

Harnessing the Digital era

Expanding Mechanisms for Self-Referrals



PARTNERSHIP

Project Description

Searching for information online can be fraught with difficulties thanks to the enormous number of websites offering advice and information. One of the main problems is being able to differentiate among the various sites and to find trustworthy sources. The Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) in North East England launched a project to explore the sources of information currently available to people interested in becoming involved in research. Armed with this knowledge, they designed and built a new site in collaboration with their patient and public involvement (PPI) group who gave invaluable input on the content, the style and the user friendliness of the site. The product is now a reputable source of online information for patients and carers of people affected by dementia and neurodegenerative diseases and it has witnessed a significant increase in the number of visitors and unique users to the site. It has also encouraged an upswing in the number of people signing up to the network's Patient List which captures patient details for possible involvement with and recruitment to local studies.

CASE STUDY

With new media leading the explosion in our access to information, it is often both daunting and challenging to find correct, relevant and current information on the internet. Searches for terms like 'dementia research' can lead to millions of sites being identified. So how do people interested in finding out more about research and in volunteering to participate in research studies and clinical trials wade through all of this information and get signposted appropriately?

The local Dementia and Neurodegenerative Diseases Research Network (DeNDRoN) in the North East of England approached this dilemma by refreshing their website completely to become a resource focussing on research going on in the local area. As a website for patients and carers as well as clinicians, researchers and healthcare workers with simple information tailored to each audience and simple forms for people to register interest in becoming involved.

Project Design and Implementation

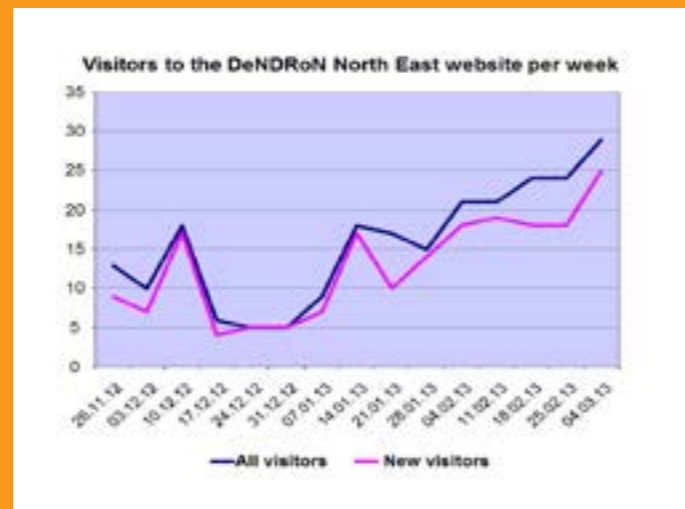
The project was set up to establish a new mechanism for patients to contact DeNDRoN's local research network directly to express their interest in research, and to join a patient list. This list collects names, contact details, and a minimum dataset of clinical information including, for example, the patient's diagnosis and date of diagnosis. With over 560 patients already signed up agreeing to be contacted about opportunities to participate in research, the emphasis was to establish whether a new web-based mechanism for patients to express interest in research was acceptable to the patient population. Moreover, the team wanted to ascertain if this approach could represent a successful strategy to increase recruitment to the patient list.

The project team did their homework first. By searching through relevant sites and investigating the content that these hosts had on research, they were able to work out who was carrying what information, where this data was sourced from and how visitors to these sites were signposted on to other sites and sources of information.

Then, using this knowledge, and in collaboration with Blumilk, a local website design company who have experience of working in the sector, they worked to create a new site. This site was aimed at improving awareness, improving user experience and increasing recruitment to DeNDRoN's patient list. Crucially they also wanted to increase the number of unique visitors to the site.

Ben Saunders from Blumilk explains how the company approached these issues. 'The target audience is predominantly older people and patients. In the design and build of the website, it was essential that we addressed accessibility and usability issues such as screen colours, resolutions, font size, navigation and online forms'. With this in mind, Blumilk developed wire frames to establish intuitive navigation that would be easy to use and presented the network with two unique concepts, each design taking into account accessibility and usability issues.

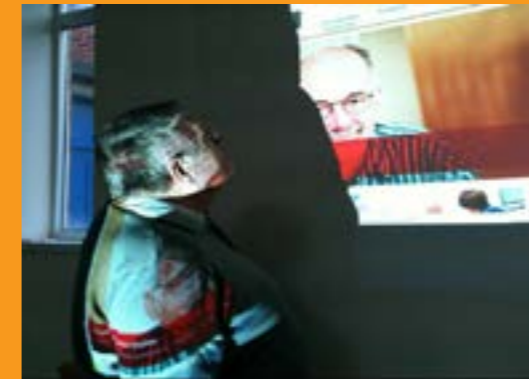
But that was just the beginning of the process. Through working with the well-established Patient and Public Involvement (PPI) group that DeNDRoN facilitates in the North East, the network



was able not just to create a new website but to road test it with the very people it was aimed at.

