

SW DeNDRoN

Integrating Networks & Embedding Research in Clinical Practice (INTERACT)

SW2 End of Project Report Appendices

Part 1 Stakeholder engagement, tips and survey

Project Title:	Embedding research consultation
Date:	Nov 2012
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LRN Region:	South West LRN
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Survey Monkey results (47 responses)

Question 1. How would you like to find out about opportunities for being involved in research?

Support groups, hospital consultants, GPs, nurses and newsletters were the most popular choices. This provides some really useful guidance for SW DeNDRoN who will renew their efforts to work closely with these groups and professionals in order to provide opportunities for research participation to as many people as possible.

Question 2. What would encourage you to be involved in research?

The most common motivation for being involved in research was the opportunity to increase knowledge, closely followed by personal reasons such as doing something positive in a negative situation. These and other insights will be helpful for our staff as they try to approach the topic of research in the most sensitive and appropriate manner.

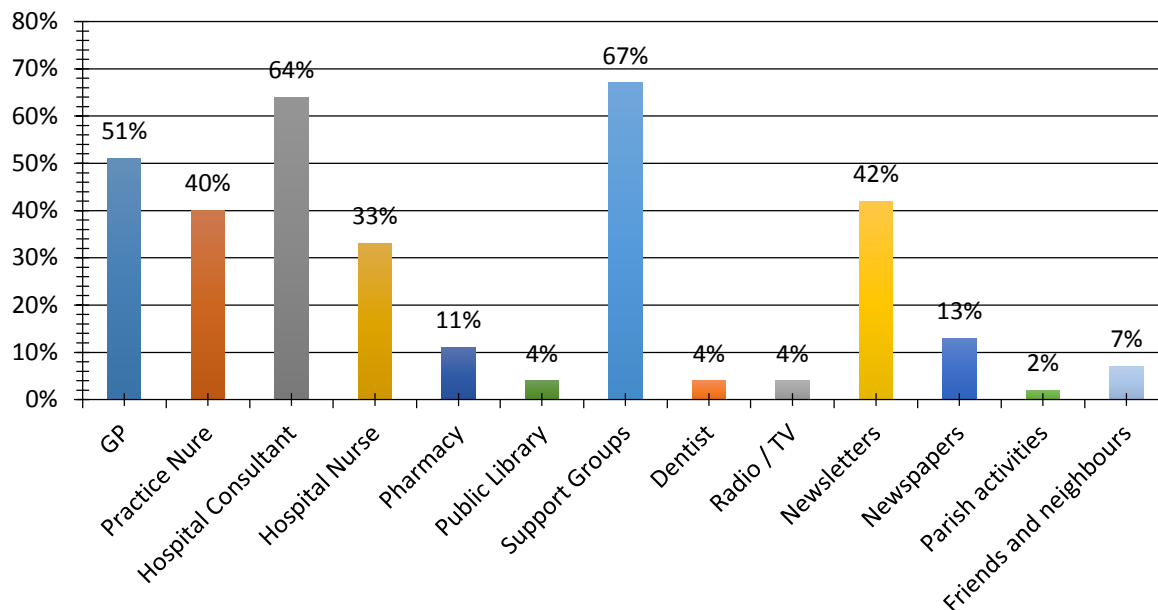
Question 3. When would you be comfortable to start discussing with a health professional opportunities for being involved in research?

Most people responded to this question with answers such as 'anytime' and 'as soon as possible'. This provides a very useful insight into the views of patients and carers about the most appropriate time to talk about research. Although diagnosis is often an understandably distressing and overwhelming time, it is also often an important time to discuss research opportunities. For example, novel medication trials often require that the patient has not yet begun a different form of pharmacological treatment. The responses to this question show that the majority of people would welcome, and understand the importance of, early discussions about research opportunities. However, some responses did touch on the sensitivity required at the time of diagnosis, and SW DeNDRoN will continue to be mindful of this in these initial discussions.

