Institution:	University of Northumbria at Newcastle

Unit of Assessment:	4 – Psychology, Psychiatry and Neuroscience

Title of case study: Improving the design of health related websites and clarifying a role for peer-to-peer healthcare

1. Summary of the impact

Research at Northumbria has identified factors associated with trust in and intention to use Internet based health advice. A model of trust in online advice was published in 2007 that showed the importance of personalised peer-to-peer health messages - this was taken up by the press and broadcast media and led to changes in industry and public health practice around (i) the use of web material as a marketing and consumer tool for big pharma; (ii) the design of contemporary e-health sites; (iii) Government policy on the use of personal patient experience to influence patient choice.

2. Underpinning research

In 2000, NCR Financial Solutions Ltd. commissioned a research project based at Northumbria University and aimed at exploring users' trust of e-commerce websites (with Professor Pam Briggs as PI). The resulting *model of trust in e-commerce* was used as the basis for a successful three year ESRC award designed to explore trust in e-health websites which were, by then, growing in number. The outputs from the resulting project "Bodies Online – Information and Advice Seeking in the Health and Fitness Domain" (RES-341-25-0046, 2003 - 2006) was to have a significant impact on academic, health and e-marketing communities and, following the submission of the final report, was rated '*outstanding*' by ESRC. Project partners from Northumbria University were Professor Pamela Briggs (PI, Northumbria since 1991), Dr Liz Sillence (post-doctoral research associate, Northumbria since 2004) and Dr. Lesley Fishwick (Senior Lecturer, Northumbria since 1990).

The project recognised that health information available online was of extremely variable quality and sought to understand how health consumers determine quality and make decisions about whether or not to trust the information and advice they find online. This approach was novel, as established work had eschewed a patient-view of quality in favour of accepted medical judgment. Patient-centric studies were conducted in three phases. In phase one, three different patient groups took part in six-month longitudinal investigations of how they selected and responded to Internet based information and advice. In phase two, over 2000 surveyed health consumers reported influences on their trust in e-health material. In phase three, website elements were manipulated to create trustworthy and untrustworthy sites which were then tested on 80 participants.

The numerous outputs from the project were described as *highly influential* in the field in a comprehensive analysis of all peer-reviewed empirical studies on trust in health websites undertaken in 2010 (*Vega, Montague and DeHart: Trust in Health Websites: A review of an emerging field, IHI '10, ACM Press*). The key outputs included a *four-factor model of trust in e-health* and *a set of guidelines for the design of good health websites*. Perhaps the most significant single finding from the project concerned the role of like-minded others in influencing patients' health decisions. Prior to this, the received wisdom was that patients would trust health material only if it came from 'reputable' sources such as drug companies, physicians or government. Indeed, only two works on trust in e-health precede our own work and both of these carried the message that physician or government involvement in web content was key (Dutta-Bergman, 2003; Semere et al., 2003).

In contrast, our group's work demonstrated that trust in a site was positively associated with contributors *who shared similar experiences* to the patient. It also demonstrated that only established organisations deemed impartial could generate trust (i.e. advice from drug companies would be regarded with scepticism, even though that advice was subject to strict legal controls).

This finding subsequently attracted attention from academic and practitioner colleagues who were interested in the ways in which patients would seek out the experiences of other patients before

making health decisions.   A new consortium was formed to investigate the role of online patient experience.   The consortium was successful in attracting a £1.9m NIHR grant beginning 2010 and the patient experience 'iPEx' project is in its third year of five (National Institute for Health Research (NIHR) programme "Examining the role of patients' experiences as a resource for choice and decision-making in health care." Grant number RP-PG-0608-10147).   In impact terms, one of the team's major objectives is to: *"advise the NHS about how patient experiences can be presented to best effect".*   Finally the work on trust has been taken up by the Health Protection Agency which is now working with Northumbria on a new project assessing trust and influence in social media communication about vaccination and antivirals during the last H1N1 pandemic.