Val Argent is one of the members of the PPI group. 'I was diagnosed with Parkinson's in 2010 and, when I was approached to become a member of DeNDRoN's PPI group I was a bit concerned that it would be just a talking shop. How wrong I was' she laughs. 'There are so many opportunities for patients and carers to get involved in just about anything. When you get diagnosed with Parkinson's it's a terrific shock. By getting involved like this, it made me feel that I was somehow fighting back a bit'

Like Val, David Gambles, another member of DeNDRoN's PPI group in the North East was also asked to help test the new site for user friendliness. 'A group of us met in the IT training suite at the local Trust and we had the full range of people from those who have set up websites to those who are almost too scared to switch on a computer. We all had a play around on the new site and the design company and the network took on board all of our comments about navigation and content and tweaked it so that now the minimum number of clicks is needed to get through the site'. He adds 'It was a privilege to trial this site and to be involved in this project'.



Dementia cafe visitor having a closer look at the website

Impact of the Project

Post-launch, the website has helped to improve awareness of DeNDRoN and of local research projects; it has increased recruitment to the network's Patient List and has increased the number of visitors to the website.

Whilst the number of people on the Patient List has not yet increased dramatically from web referrals, there have been positive results in other areas, particularly in generating contacts from lay people, and new members for our local PPI group and clinicians interested in research. It is important to note that almost half of the patients on the Patient List have been offered a clinical trial and, notably, the vast majority of those offered study participation have accepted.

With regards to new people visiting the site, the increase is quite impressive. Between December 2012 and March 2013, the numbers of people visiting the site rose by around 120% and by January 2013 over 90% of the visitors were unique users and the average length of time spent browsing was in excess of five minutes.

Going forward, the project team is keen to work with local and national charities to get reciprocal links placed on sites that can drive new traffic to the DeNDRoN site. And important new content in the form of a section on the outcomes from research studies is being added. The PPI group have told us that knowing what happens when a research study finishes is important.

Conclusion

Considering the number of sources that people can get access to online, it is often challenging to create a new website that will drive potential users to it, a website that offers something new and different. The local research network in the North East of England opted to build a site with an experienced website design team and in collaboration with DeNDRoN's PPI group in the area. The unique feature being that it contained real, valuable, local information and delivered what patients asked for. This led to a site that has a high degree of usability and a new valuable resource for both the users and North East DeNDRoN.

Challenges and Learning Points

One of the main learning points gained from the project was the recognition that website design is a complex and challenging task and one that is very time consuming. Dr Margaret Piggott, DeNDRoN's Data and Communications Manager in the area, quickly recognised some of these issues. 'We underestimated how much experience you need in web design to understand the full extent of simple navigation, clear messaging and interesting content. This is particularly pertinent when you consider that some of our audience has dementia or memory problems. Building a site that is accessible to everyone we want to target has its own special set of additional challenges'

Dr Bob Barber, the Director of the local DeNDRoN network, recognises that it is too early to verify how effective this work has been, however early indications are positive 'Revamping the local DeNDRoN website was a great idea and there are national drivers encouraging this sort of website development but the aim of it being able to act as a 'one stop shop' was too premature given its enormous scope, the content that we need and the number of other competing sites out there'

Dr Barbara Wilson, Clinical Trials Officer with DeNDRoN, agrees that keeping the website content new and fresh is a challenge. 'When editing existing web pages and creating new ones, it is important to remember that too much text will just alienate the viewer. You need good, engaging photographs and pictures that aren't simply the stock imagery that populates many similar sites', doing this in a visual way can be a challenge, but our feedback showed that it will help engage users.



Dr Margaret Piggott, NE DeNDRoN's Data & Communications Manager

PATIENTS IN RESEARCH

Tips

- Assess similar websites in the sector looking at everything from usability to the structure and content of any forms or sign-up service that they have online
- Identify an experienced web design company, if there is not sufficient in-house resource to build a site, and work closely with them and site users who can help to shape a site that is fit for purpose
- Ensure that, once a website has been set up, it is constantly and consistently refreshed with new content
- Recognise that writing this new content and sourcing appropriate imagery for a site is resource intensive but vital



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