Website Overview Briefing

Organization –   **North East DeNDRoN**
Current web address – http://www.northeastdendron.org.uk/

We are an NHS organisation that promotes, recruits to, and carries out research in dementia and neurodegenerative diseases including Parkinson's, Huntington's disease, motor neuron disease, Progressive Supranuclear Palsy, corticobasal degeneration and multiple system atrophy. Our bottom line is numbers of patients recruited to clinical studies.

As important is the promotion of research in the NHS. We need to increase the research activity of clinicians and health professionals; increase the number of research studies; extend research opportunities across the North East: have different types of research including commercial studies in all the diseases we investigate; and involve patients and carers in what we do and how we do it.
We run a Patient List of people with a diagnosis of dementia of any kind, or Parkinson's disease, or progressive supranuclear palsy or multiple system atrophy (patients with Huntington's disease or motor neurone disease can register interest in participating in research through their relevant medical charity websites).

We have a list of control volunteers too, older people without a diagnosis of the diseases we are researching.

We have a Patient, Carer and Public Involvement Panel

We need a website through which patients can put themselves forward to join the Patient List so they can be invited to join clinical studies suitable for them. It needs to be simple to use.

The website should describe the current studies, and be useful for doctors too. Links from the simple study descriptions to the UK Clinical Research Network Study Portfolio entry for each study.

Newsletters, the study adoption form and similar documents to be downloadable pdf. A page describing the team members to be included. An area of the site summarising the outcomes of previous studies to be added later

Site to include links to relevant organisations – and importantly reciprocal links on theirs e.g. Alzheimer's Society, Parkinson's UK, PSP Association, Motor Neurone Disease Association, Huntington's Disease Association, Multiple System Atrophy trust, LINk's (Healthwatch), Mental Health North East, North East Neurosciences network, Age UK, Elders Council, U3A, DeNDRoN national public site, Other DeNDRoN local areas, Alzheimer's Research UK, relevant University research groups

Main Contacts -

Dr Margaret Piggott (Data and Communications Manager)
Dr Daniel Herron (Local Research Network Manager)

Final Approval - Dr Robert Barber (Clinical Director)

Project to start immediately and be completed by March for end of year budget deadline. Also current site host subscription due 1st February 2012

Current website

http://www.northeastdendron.org.uk/ is out of date (new site must be easily updatable) Hosting is by US company – needs to be UK based. Amateur design and execution. Extremely cumbersome updating mechanism meant the job got postponed until whole site out of date. Faults arose because too big a job to be tacked onto other job roles which were already full, underestimate of expertise required.

Don't know usefulness as no interaction with site and no visitor counter. Need site to allow patients to contact us.

However site is simple, no distracting elements at sides, large font, uncluttered, clear areas useful for patients and clinicians, brief understandable descriptions of research studies, links to UKCRN portfolio entry for studies for in-depth info for studies

Objectives for website

▪ Motivate patients to register their interest in joining the Patient List
▪ Increase clinicians' interest in carrying out research

'Increase customer satisfaction' 'reduce time spent searching for information' make information about us and the research studies easily findable

Specific Success Measures

1. The NE DeNDRoN website having a user-friendly mechanism for patients to self-refer to the Patient List (supported by views in patient survey).

2. 20+ patients using the website to initiate the process of signing up to the Patient List post implementation – in a two month period.

3. Number of site visitors increases by 100% (but we don't have a visitor counter currently).

4. We propose to examine recruitment to a particular clinical study in Parkinson's disease (PRoBaND) using the website as a pilot study running between June and December 2012 with a view to extend this mechanism to other regions of the country – measure how many patients ask for more information and / or express an interest in joining this study.

We will seek feedback from users.

Target audience

1. Patients with dementia, Parkinson's' disease, other neurodegenerative diseases

who may be web-naïve, wary users, older, with some visual impairment (probably age-associated) – alternatively some are very sophisticated web users. All these people may be looking to see what research is going on altogether, and specifically looking for what research projects they could join. Relatives and Carers may also be looking for what research studies we can offer them and their relative.

2. People looking to express interest in joining Patient List or control volunteers list, or get involved in other ways.

3. Clinicians and other health professionals, who may be quite experienced web users (or surprisingly inexperienced) who require to find information about clinical studies, study development and what services we can offer them, quickly; also to download the current study adoption form.

DeNDRoN is perceived as –

- For those that know, as a unique organization for dementia, Parkinson's disease and neurodegenerative disease research in the NHS, instrumental in recruiting 1,979 research participants to in the North East in 2010 - 2011.
- For clinicians who carry out research with our help, seen as a vital element ensuring successful recruitment and completion of research.
- To our Patient, Carers and Public Involvement Panel as the only research organization in the NHS for their diseases.
- For medical charity branches and patient organizations, as a group enthusiastically championing research.

While growing, our research portfolio has a long way to go (grow). We are not well enough known.

There will also be people with a more negative view – perhaps because it is not our job to develop research grant applications, just to ensure the success of those that are funded and adopted by the NHS National institutes for Health Research

We want people to use the site

For patients and carers - To see what research is going on all over the region. To express interest in research in general. To notify us of their interest in joining the Patient List.

For clinicians – to see what research is going on and where and who is the Principal Investigator, and which ones they can refer their patients into. To see what support DeNDRoN can give them for research study development and executing research

For our Patient Carers and Public Involvement Panel, quick guide to what we are doing at any time

Site to have

ease of use, comprehensive information at appropriate level
Bring together all the NHS research in dementias and neurodegenerative diseases in

the North East

Site to allow people to let us know if they are interested in finding out more about any of the research studies, joining the Patient List, becoming a control volunteer, joining a particular research study, to know more about the Patient Carer and Public Involvement panel

Site to be

Clear, easy, non-distracting, simple, informative, responsive, not intimidating, accurate, up to date, not patronizing, helpful, searchable, comprehensive, inclusive,

Other sites from organizations we interact with -

http://www.parkinsons.org.uk/default.aspx

easy to navigate site, the 'model' we want to follow

http://www.alzheimers.org.uk/site/

clear searchable site with a lot of information for different users – however many NHS organizations do not allow social network sites at all including ours, and this site has youtube etc .

http://www.ntw.nhs.uk/

this is our host NHS Trust website, difficult to navigate, obscure terminology, unattractive, using search tool gives poor results. Our NHS Trust (Northumberland Tyne and Wear NHS Foundation Trust) still only has internet explorer 6, and quite a few of our target clinicians are in this Trust.