3. References to the research

Briggs, P., Burford, B., De Angeli, A and Lynch, P. (2002). 'Trust in online advice'. *Social Science Computer Review*, 20 (3), 321-332. DOI: 10.1177/089443930202000309

Sillence, E., Briggs, P., Fishwick, L. and Harris, P. (2004). 'Trust and Mistrust of Online Health Sites'. *Proceedings of CHI'2004*, April 24-29 2004, Vienna Austria, p663-670. ACM press DOI: 10.1145/985692.985776

Sillence, E., Briggs, P. Harris, P, Fishwick, L. (2006). 'A framework for understanding trust factors in web based health advice'. *International Journal of Human Computer Studies,* 64 (8), 697-713.DOI: 10.1016/j.ijhcs.2006.02.007

Sillence, E., Briggs, P. Harris, P, Fishwick, L. (2007). 'How do patients evaluate and make use of online health information?' *Social Science and Medicine*, *Volume 64, Issue 9*, *Pages 1853-1862* DOI: 10.1016/j.socscimed.2007.01.012

Harris P.R., Sillence, E., Briggs. P. (2009). 'The Effect of Credibility-Related Design Cues on Responses to a Web-Based Message About the Breast Cancer Risks From Alcohol: Randomized Controlled Trial'. *J Med Internet Res*: 11(3):e37 DOI: 10.2196/jmir.1097

Harris, P., Sillence, E. and Briggs, P. (2011). 'Perceived threat and corroboration: Key factors that improve a predictive model of trust in Internet-based health information and advice'*. Journal of Medical Internet Research*, 13(3): e51. DOI: 10.2196/jmir.1821

Funding

2000 NCR Financial Solutions Ltd. award of **£34,000** to study trust in e-commerce. (Briggs Co-I)
2003-6 ESRC award of £110,000 "Bodies Online – Information and Advice Seeking in the Health and Fitness Domain" (RES-341-25-0046) (1.4.2003 - 31.3.2006) (Briggs Co-I)
2010-14 NIHR award of **£1.9 million** (led by Oxford University) to investigate 'online patient experience' (£292K to Northumbria University) (Briggs Co-I)
2013-15 Department of Health Policy Research Programme Award*: Improving communication with the public about antivirals and vaccination during the next pandemic* (led by Public Health England). Total award: £506,878, **£85,000** to Northumbria University (Briggs Co-I)

4. Details of the impact

Major findings from the 'bodies online' project were disseminated in academic conferences (e.g. a 2004 SIGCHI conference paper, "Trust and Mistrust of online health sites" - downloaded 3,040 times) and published in academic journals, with one of the most significant papers (176 citations) published in 2007. Specific findings (concerning design factors that predicted trust in e-health websites) were heavily reported in the press and broadcast media (a link from the BBC news website is included as an example below).   The media attention in turn led to a series of invitations to professional conferences, including invitations to the eyeforpharma e-Marketing Summit in 2008 and to the World Health Summit in 2009.   The team were invited to speak to health organisations including the NHS, Microsoft (Healthcare Division), Bayer Scherring and Dipex (a charity specialising in providing web based patient experience material).   The work also caught the attention of the computing community with an article about the work appeared in PerAda magazine (2008).

The research has influenced the design of e-health websites with many sites now using patient authored content and social media. Additionally, new Internet start-ups sprang up to connect patients together, some of which were directly influenced by our work. In support of our role in this

process, we can document six examples of collaborative work and influence:

(i)   The pharmaceutical industry responded to presentations of our work and revised their website and patient support materials accordingly.   Bayer Scherring's global head of e-marketing invited Briggs to Berlin to make a podcast summarising the findings of the bodies online project, to be distributed to all e-Marketing staff. In a written testimonial,   He states:

The work of Professor Pamela Briggs ... has been extremely influential on the development of global digital strategies adopted by Schering AG and subsequently by Bayer Healthcare. The therapeutic area specifically and immediately impacted was cardiovascular risk management (stroke prevention), but Professor Briggs' recommendations had much broader relevance across all therapeutic areas and brands. Her counsel that 'The most important advice for those trying to promote health information online is the use of engaging stories about people with similar experiences'…is now well understood and accepted as axiomatic in digital healthcare and in particular health 2.0. Professor Briggs' research findings were truly pioneering in 2007. Today, with social media far more widely adopted and patient story telling taken for granted, her insights can be regarded as remarkably prescient.

(ii)   Briggs consulted on the early design of *Imedo.de* – a web 2.0 health portal that provides social networking support for patients, developed by Christian Angele and colleagues and which now has over 100,000 users.   At an early stage in the development of the site, Mr. Angele contacted Briggs, having heard about her work through the media and subsequently read some of the team's research papers.   Briggs agreed to act as an informal consultant in the design of the site, recommending the use of patient authored content and social media input in various ways.   Following the launch in 2007, Wirtshafts Woch included Christian Angele in the '50 most interesting young entrepreneurs in Germany' and the site imedo.de was listed by Business Week as one of the 50 most interesting start-ups.

