

Design rules & Web 2.0: Mismatched models of how people use the Internet for healthcare

Dr Henry W W Potts

Centre for Health Informatics and Multiprofessional Education (CHIME)

Division of Population Health UCL Medical School

h.potts@chime.ucl.ac.uk

≜UCI

Conflicting views of the Internet Remember 5th November 2008?

- Hazel Blears, Secretary of State for Local Government: "mostly, political blogs are written by people with disdain for the political system and politicians, who see their function as unearthing scandals, conspiracies and perceived hypocrisy. Until political blogging 'adds value' to our political culture, by allowing new voices, ideas and legitimate protest and challenge [...] it will continue to fuel a culture of cynicism and despair." (reported at
 - http://www.guardian.co.uk/politics/2008/nov/05/hazel-blears-politics-media-labour)
- As my then flatmate pointed out, this was the day after "Obama swept to power partially through the efforts of small fundraisers and supporters, mobilised and working via the internet and mobiles"

ŮUCL

Models of patient use of the Internet (& more)

- Hugh Rogers and Lynne Maher at the NHS Institute for Innovation and Improvement, and Paul Plsek: "Better by design: using simple rules to improve access to secondary care", BMJ 2008; 337: a2321
- "Web 2.0" so-called second generation of web development characterised as facilitating communication, sharing, collaboration and 'produsage'; examples include social-networking sites, wikis, blogs and folksonomies
- Henry Potts: "Is e-health progressing faster than e-health researchers?" Journal of Medical Internet Research 2006, 8(3): e24



Most patients in the NHS are not like Ginny, an investment banker in her 30s



Far more are like my mother, in her 70s, with multiple co-morbidities and fairly technophobic

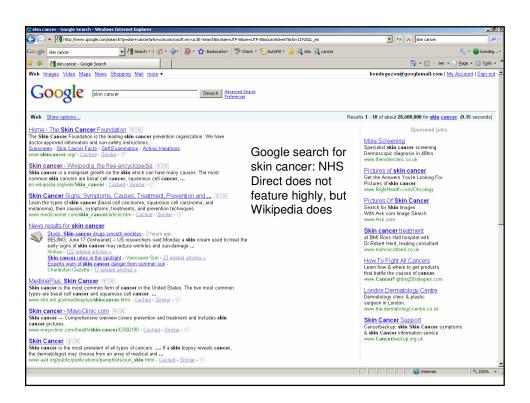
≜UCI

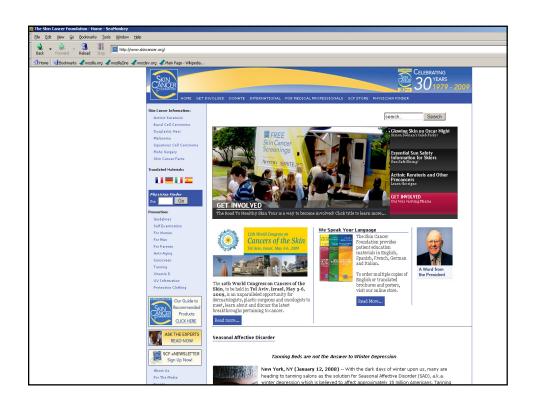
What would you do if you were Ginny?

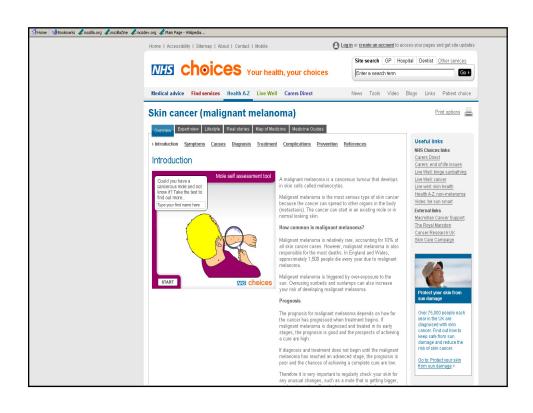
- Ring your GP surgery?
- · Search for "skin cancer" on Google?
- Search for "skin cancer" on Wikipedia?
- Visit the NHS Direct Online page on "skin cancer"?

