Impact case study (REF3b)

Institution: University College London

Unit of Assessment: 4 - Psychology, Psychiatry and Neuroscience

Title of case study: Improving reading and visual search in stroke patients

1. Summary of the impact

Research by Dr Alex Leff at the UCL Institute of Neurology in collaboration with UCL Multimedia, has led to the development of two free online therapies for stroke patients with visual deficits. Read-Right (launched June 2010) treats patients with hemianopic alexia (the commonest acquired reading disorder) and Eye-Search (launched September 2012) treats spatial disorientation and visual search impairment. The websites contain: 1) diagnostic tests, 2) therapy, and 3) interval tests. These materials have been developed from peer-reviewed research. The websites are also research tools; patients sign an online consent form and their data are used to test whether online therapy actually works. At 31 July 2013, 657 patients were using Read-Right and 217 Eye-Search.

2. Underpinning research

Dr Leff is a world expert on hemianopia, how this affects reading, and how it can be remediated **[1, 2]**. Initial work demonstrated that patients with hemianopia (a visual field defect), that affected their text reading, could benefit from reading moving text. This was done in the context of a placebo-controlled trial **[3]**.

In that study, the therapy materials (moving text) were recorded onto VCR tapes and posted to participating patients. When it proved successful, there was no clear way to make the therapy available for suitable patients. Leff therefore began a collaboration with the UCL Multimedia team (Maurice Brown, Multimedia Developer and Patrick Robinson, Multimedia Manager) who suggested using the internet to deliver the moving-text therapy. A working prototype was developed but it soon became clear that more resources would be required to deliver a patient-friendly version that could be used without the help of a health-care professional. This prompted two immediate questions: if patients were to use the therapy themselves, how would they know they had the condition? And, how would they know if the therapy was working for them? Leff expanded the brief to include an online visual field test and interval tests of reading ability that users would be directed back to after set periods of practice. He applied to The Stroke Association and received a research grant for £162,000 to make the Read-Right website a therapy and research tool. The bulk of the grant was used to fund the salary of a full-time web designer (Yean-Hoon Ong) who is responsible for the design, functionality and user-support of both sites.

Patients with hemianopic alexia were recruited from Leff's NHS hemianopia clinical service at the National Hospital for Neurology and Neurosurgery, UCLH. They have been actively involved in the design of both websites, meeting regularly with Ong and Leff to iteratively test and implement all aspects of the sites.

The visual field test was validated in a study undertaken at the Institute of Neurology in 2011. The results were published in 2012 with an accompanying editorial commentary on 'internet teleneurology' **[4]**. Analysis of the Read-Right patient data in 2011 demonstrated significant therapeutic effects on reading speeds comparable with previous trials, achieving a clear dose effect of 46% after 20 hours of practice **[5]**.

Prompted by the success of Read-Right, Leff decided to apply to The Stroke Association for a no-cost extension to allow Ms Ong to work on a new, more ambitious therapy site that would target the more common problem that almost all patients with hemianopia have: difficulty finding things.

The Eye-Search therapy web app contains: a more effective version of the Read-Right visual field test; a sensitive test of visual neglect (developed with the help of Professor Masud Husain, UCL); an activities of daily living assessment (developed with the help of Stephanie Wolff, occupational

therapist, Manchester); and a timed test of visual search (main outcome measure). The therapy, finding a ball that jumps semi-predictably into the affected visual field, has been shown by the team to improve visual search speeds in patients with hemianopia **[6]**.

3. References to the research

[1] Leff AP, Behrmann M. Treatment of reading impairment after stroke. Curr Opin Neurol. 2008 Dec;21(6):644-8.
http://dx.doi.org/10.1097/WCO.0b013e3283168dc7

[2] Schofield TM, Leff AP. Rehabilitation of hemianopia. Curr Opin Neurol. 2009 Feb;22(1):36-40.
http://dx.doi.org/10.1097/WCO.0b013e32831f1b2c

[3] Spitzyna GA, Wise RJ, McDonald SA, Plant GT, Kidd D, Crewes H, Leff AP. Optokinetic therapy improves text reading in patients with hemianopic alexia: a controlled trial. Neurology. 2007 May 29;68(22):1922-30.
http://dx.doi.org/10.1212/01.wnl.0000264002.30134.2a

[4] Koiava N, Ong YH, Brown MM, Acheson J, Plant GT, Leff AP. A 'web app' for diagnosing hemianopia. J Neurol Neurosurg Psychiatry. 2012 Dec;83(12):1222-4.
http://dx.doi.org/10.1136/jnnp-2012-302270

[5] Ong YH, Brown MM, Robinson P, Plant GT, Husain M, Leff AP. Read-Right: a "web app" that improves reading speeds in patients with hemianopia. J Neurol. 2012 Dec;259(12):2611-5.
http://dx.doi.org/10.1007/s00415-012-6549-8

[6] Jacquin-Courtois S, Bays PM, Salemme R, Leff AP, Husain M. Rapid compensation of visual search strategy in patients with chronic visual field defects. Cortex. 2013 Apr;49(4):994-1000.
http://dx.doi.org/10.1016/j.cortex.2012.03.025

4. Details of the impact

Outcomes for patients have improved

There are at least three peer-reviewed articles proving that moving text therapy is effective for hemianopic alexia, with the first dating back to 1993. Despite this, until the launch of Read-Right, the therapy was not available for suitable patients to access. We decided to make the therapy freely available.

