

Improving web-based information on DeNDRoN research - Communications strategy

Background & context

There are a wide selection of websites currently providing information on living with and managing dementia and other neurodegenerative diseases, however very few of these sites provide any information or links to information on research and opportunities for involvement in research (except for those that are dedicated to the provision of research information).

This project aims to remedy this problem and increase the 'research' focussed information published on the top disease focussed web-based information sources, to make information available and raise awareness of dementia and neurodegenerative disease research.

Communication Objectives

The objective is to make information available and raise awareness of research and opportunities for research in dementia and other neurodegenerative diseases.

A number of organisations have been identified for each disease and it is planned that they will work in partnership with DeNDRoN to include differing levels of information on their websites (see *Approach*).

Success will be measured against how many of these organisations positively engage with the project. It is hoped that 80% of the organisations identified will become involved by July 2012.

Target audience

The target audience for this project can be divided in to two different groups:

1. Patients, carers and wider family (public), health and care professionals (both NHS and private organisations)
2. Researchers and healthcare professionals

Patients, carers and wider family, health and care professionals

This target group is by far the larger of the two. The internet has become a very widely used information resource and is often the first port of call for information. As many people are affected in some way by these diseases, it is believed that internet searches provide this group with a good source of knowledge, from very basic to extremely detailed.

Researchers and healthcare professionals

This target group refer to the interest to gain information on the latest research, or arrangements for the provision of care, in particular 3rd sector organisations or outputs for research studies.

Stakeholders

Stakeholders are defined as anyone who is, or can be, affected by the project.



For this strategy, stakeholders are identified as:

- those with the diseases and their families
- anyone who cares for the above (professional and non-professional)
- researchers and health professionals
- organisations which provide information on these diseases (identified in table 1 below - broken down into the four disease areas)
- DeNDRoN Projects Manager
- DeNDRoN's Communications Manager
- INTERACT Project Board.

Table 1

| | Dementia | Huntington's Disease | Parkinson's Disease | Motor Neurone Disease |
|----|-------------------------------------|----------------------------------|-----------------------------|----------------------------|
| 1 | Dementia UK | Huntington's Disease Association | Parkinson's UK | MND Association |
| 2 | Alzheimer's Research UK | HDBuzz | NHS Choices - Carers Direct | NHS Choices |
| 3 | Alzheimer's Society | Brain Research Trust | Age UK | Boots WebMD |
| 4 | RD Psychology | BBC | NHS Choices | Brain Research Trust |
| 5 | Dementiaweb.org.uk | NHS Choices | Boots WebMD | BBC |
| 6 | The Princess Royal Trust for Carers | Boots WebMD | Brain Research Trust | Brain and Spine Foundation |
| 7 | Age UK | | Patient.co.uk | |
| 8 | Joseph Rowntree Association | | Net Doctor | |
| 9 | NHS Choices - Carers Direct | | | |
| 10 | NHS Choices | | | |
| 11 | Boots WebMD | | | |

These organisations have been identified through conducting the same three searches in Google, for each of the four diseases:

- "Information on (disease)"
- "Living with someone with (disease)"
- "Caring for someone with (disease)"

On posing these searches, the most frequently returned websites were identified. All of the above contain a good level of general information about each of the diseases. Some also contain differing levels of information on research and opportunities for involvement, but most do not refer to research at all.

Key messages



The key message of for this strategy is to raise patient, public and professional awareness of research/research opportunities and DeNDRoN by providing simple, easy to understand information:

- Research – what it is, why is it done, who supports it (government, policy etc), NIHR Portfolio
- Involvement – benefits of involvement, expressions of interest (while managing expectations), UK Clinical Trials Gateway
- DeNDRoN – promoting the network to researchers and public

Information will be tailored to the individual organisation and their target audience.

Approach (activities)

The stakeholder plan will identify how ‘first contact’ will be made. This will be through one of the following approaches:

1. via the Assistant Director of DeNDRoN.
2. via the communications team.
3. from the project board.