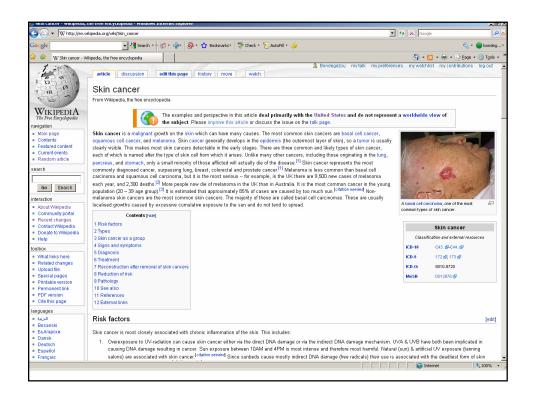
"The Internet has become a favored source to find health information. Worldwide, about 4.5% of all Internet searches are for health-related information. [...] Most users of online health information are looking for information about specific health conditions because they or someone they know was diagnosed with a medical condition. They typically use general search engines to find online health information and enter short phrases, often misspelled. They seldom go beyond the first page of a search. Both their search and evaluation skills are limited although they are concerned about the quality of online health information. They avoid sites with overt commercialism, but often do not pay attention to indicators of credibility. Online health information is used to fill an information void"

(Morahan-Martin 2004, Cyberpsychology & Behavior, 7: 497-510)



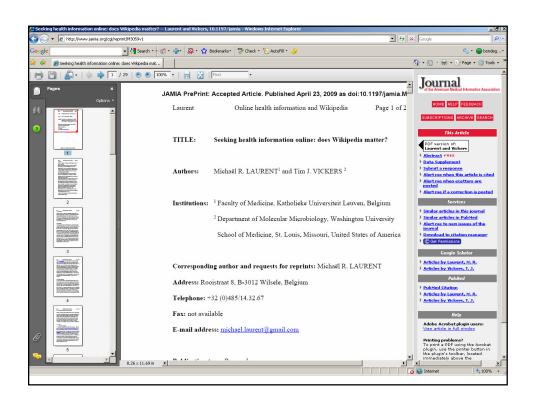






Audience participation zone!

- Who uses Wikipedia?
- Who uses Wikipedia for work?
- · Who edits Wikipedia?
- In a survey of medical undergraduates at one London medical school in 2007/8, I found 83% (38/46) reported using the site as a learning resource, with 9% (4/49) having edited it



"Wikipedia ranked among the first ten results in 71-85 % of search engines and keywords tested. Wikipedia surpassed MedlinePlus and NHS Direct Online (except for queries from the latter on Google UK), and ranked higher with quality articles. Wikipedia ranked highest for rare diseases, although its incidence in several categories decreased. Page views increased parallel to the occurrence of 20 seasonal disorders and news of three emerging health concerns. Wikipedia articles were viewed more often than MedlinePlus Topic (P = 0.001) but for MedlinePlus Encyclopedia pages, the trend was not significant (P = 0.07-0.10)."

(Laurent & Vickers 2009, J Am Med Informatics Assoc)



Who writes Wikipedia pages?

Top editors of "skin cancer" page

- Buzybeez: 21 edits no user page; blocked because of edits concerning St Christopher Iba Mar Diop College of Medicine, a UK-based private medical training establishment accredited in Senegal but not the UK and now specifically blacklisted by the GMC
- Northerncedar: 20 edits no user page; Talk pages imply a dermatologist
- Malo: 17 edits Administrator, no other personal info; seems particularly interested in military history
- Versageek: 16 edits Administrator, no other personal info
- Jfdwolff: 15 edits Dutch doctor working in the UK, published in academic journals; Administrator
- Lipperman: 11 edits no user page
- · Gerriet42: 10 edits German chemist



UCL

Portal: Medicine 'selected articles'

- Nutrition
- Insulin
- Vacutainer
- · Helicobacter pylori
- Asthma
- · Female hysteria
- Influenza A virus subtype H5N1
- Forensic facial reconstruction
- Metabolism
- Influenza