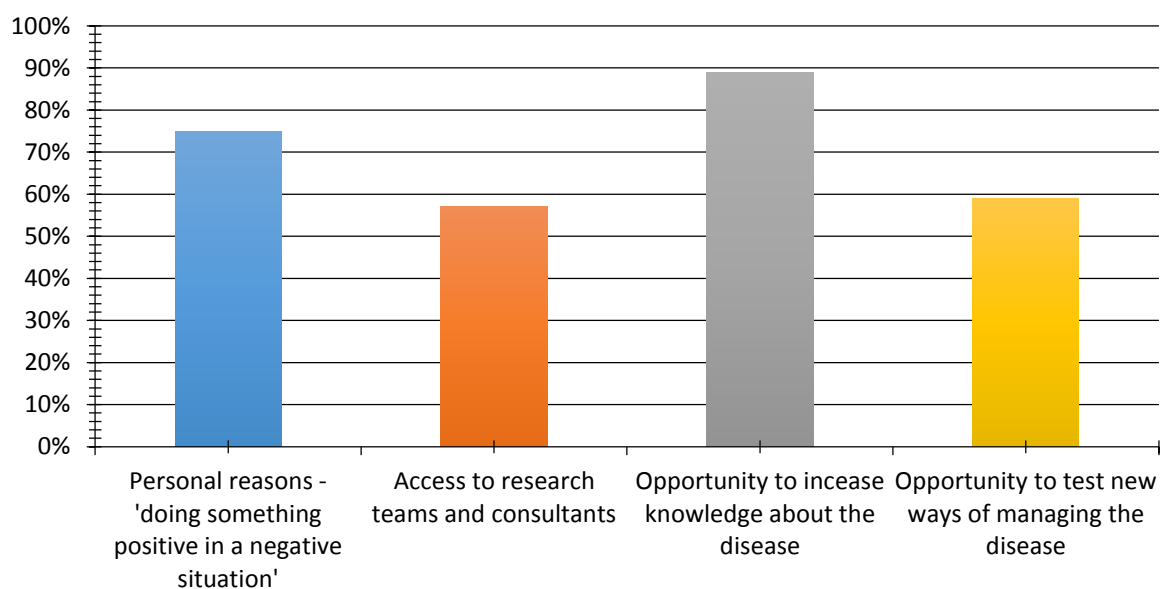
Question 4. What information would be interesting in a research newsletter for patients and families?

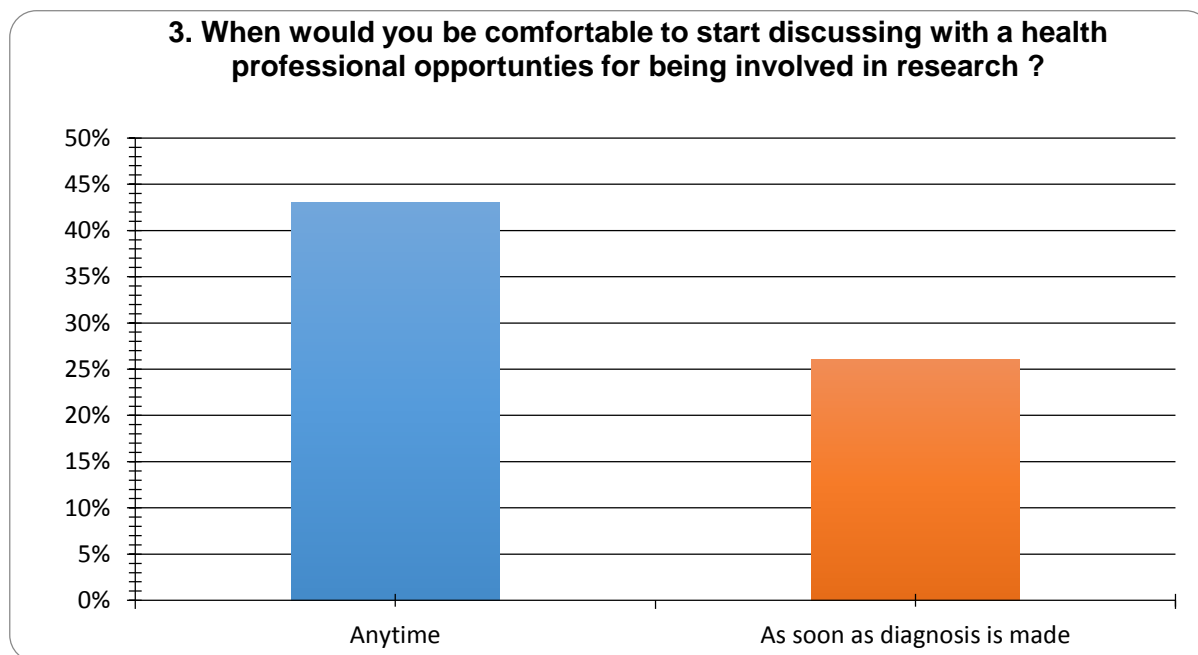
There were a number of suggestions for content in future newsletters which were grouped together into three categories: clinical and research information, support and advice, and communication. These ideas will be used to inform our next and future editions of the South West DeNDRoN newsletter.

