street Address	
TOWN	Postcode
Telephone numbers, and good times to phone	
Email address	
How heard about it? Have you seen DeNDRoN publicity? Yes / No	
Why interested? What's your personal connection with this topic? (e.g. Pt / carer / ex-carer / medical charity staff)	
Do you know anyone else who's possibly attending?	
Are you involved in a branch of medical charity?	
Do you mind us letting them know that you're interested?	
If more than one group, which are you interested in? .. / .. / .. / All	
If all, do you have a preference? ..	
Are you likely to come? Definitely?	
DEPENDS ON WHAT...?	
Not sure but happy to be contacted?	
OTHER RECORDS:	
Know the venue/Need a map?	
Have you told caller if the plan is to 'tape' record for writing up, and whether the report will include names or not, and whether any recording will then be erased.	Have you told the caller this? YES NO
Are they likely to claim transport and any other costs?	
Any relevant disabilities (inc. wheelchair, hearing/speech/sight problems)	
Any dietary preferences (w.r.t. sandwiches)	
Anything else they or we need to know?	
<p>PLANS ? ACTIONS ?</p>	

- Stress they need to register to attend. For this reason, we may not put precise venue information on the flyers
- Tell them we plan to double-check with them nearer the time to make sure they are still interested
- Expenses take time to be reimbursed

SOME POSSIBLE ISSUES WHICH MAY COME UP IN INITIAL ENQUIRIES

Aim of focus group: Small discussion groups to look at a particular topic:

- No medical knowledge or expertise is necessary.
- It's part of involving patients and carers in improving clinical research.
- E.g. If the topic is "Barriers to recruitment in dementia and neurodegenerative disease research – and how to overcome them", the group will explore possible reasons why patients do or don't choose to take part in clinical research (practical, social)
- Will be friendly and informal
- We're working with medical charity local offices

Who: A mix of patients with and carers of people and ex-carers:

Limit is officially TEN (plus local DeNDRoN staff)

(Assume one or two may not turn up, could potentially book say eleven or twelve?)

- Because places are limited, you need to register that you'll be attending
- If specific to one condition, consider whether it would be appropriate to include some people concerned with other DeNDRoN-relevant diseases
- NO MEDICAL DETAILS to be stored on DeNDRoN databases

Practicalities:

- Consider steps or access issue
- Sandwiches, tea, coffee and fruit juice should usually be provided
- Consider expenses: LRN Office will presumably be happy to discuss travel arrangements and other possible costs. Any fares refunded will take maybe several months to come through.

Some DeNDRoN basic phrases to use on the phone:

- DeNDRoN LRN is the local part of the national Dementias and Neurodegenerative Diseases Research Network.
- Set up by the Department of Health.
- Covers Alzheimer's disease, other dementias, PD, MND, and HD.
- It doesn't fund research BUT it coordinates and provides trained staff to run studies.
- Gets local researchers, doctors, nurses, patients, carers, wider public, funders, academics and local NHS and talking and planning together to improve the quality of research.