- · Sexually transmitted disease
- · Hodgkin's lymphoma
- Fever
- Smallpox
- Vaccination
- Renal cell carcinoma
- · Cholangiocarcinoma
- Ambulance
- · Colorectal cancer
- Cirrhosis

≜UCI

Most viewed (Aug 2008)

126. Sarcoidosis

271. Bipolar disorder

292. Pneumonia

367. Magnesium stearate

388. Schizophrenia

431. Tramadol

445. Asperger syndrome

501. Tuberculosis

515. Autism

548. Circumcision

575. AIDS

611. Oxycodone

618. Psychology

635. Multiple sclerosis

654. Cancer

665. Meningitis

751. Lyme disease

756. Pregnancy

771. Down syndrome

784. Gout

UCL

Laurent & Vickers (2009) keywords Medline Plus random sample

- bariatric surgery
- · birth control
- Bell's palsy
- genetic counseling
- · homeopathy
- · West Nile virus
- Giardia infections ["Giardiasis"]
- pulmonary hypertension
- radiography
- · arachnoiditis

- rubeola ["measles"]
- gastric cancer ["stomach cancer"]
- braces, oral ["dental braces"]
- · septic arthritis
- · ergonomics
- fitness ["physical fitness"]
- caregivers
- dental caries
- hypertension
- carcinoma

≜UCI

Laurent & Vickers (2009) keywords NHS Direct Online random sample

- voicebox cancer ["laryngeal cancer"]
- anal fissure
- threadworms ["pinworm"]
- pubic lice ["crab louse"]
- thrush oral (babies) ["oral candidiasis"]
- vitiligo
- · thrombosis
- leg ulcer, venous ["venous ulcer"]
- ear infection (inner) ["labyrinthitis"]
- SSRIs (selective serotonin reuptake inhibitors)

- counselling [redirects to "List of counseling topics", from which randomly select "grief therapy"]
- · Kaposi's sarcoma
- seasonal allergic rhinitis ["rhinitis"]
- hiatus hernia
- corticosteroid preparations (topical) ["topical steroid"]
- · conjunctivitis, allergic
- influenza vaccination
- hernia
- iritis
- · positron emission tomography

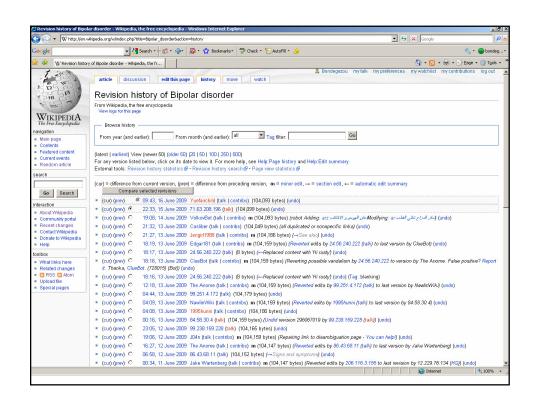


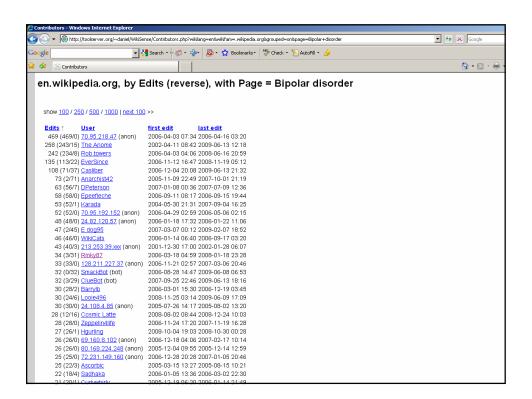
Laurent & Vickers (2009) keywords NORD random sample

- chronic fatigue syndrome
- fragile X syndrome
- anemia, hereditary nonspherocytic hemolytic ["glucose-6-phosphate dehydrogenase deficiency"]
- melorheostosis
- Turcot syndrome
- · Frey's syndrome
- VACTERL Association
- Fukuyama type congenital muscular dystrophy
- psoriasis
- Townes Brocks syndrome
- · anemia, Fanconi

