



Striving to be Heard above the Noise

Improving web based information on
DeNDRoN research

Project Description

We are constantly being bombarded by information about our health and our lifestyles and more and more people are now turning to the internet as a tool for self-diagnosing. However, with so many online resources available it is often difficult to navigate a way through the multitude of sites to find information that is both accurate and consistent. The Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) launched a project to investigate where patients or carers for people with dementias or other neurodegenerative diseases turn to for help. Establishing a list of the top ten sites for each of the disease areas that the network supports, the project team approached each of these sites to offer them information about research and information for their visitors about getting involved in research. By giving them access to this, the team hoped to drive traffic to the DeNDRoN website and to encourage active sign up to the network's 'consent for contact' patient register using sites that were already the patients' favourites.



PARTNERSHIP



CASE STUDY

In today's media-friendly society, it is vital for any new enterprise or organisation to have a credible digital presence. However, with new websites mushrooming on a daily basis, it is often difficult to get your voice heard above the growing noise of other sources of information available on the internet. For the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN), this issue is particularly acute given the broad range of diseases and conditions that it supports.

Impact of the Project

Many of the sites that DeNDRoN approached were receptive to information and although, in some instances, it took several approaches in order to achieve any traction, some have been very enthusiastic about this collaboration.

Tim Parry, Head of Communications and Public Affairs with Alzheimer's Research UK is one such advocate. "The Prime Minister's Challenge on Dementia very clearly sets out a renewed national ambition to give people with dementia, their carers and their families the services and support that they need. And one of the best ways to do this is through research as it is only through research that we find new treatments, new ways to diagnose dementias and new care pathways. As an organisation, we are working with DeNDRoN to promote dementia research and the importance of public involvement to help meet the Prime Minister's key commitment of offering people the opportunity to participate. People with dementia and the general public want to get involved with research, and they can make a significant contribution to progress, so we need to make it easy for them to get on board."

Given peoples' growing curiosity about their health and about advances in science and medicine which frequently feature in our morning newspapers, it is perhaps surprising that relatively few websites provide significant information or links to information on research and opportunities for involvement in research. This is even more acute when working with DeNDRoN diseases, none of which have a cure or effective, long-term treatments. DeNDRoN established a project to remedy this situation. The goal was to increase the research focused information published on the top disease centred web-based resources by making information available to them in order to raise awareness about dementia and neurodegenerative diseases research.

Project Design and Implementation

First, DeNDRoN had to establish the baseline data on the breadth and depth of research information currently available. Natasha Carrick, Communications Manager for DeNDRoN, explains. "Before this project started, I went on a Search Engine Optimisation (SEO) course. SEO really helps to promote the visibility of a website by identifying the main search terms that drive people to it. For us, this meant that we could then run the project based on the actual keywords that patients and carers use when searching for information."

The DeNDRoN team identified the main websites recognised by a simple Google search of the following keywords:

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

For each of the disease areas – dementia, Parkinson's, motor neurone disease and Huntington's disease – the team systematically gathered information on each site that was identified and logged the top ten.

As expected, the charities that offer support and information to people with the given disease came out very highly on these lists but the team were surprised at some of the other sources that patients and carers are frequently accessing. Natasha Carrick continues "We found that sites like NHS Choices, the BBC and BootsWebMD, the site run by the high street chemist, also featured very highly."

Having identified the websites most frequently accessed using these search terms, the team then invested some time in looking at the research information that was available on each of these sites.

With the obvious exceptions of the sites dedicated to the provision of research information, the team soon discovered that very few of the sites identified provided any information or links to information on research and opportunities for involvement in research.

Adam Smith, programme manager with DeNDRoN, explains the next stage of the project "We assessed what research information already existed on these sites, what we would like to be there, and if we already had any contacts with the hosts – making a plan for how and who would approach each. This allowed us to involve our directors and the wider team, and using a variety of communication methods."

Level 1 identifies minimum involvement such as a link from the participating organisation's website to a specifically created page on the DeNDRoN website which housed top level information on research and research involvement with links to other parts of the DeNDRoN site which may be of interest.

Level 2 identifies full involvement on a very different scale, where we would provide specific research content for the site to feature or collaborate on dedicated new information on research relevant to the audience e.g. How to become involved in a specific region, what being in research might mean.

Alex Moores, the project lead explains the measures of success. "The most important measure of success was to engage with as many of the organisations that our research had identified and to get active participation from 80% of them. We wanted to increase the number of overall page views per site and, in particular, increase the number of hits to DeNDRoN project specific pages from external websites. The icing on the cake was to see if we could catalyse a significant increase in the number of referrals to the network's 'consent for contact' patient register and get the DeNDRoN site to rank as number one with Google."

Challenges and Learning Points

The aim of the project was to raise awareness of research, research involvement opportunities and, of course, DeNDRoN. The main challenge was to engage with as many of the identified organisations as possible, by ensuring that the 'offer' was appropriately tailored.

"The initial response to our contact was really quite poor" says Alex Moores. 'But it's possible that these sites are receiving a lot of requests from external organisations and that our request got lost in the noise. It's also possible that the letters and emails that we sent were perhaps not personal enough and tailored sufficiently to each organisation that we were approaching. However those organisations that did respond were very enthusiastic and particularly keen to be seen as delivering for dementia as a national priority. As a result of the project DeNDRoN has established much stronger working relationships with all five of the big charities and has begun work to tailor communication materials for specific groups."

The most impressive outcome lies in the statistics. To coincide with this project, the new DeNDRoN website was launched in July 2012. In the first 2.5 weeks alone the site received 3,000 hits due to promotion via the network's new charity partners, newsletter, articles, and, of course, the enhanced SEO. Since the launch, there have been over 25,200 visits, of these; almost 15,000 have been unique visitors to the site. In direct comparison visitors from the previous year stood at just 5,500.

The screenshot shows the DeNDRoN website interface. At the top right, there is a search bar with the text "National Health Service" partially visible. Below the search bar is a navigation menu with tabs: "Discover DeNDRoN", "Researchers", "Patients and Carers", "Industry Partners", and "Health". The "Discover DeNDRoN" tab is active. Below the navigation menu, there is a large green circular logo with the word "DEMENTIA" inside. To the right of the logo, there is a call to action: "Help change the future of your disease. Take part in research." with a "Click Here" button. On the right side of the page, there is a map of the United Kingdom and a list of search options: "Find Your Local Network", "Search for Studies", "Dementia Research", "Huntington's Research", "Motor Neuron Research", "Parkinson's Research", and "Other Neurodegenerative Diseases".

PATIENTS IN RESEARCH

Tips

- Dedicate time and resource to investigating the main sources of disease-specific information available online and establish what, if any, links are made to involvement in research studies or clinical trials
- Construct a list of the relevant sites and devise a number of communication tools to be used for contact purposes.
- Ensure that appropriate messages are given to these organisations and tailored to the site's main target audience
- Identify key gatekeepers at each organisation and use whoever is most appropriate to make contact, exploiting whatever links you already have



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