The letter / email / phone call will be used to outline the aims and objectives of the project and how DeNDRoN wish to work collaboratively with them. Information will be provided on actions they need to take if they want to become involved or would like further information.

Follow up communications will be made via the DeNDRoN Communications Manager where links are already established, or Project Manager where there are no existing links.

Prior to initial contact, consideration will be given to each individual organisation in terms of what level of involvement they may wish to have and should be offered. For example, a large charity may wish to include more information than an ‘information only’ site and as such, different options will be presented to them.

Two options will initially be available:

Level 1 – minimum involvement

This will simply be a link from the participating organisations’ websites to a specifically created page on the DeNDRoN website. The DeNDRoN page will contain information on:

- Research – what it is, underpinned by government policy, etc
- Involvement – an expression of interest leaflet, links to UK Clinical Trials Gateway site, link to the National Dementia Strategy and other policies (where appropriate), link to the ‘Research People’ page on the NIHR CRN CC website (videos of people involved in research), link to patientsclinicaltrials.com – a patient’s perspective on clinical trials (*as this is sponsored by Roche I wasn’t sure whether this was appropriate but it does have something to do with Simon Denegri*)
- Links to other parts of the DeNDRoN site which may be of interest (to be identified)



Level 2 – full involvement

Rather than a simple link to DeNDRoN, this will be a new page / section on the organisations’ website. A package will be developed which will include:

- Research – what it is, underpinned by government policy, examples of studies, etc
- Involvement – an expression of interest leaflet, links to UK Clinical Trials Gateway site, case studies, +++
- Link to the National Dementia Strategy and other policies (where appropriate)
- Link to the ‘Research People’ page on the NIHR CRN CC website (videos of people involved in research)
- Link to patientsclinicaltrials.com – a patient’s perspective on clinical trials (*as this is sponsored by Roche I wasn’t sure whether this was appropriate but it does have something to do with Simon Denegri*)
- Link to the DeNDRoN site
- Images

Organisations will have the option to tailor the information provided for Level 2 involvement to fit in with their own corporate branding. To ensure information remains factually accurate and for consistency of message across all organisations participating at this level, they will be required to seek formal approval of how they use the information by the DeNDRoN Communications Manager, prior to publishing the information on their website.

Risks/challenges

The aim of the project is to raise patient, public and professionals’ awareness of research/research involvement opportunities and DeNDRoN. The main challenge is to engage as many of the identified organisations as possible, by pitching the first approach appropriately.

There is a risk that the majority of the organisations will not wish to be involved, or only opt for Level 1. Although this is achieving part of the aim of the project, it is likely that this will not lead to an increase in knowledge of research and opportunities for involvement as widely as Level 2 involvement would.

Key dates

Key dates for the project are identified in table 2 below.

Table 2

| Ref. | Deliverable | Date |
|-------|--|------------------|
| IN1.4 | Develop content options | Feb – April 2012 |
| IN1.6 | Establish communications with identified sites | April 2012 |
| IN1.7 | Commence implementation of options | May – July 2012 |
| IN1.8 | Final report and evaluation | July 2012 |
| IN1.9 | Different options packaged for use by further identified organisations | July 2012 |

Evaluation

Success measures identified for the project are:

- Participation of 80% of organisations identified
- Increase in the number of referrals (relating to the project) to registers (RAFT)



- Increase in the number of page views over all (DeNDRoN) and site views (organisation)
- Agreement for routing support for studies/research involvement from organisations
- Return of expression of interest leaflets

A report will be provided to the INTERACT Project Board, reviewing project objectives, detailing activities taken, identifying successes, reviewing risks and issues, lessons learnt and next steps.

Action plan

Key actions for the project is identified in table 3 below. A more detailed plan is available in Microsoft Project.

Table 3

| Action | Responsible |
|--|--------------|
| Develop content options | AM / NC / PG |
| Produce initial contact communications | AM / NC |
| Establish communications with identified sites | PK |
| Follow up communications with identified sites | AM / NC |
| Commence implementation of options | AM / NC / PG |
| Final report and evaluation | AM |
| Different options packaged for use by further identified organisations | AM |