- thrombocytopenia, essential ["idiopathic thrombocytopenic purpura"]
- · urticaria, cholinergic
- achalasia
- trismus pseudocamptodactyly syndrome ["MYH8"]
- mantle cell lymphoma
- Setleis syndrome [no article]
- myopathy, desmin storage [no article]
- Weismann Netter Stuhl syndrome [no article]
- chromosome 18q- syndrome [no article]







Edit counts

- Edit count is an approximation for contributions
- Note importance of maintenance as well as content creation
- Maximum number of edits made by an editor on an article ranged from 2 ("Fukuyama congenital muscular dystrophy" and "MYH8") to 1052 ("autism")
- For each article, record all editors who had made at least 10 edits

≜UCI

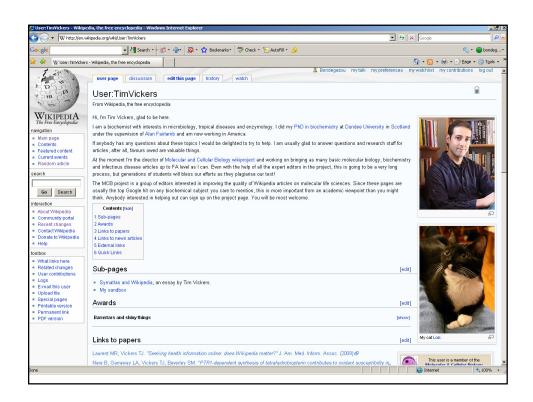
Editors

- The number of editors who had made more than 10 edits ranged from 0 to 104 ("homeopathy"); median is 5.5.
- The number of IP address (anonymous) editors who had made more than 10 edits ranged from 0 to 26 ("bipolar disorder"); median is 1
- The number of bot editors who had made more than 10 edits ranged from 0 to 5 ("psychology" and "Down syndrome"); median is 0

Editors

- 735 identified accounts have edited at least 10 times at least one of the sampled articles
- Some have edited at least 10 times multiple sampled articles
- Across the 5 samples, Cronbach's α for number of articles edited is 0.55

• Number of articles edited at least 10 times ranges from 1 (597/735; 81%) to 36 • Define high-editing group as having edited (at least 10 times) at least 5 article: 21 editors (3%)



Editors – who are they? (audience participation pt. 2)

Are they...?

- Health care professionals (Sanger 2009)
- Patients/carers (Web 2.0 in action)
- Lay people (Web 2.0 in action in a different way)
- Computer geeks (stereotype)

735 frequent editors of Wikipedia articles related to medicine

- 101 no user page
- 296 have user page with no demographic information
- 87 are administrators
- Nationality
 - US: 120
 - UK: 42
 - Australia: 25
 - Canada: 19 - New Zealand: 4
 - Other: 34
- 103 ♂, 22 ♀, 610 not stated

This is out of proportion to these countries' relative populations with Australia particularly over-represented, UK somewhat over-represented and US somewhat under-represented: $\chi^2(4) = 29.3, p < 0.001$

Frequent editors of Wikipedia articles related to medicine

- Doctor: 29
- Other healthcare professional (inc. EMT): 18
- Medical/other HCP student: 17 (3 also already other healthcare professionals)
- Academic relationship in healthcare: 6
- Complementary practitioner: 2
- Other health-related: 7
- Degree as HCP: 39 + 16 studying
- Postgrad qualification in biomedicine: 13 + 7s
- Undergrad qualification in biomedicine: 11 +
- Postgrad qualification in science: 21 + 3s
- Undergrad qualification in science: 22 + 4s
- Postgrad qualification in other: 20 + 4s
- Undergrad qualification in other: 20 + 6s No degree (college drop out): 1

Any science qualification: 144 Graduate (or undergraduate student): 194

Qualified healthcare professional: 47

- No degree: 1
- Among those with some personal info not stated: 143

Broadly qualified (HCP or biomedicine qualification): 94

Of those who state some personal info: 14% are qualified HCPs, and 28% are broadly qualified. 43% are science graduates (or studying towards). 57% are science graduates (or studying towards).