Read-Right went live in June 2010 and has had 16,703 unique visitors generating 177,078 page views from 30,878 visits. 38% of visits are returning visitors. **657** patients with hemianopic alexia have used or are using the site.

Eye-Search went live in September 2012 and has had 3,090 unique visitors generating 37,885 page views from 7,281 visits. An impressive 57.5% of visits are returning visitors. **217** patients with hemianopia have used or are using the site.

Patients from all over the world can benefit from these applications. At present, the top five countries where users log in from are: UK (48%), USA (25%), Australia (10%), Canada (3%) and Japan (3%) **[a]**.

Patients can fill in an on-line questionnaire to let us know how much they have benefitted or not. Not everyone fills it in, but those who do rate Read-Right as 7.7/10 and report that they are now reading between 30 and 60 minutes more per day.

One patient reported that "*Read-Right has restored my self-belief and allowed me to take control of my own recovery*" **[b]**.

A novel clinical intervention has been developed, trialled and positive outcome demonstrated

Both websites contain clinically-proven therapeutic interventions that have been trialled in phase II studies. The data collected from patients using the applications are akin to a phase IV clinical trial (real-world efficacy outside close monitoring that occurs in smaller trials). This has led to two peer-reviewed publications to date **[see section 3]**. It is the first time that web-based therapies for neurological conditions have been proven to work.

Public involvement in research has improved

Since 2008, 42 patients with hemianopia have helped us in person to develop both therapy web sites. Most have come on one or more occasion to UCL Multimedia to 'beta' test various components of each application. Many more patients (~100) have been involved in online testing and have provided feedback once the therapy applications have been released. This has led to changes being made to the 'live' versions.

One patient, Mr Mark Jarvis, has been heavily involved in developing the applications and engaging with the research. Jarvis helped Read-Right through many iterations. He also fronts the explanatory video that appears on the website and on the UCL part of YouTube **[c]** (675 views to 31 July 2013). He was also the focus of a *Mail on Sunday* article (11th Jul 2010) **[d]**.

Jarvis and Leff have subsequently taken part in a Research Volunteers Workshop UCL (10 Jun 2011), highlighting the patient involvement in development Read-Right **[e]**.

Public awareness of a health benefit has been raised

Read-Right was profiled as an example of how patients with stroke could embrace new technology to improve their outcome in Media Planet (distributed with *The Independent)* in May 2010 **[f]** and in an article in the *Daily Express* (15 January 2013) **[g]**.

The Stroke Association have highlighted both web applications in press releases and also on their website. Read-Right has also featured in Stroke Matters (Nov 2010), a publication that goes out quarterly to all subscribers (free) **[h]**.

5. Sources to corroborate the impact

[a] Full report on website stats available on request.

[b] Quoted in August 2013 leaflet from Stroke Association *Your Impact on Stroke* highlighting positive outcomes from research they have funded. Copy available on request.

[c] http://www.youtube.com/watch?v=Ec5sRGNPKIM

[d] Mail on Sunday article on Read-Right web-based therapy site, 11 Jul 2010. Positive article outlining the clinical problem and web-based therapy. Includes an interview from one of the patients who was instrumental in testing the site before it went live. http://www.dailymail.co.uk/health/article-1293661/How-internet-help-stroke-victims-read.html

[e] Research Volunteers Workshop UCL, 10 Jun 2011. Panel presentation by researchers and volunteers, leading to a UCL report being published that highlighted the patient involvement in

development of Read-Right. "*How patients have helped us with our research*" Jul 2011. Read-Right featured as one of seven examples of how patients are directly involved in research development at UCL.

[f] Media Planet (distributed with The Independent), May 2010. Read-Right was profiled as an example of how patients with stroke could embrace new technology to improve their outcome. Copy available on request.

[g] Daily Express, "High Tech games that can rewire the brain", 15 January 2013. Read-Right was highlighted as an example of how patients with stroke could embrace new technology to improve their outcome. http://www.express.co.uk/life-style/health/370785/High-tech-games-that-can-rewire-the-brain

[h] Stroke Matters, Nov 2010. The Read-Right project made the front page of The Stroke Association's quarterly round up of research news. Copy available on request.