(iii)   At an early stage in our research, the team recognised that *Healthtalkonline.org* (operated by the Dipex charity) provided one of the most successful 'patient experience' websites in the country and sought to work with them to influence the design of their future sites. The charity was chosen by the Department of Health from over 120 applications to participate in the testing phase of its new Information Accreditation Scheme that will 'kite mark' organisations that produce health and social care information.   Liz Sillence collaborated with Dipex in the production of two professional journal articles immediately following the *bodies online* project and the wider Northumbria team worked with them recently (2013) on a new framework for patient engagement (http://care.cs.columbia.edu/chi2013health/CRPapers/Briggs.pdf) and on the construction of a new set of web design guidelines around peer-to-peer healthcare.

(iv)   Omnimedicalsearch.com claims to be the most comprehensive medical and health search engine platform on the internet, focusing on results from authoritative sources. In 2008 it released a health and medical forum search engine designed to connect patients and caregivers with others who want to share and discuss personal experiences.   The press release (link below) quoted the founder as noting:

Today's online message boards, chat rooms and forums, those online-communities, are an excellent way for people to connect. OmniMedicalSearch wanted to better serve the online communities by offering a directory and search option which encompasses more than 120 different online forums.

and supported this statement with evidence pulled from the bodies online project and linked to the ESRC pages about the project.

(v)   The change to e-health design in the commercial sphere has subsequently been reflected in UK government policy initiatives for the NHS.   Initially, the Northumbria team was highly critical of the NHS web presence which offered little more than online patient information leaflets. However NHS choices, itself launched in 2007, had a stated aim to personalise healthcare and provide information that would 'allow patients to make meaningful choices about when and where to receive their treatment'.   The Northumbria team was involved in

discussions with the NHS as well as with Microsoft Health (then working on a major NHS software project) during 2008, but developed a closer relationship with NHS choices through Bob Gann (until recently NHS Choices head of strategy and engagement) who writes (November 2012):

Two of the most important planks of the Department of Health's Information Strategy are the need to recognise an increasingly diverse information environment and the importance of patient voice and experience...Work at Northumbria on models of trust in online health information, and particularly guidelines on good quality health websites, has been very influential in developing our thinking on appropriate quality assurance. On the second, we have been very pleased to work with colleagues from Northumbria as well as other centres in the iPex project on patient experience...This has helped shape our policy thinking on key issues in capturing and publishing patient experiences.

(vi)   Finally, the published research directly informed the development of the German national evidence-based health website Gesundheitsinformation.de/Informed Health Online (developed by the Institute of Quality and Efficiency in Health Care - IQWiG). The process for the development of this site is described by Hilda Basian (2008) where she cites the Northumbria work in the justification for recommending the inclusion of a patient experience component. The website had over 300,000 page views in January 2008 and the French National Health Authority (HAS) translated the material for use within the French Healthcare system during 2008.

5. Sources to corroborate the impact

The Imedo website: www.imedo.de (plus letter from them about the Northumbria collaboration)

Email from former Global Director of e-Marketing, Bayer Scherring confirming the transformational nature of the work

PerAda magazine article here: http://www.perada-magazine.eu/pdf/1287/1287.pdf

A briefing document produced as part of e-society initiative is available here: http://www.york.ac.uk/res/e-society/projects/9/9briefingdoc.pdf

Programme for the World Health Summit 2009 is available here: http://www.worldhealthsummit.org/fileadmin/downloads/whsSummitProgram.pdf

A sample of media coverage (BBC news) is given here: http://news.bbc.co.uk/1/hi/health/6422157.stm

Two samples of practitioner-focused coverage (e-health insider, PerAda) are given here: http://www.ehi.co.uk/news/EHI/2530/consumers-prefer-the-'personal-touch'-for-online-health

IPex briefing paper for the new NIHR project: http://www.ipexonline.org/sites/default/files/iPEx%20Briefing%20Paper%201%20June%202011.pdf

Omnimedicalsearch reference: http://www.marketwire.com/press-release/omnimedicalsearchcom-launches-health-and-medical-forum-search-engine-818057.htm

EU portal link to our work: http://ec.europa.eu/research/headlines/news/article_05_04_04_en.html

Bastien, H (2008). Health literacy and patient information: Developing the methodology for a national evidence-based health website. *Patient Education and Counselling*, 73(3), 551-556.