

## PROJECT BRIEF

**Project name** Improving web based information on DeNDRoN research

**Release** FINAL – 13<sup>th</sup> February 2012

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<b>National Project Board Champion:</b>	N/A
<b>Accountable Body:</b>	DeNDRoN Programme Office

### Executive Summary

The internet is increasingly used as the primary source of information for people who have dementia and neurodegenerative disease, their carers / wider family and health / care professionals.

There are a wide selection of websites currently providing information on living with and managing these diseases. However, very few of these sites (including the most visited) provide any information or links to information on research and opportunities for involvement in research. Even a dedicated search for 'Participating in Dementia Research' will not easily direct the user to simple information on how to get involved.

This project aims to remedy this problem, and utilise the existing top web-based information sources to make information available and raise awareness of dementia and neurodegenerative disease research. This will be achieved through engaging with the hosts of those sites and working with them to provide simple easy to understand information providing on research opportunities and DeNDRoN.

In the first instance the project will focus on the top 10 most visited sites for dementia, motor neuron disease, Huntington's disease and Parkinson's disease, in England (a total of 40 sites). Utilising and building on existing strong relationships where possible, and using available content to raise patient, public and professionals awareness.

This project will take place between February 2012 and July 2012.

### Revision History

Revision date	Author	Summary of Changes	New Version
09/02/12	Alex Moores	Produce first draft	0.1
13/12/12	Adam Smith	Minor edits	0.2

## Project Definition

### Objectives

The overall objective of this project is increase general awareness of the opportunities to support and participate in clinical research. This will be achieved through working with, and partnering the most-used disease specific 'information source' websites to publish content on research opportunities, sign-posting patients, public and health/case workers to DeNDRoN.

### Scope / Exclusions

- The scope will initially extend to the top 10 most visited websites for dementia, motor neurone disease, Huntington's disease and Parkinson's disease in England. Consideration will be given to rolling out further if project is successful.
- The project will work in partnership with identified organisations to encourage the inclusion of research information on their websites and to link back to the DeNDRoN website.
- The project will oversee develop of 'standard' content which can be provided in a finished or developmental state.
- The project will commence in February 2012.

### Project Deliverables

DELIVERABLES		TIMESCALE
IN1.1	Where possible establish base-line measures and complete delivery plan	Feb 2012
IN1.2	Evaluate and identify sites	Feb 2012
IN1.3	Develop communications approach (detailing engagement plan for each identified site)	Feb - Mar 2012
IN1.4	Develop content options	Feb - Apr 2012
IN1.5	Establish process/procedure for management of outputs, eg returned expression of interest forms	Apr 2012
IN1.6	Establish communications with identified sites	Apr 2012
IN1.7	Implement options	May – Jul 2012
IN1.8	Final report and evaluation	Jul 2012
IN1.9	Different options packaged for use by further identified organisations	Jul 2012

## **Governance / reporting requirements:**

1. Establish local governance and project management arrangements.
2. Provide monthly highlight report to national project board (1<sup>st</sup> of each month)
3. Maintain a project risk register using <https://portal.nihr.ac.uk/sites/dendron/dp>
4. Participate in meetings
5. Provide ah-hoc reports and updates as required.

## **Interfaces**

- Dementia, motor neuron disease, Huntington's Disease and Parkinson's Disease organisations in England
- DeNDRoN Communications Team
- DeNDRoN LRNs and Hubs
- INTERACT Projects EA1 and SC2
- Content authors
- INTERACT Project Board
- INTERACT Project Manager

## **Success Measures**

- Participation of 80% of organisations identified.
- Increase in the number of referrals (relating to the project) to registers (RAFT).
- Increase page views per site/overall.
- Increase hits to DeNDRoN project specific page from external websites.
- Agreement for routine support for studies/research involvement from organisations.