1. How do you like to find out about opportunities for being involved in research ?



2. What would encourage you to be involved in research ?





Clinical and research info:

- Progress in treatments
- Latest medications
- Details of new and existing research programme e.g. Parkinson's Society magazines
- Opportunities to participate in treatment research
- What research is about, and its aims and goals
- Information on how the diseases might progress
- Results of research with how these are, or will be, implemented, include contact details. How results are relevant and will be of practical use
- Research info or survey from a patient's perspective comparing when the illness was diagnosed to when the patient felt the illness started.
- Case studies
- Benchmarking data with other regions on projects, funding streams, local recruitment, outcomes of research
- Subject of research, funding, ethical issues, confidentiality, aims, numbers involved, length of research

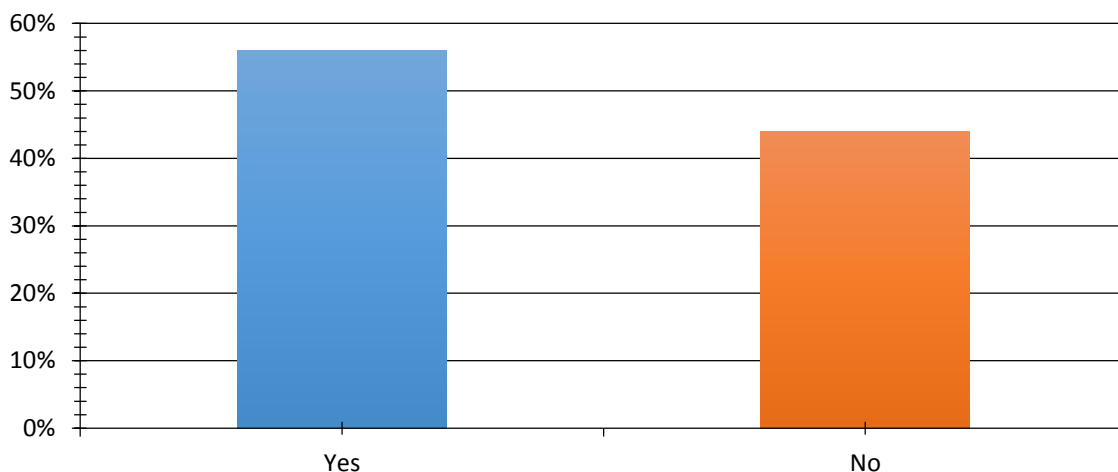
Support:

- Advice on coping strategies as the diseases progress
- Advice on care options
- Suggestions for making day to day life more interesting and comfortable for elderly patients with dementia or neurological conditions
- Local people - professionals groups etc involved in research
- Help for carers

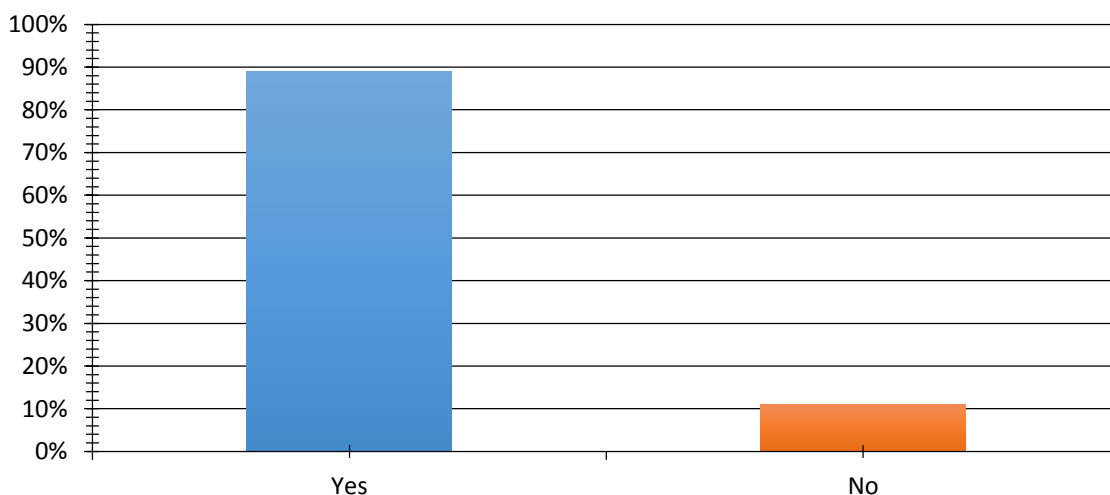
Communication:

- Researchers need to use language the readers understand, and communicate frequently
- Honest facts

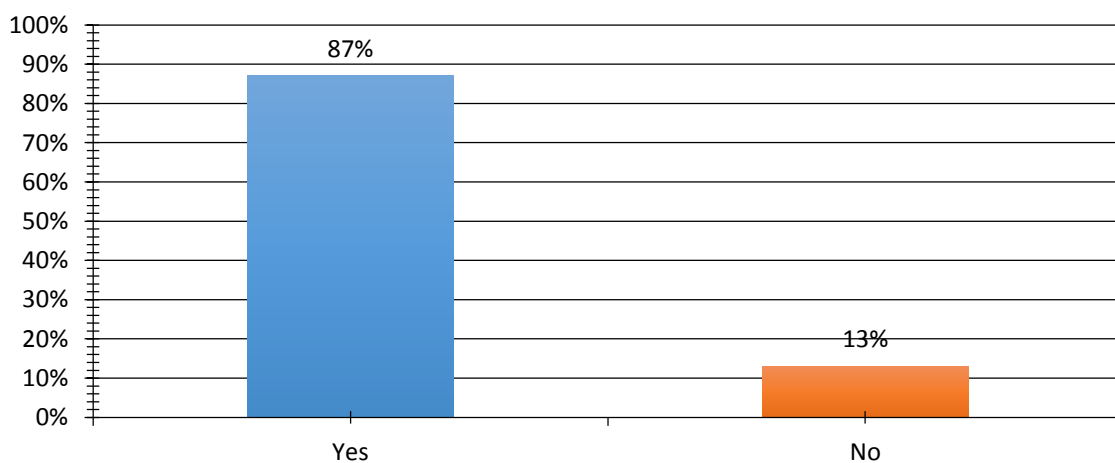
5. I am interested in joining your Patient Advisory Panel



6. I would like to receive your newsletter



7. I would like to know how to become involved in a research study



Stakeholders engaged

SW DeNDRoN PPI rep (south Gloucester)
SW DeNDRoN PPI rep and carer (Devon)
SW DeNDRoN LRN manager
DeNDRoN Clinical Studies officer (south region - Plymouth)
DeNDRoN Clinical Studies Officer (north region - Bath)
Research manager
PD research director (Plymouth)
PD research director (Bristol)
Dementia research director
MND research director
HD research director
SW PPI Forum
Primary Care Research Network
Diabetes Research Network
R&D director at Avon and Wilts MH Trust
University of West of England
Area manager, Alzheimer's UK SW
Alzheimer's Society (Bristol)
Alzheimer's Society (Exeter)
Locality Manager Devon, Cornwall and Isles of Scilly
SW Dementia Partnership, NHS South West
MND Association (West and north)
SWANO (SW Alliance of Neuro Organisations)
MND Care co-ordinator
Regional Manager, Parkinson's UK SWANO
Research Interest Group for Parkinson's (Taunton)
Parkinson's Supranuclear Palsy Association
Parkinson's UK Nurse specialist, North Devon Hospital
Senior research nurse at Frenchay, Movt Disorders
Parkinson's UK co-ordinator
SW Regional Manager and local branches
Parkinson's UK
Parkinson's UK Mid Cornwall Branch secretary
Huntington's Disease Association (Bristol)
Memory Café project (Cornwall)
Dementia advisor (Bristol). Based in GP practices
Dementia advisor (Somerset)
Research Nurse (Taunton)
Clinical Studies Officer (Bristol, Western)
PD research nurses (Barnstaple)
Research practitioner (RD & E)
Peninsula Patient Involvement Group (PenPIG)
PenCLAHRC

