National Institute for Health Research

The information below was distributed to anyone who might answer the phone to members of the public and other stakeholders who wanted to find out more about DeNDRoN and getting involved in research, for example reception staff. Those who received this guide were fully briefed at a workshop session prior to the project starting. This script is to accompany the self-referral form which aims to capture accurate patient/stakeholder information. The form can be found on the next page.

Points to discuss on the phone

Ask if would like us to call them back to save them cost. Advise this may take a few minutes and emphasise that any information they give to you will be confidential.

Where the leaflet was picked up from?

Does the leaflet have a reference number on? Write down if yes.

Are they a Carer? Patient? Control?

Are they interested in taking part in research or just hearing about what we do?

If they are interested in taking part in research find out what sort where interest lies:

- Questionnaire studies
- Current drugs (comparing medications etc)
- New treatments
- Placebo controlled studies (Placebo definition: Substance having no medicinal properties, dummy/sugar pill)
- Assisted technologies (new technologies being created to help in the home for example)
- General interest in the development of research including
 - Helping with development of new studies
 - Review research paperwork
 - Patient & Public Involvement (PPI)
 - Dementia research forum
 - Steering group to help with development of DeNDRoN (currently don't need member but maybe in future)
- General interest in wanting to be kept up to date with research studies, newsletters etc.

If interested in what DeNDRoN is or for more information then follow up with information such as

"DeNDRoN stands for Dementias & Neurodegenerative Diseases Research Network (DeNDRoN). DeNDRoN is funded by the National Institute for Health Research as part of the Clinical Research Network. DeNDRoN is a UK-wide initiative that aims to improve the speed, quality and integration of research in dementias and neurodegenerative diseases, resulting in improvements in prevention, diagnosis, treatment and care for patients."

Are the happy to be added to the database?

In what capacity – for self referring into research or for general updates etc? **Complete self referral sheet!**

RESOURCES



Development & Implementation of a local communications plan Self referral sheet

Today's date

Ν Is the caller the patient?

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If the caller is the patient please complete part 1 If the caller is the carer of a patient please complete part 2 If the caller is neither a patient nor carer please complete part 3

Part 1 - Patient Information

Patient name:
Patient address:
Contact telephone number:
Date of Birth:
lospital:
Consultants Name (If Known)
Diagnosis and date of diagnosis if known
Nemory Assessment Service
SP Contact details:

Area of interest in research:	

Are they willing to be added onto the database?

Υ	Ν

Part 2 – Information from caller if they are a carer

Establish relationship to patient:
Callers Name:
Callers Address:
Contact telephone number:
Contact email address:
Area of interest in research:
Are they willing to be added onto the database? Y N

Part 3 – Information from caller if they are neither a carer or patient

Callers Name:	
Callers Address:	
Contact telephone number:	
Contact email address:	
Area of interest in research (E.g. would they be interested in being a control or would they like to be sent the newsletter etc)	

Are they willing to be added onto the database?	Y	Ν