UCL

Patients and others affected by a condition

- Out of 96 articles, 93 show the same pattern: for these, there is little evidence
 of people with the condition concerned actively editing.
 - "Oxycodone", edited by someone with chronic pain who takes oxycodone
 - "Hodgkin's lymphoma", edited by a lymphoma survivor
 - "Psychology", edited by someone with ADHD
 - "Down syndrome", edited by a volunteer in sport for athletes with disabilities
- Other articles are edited by people with unrelated conditions:
 - "Lyme disease", edited by someone with Asperger's
 - "Psoriasis", edited by someone with Asperger's
 - "Asthma", edited by someone with Asperger's and dyslexia
 - "Circumcision", edited by someone with asthma
 - "Idiopathic thrombocytopenic purpura", edited by someone with unspecified agerelated health and vision problems
 - 3 unrelated articles edited by someone who is blind



Patients and others affected by a condition

But three articles show a very different pattern:

- · "autism"
 - of 52 editors (with at least 10 edits): 1 autistic or Asperger's, 4 with Asperger's, 1 father of an autistic child, 1 with OCD/ADD, 1 with ADHD – 15%
- "Asperger's syndrome"
 - of 63 editors: 7 with Asperger's, 1 autistic or Asperger's, 1 mother of someone with Asperger's, 1 ADHD with possible erroneous past diagnosis of Asperger's, and an "autism awareness campaigner" – 17% (obviously considerable overlap in the editors of these two articles)
- "chronic fatigue syndrome"
 - of 32 editors: three editors with CFS and a fourth with post-polio syndrome and ADHD – 13% (in addition, two other editors have user names implying they may have CFS)

High-editing group

- More likely to have details on their user pages
- · More likely to be administrators
- More likely to be a doctor/medical student
- None profess to any conditions

Who writes Wikipedia pages? Preliminary observations...

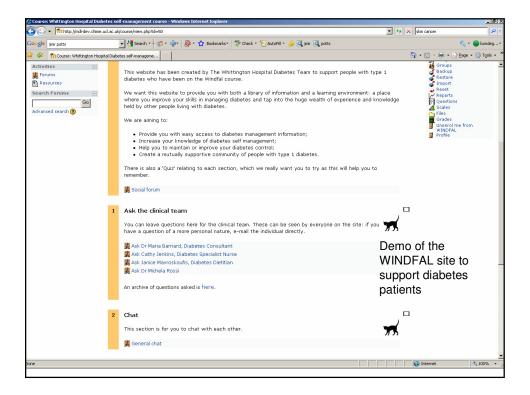
- Australians over-represented
- Men over-represented
- · 'Computer geeks'
- Doctors & dentists to some degree
- Academics to some degree
- · Those with certain conditions

Is this how Web 2.0 is meant to work? Is this truly a democratisation of the production of information?



Kummervold et al. (2008)

- http://www.jmir.org/2008/4/e42/
- "The percentage of consumers using the Internet for health purposes in other, more interactive, ways did increase [...] to 22.7% (21.7 23.6) in 2007 [...] In 2007 a total of 9.9% (9.2 10.6) have participated in health related forums or self-help activities more than once a year. The study also shows that 8.5% (7.8 9.1) order medical health products online, 11.1% (10.4 11.8) have online communication with health professionals whom they have not previously met, and 6.9% (6.3 7.4) have used the Internet to interact with known health professionals. The use of all interactive, health-related online services increased significantly."





Funding models

We still struggle with appropriate funding models for online health sites or interventions – consider these case studies

- WINDFAL
- UCL Student Support Group
- · Beating the Blues
- sextherapylondon.nhs.uk
- Xanthis anthis

Cite as: Potts HWW (2009). Design rules & Web 2.0: Mismatched models of how people use the Internet for healthcare. Invited talk at LifeGuide workshop, University College London, June 2009.