Top tips to maximise response rates

- Provide an incentive to complete the questionnaire
- Follow up within 2 weeks
- Let people know a questionnaire is coming. Potential respondents should be made aware of the importance of the imminent survey through media, post, staff newsletters or other means.
- Keep the covering letter simple. Write in plain English and use only to explain the purpose of the survey and assure the target population of their confidentiality. Personalise the letter by sending it to specific individuals where possible.
- Ensure you include a pre-paid pre-addressed envelope that is the correct size for the questionnaire.
- Ensure you have translated copies of the questionnaire for the most commonly used languages amongst your target population.
- Set up a telephone helpline for respondents to contact. Provide a named contact if possible
- Arrange for reminder letters or postcards or phone calls to non-respondents.
- The design and appearance of the questionnaire is of critical importance. Make sure the wording is clear and formulated in such a way as to engage the respondent

Ref: various web survey websites

Measuring Success against the Delivery Plan

Objective	Actions	Measure of success
<p>1. Establish baseline measures and produce high-level delivery plan.</p>	<p>Engage LRN team and key PPI stakeholders in developing the delivery plan</p> <p>To conduct a data analysis and consultation to establish geographical scope of project (see note 1)</p> <p>Review any other PPI projects by the NHS /NIHR with a view to working in partnership and optimizing resources including making links to appropriate PPI websites (see note 3)</p> <p>Identify stakeholders/ focus group in selected regions (see note 2)</p> <p>To agree baseline measures (see note 1)</p> <p>Review best practice at Merseyside and Newcastle</p>	<p>Delivery plan signed off by LRN lead. Achieved</p> <p>Baseline measures agreed, obtainable and sourced. Achieved</p>
<p>2. Agree all 'activities' to support engagement e.g. Survey, workshops, focus groups, talks, 1-2-1 meetings</p>	<p>Establish a calendar of current PPI activities and events during May – Sep. Ask DeNDRoN staff and charities.</p> <p>Agree a process that is compliant with info governance to send patient info from consultation project to established local consent lists</p> <p>Take the opportunity to link with DeNDRoN's RAFT project (Recruitment And Feasibility Tools)</p>	<p>Achieved</p> <p>Achieved</p> <p>Partially achieved. Patients willing to be involved are signposted to trust held databases</p>

	<p>Develop DeNDRoN material for agreed activities</p> <p>Test material in selected regions</p> <p>a. Posters, publications</p> <p>b. Focus groups</p> <p>c. Targeted surveys</p> <p>d. Passive website info and feedback</p> <p>If possible use local media too, e.g. radio, newspaper</p> <p>Conduct an evaluation on effectiveness of the agreed activities applied in different regions to patients with different diseases</p>	<p>Achieved</p>
3. Agree questions for consultation	<p>Literature review of existing PPI questions</p> <p>Test questions with service users</p>	<p>Signed off by local comms teams and DeNDRoN comms</p> <p>Achieved</p> <p>Tested with service users</p> <p>Achieved</p>
4. Undertake engagement	<p>Test engagement and refine</p> <p>Ask service users preferred level of involvement:</p> <ul style="list-style-type: none"> - Newsletter - Advisory panel - Consent list 	<p>Gain input from over 200 people, distributed across the region and the disease areas</p> <p>Increased patient engagement in</p> <ul style="list-style-type: none"> - Newsletters - Advisory panel - Consent list <p>Achieved</p>

	Ensure robust information governance around patient information storage	
5. Complete final project report, measurement of success, case studies and report on feedback from sessions		Report completed on time Achieved
6. Establish PPI / 3 rd sector advisory board for long-term support / agree on individuals support for work (what can they do to help)	Develop TORs and governance for Patient Advisory Panel	Sustainable and effective PPI advisory group established Achieved, early evaluation during Nov and Dec 12 to check sustainability
7. Identify future actions/ possible projects resulting from consultation	Engage with MHRN and PCRN	Submission of recommendation for future actions / projects to SW LRN and DeNDRoN CC Partially achieved