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

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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”
Models of patient use of the Internet (& more)

- “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

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On a Monday morning, Ginny (age 34, single, works at a London Investment bank, commutes daily from Sussex) shows a new mole on her abdomen that has grown irregularly and discoloured over the past year and has now started to itch.

After having her new mole counted off by a specialist, she is scheduled to see the general practitioner’s surgery in her village. The receptionist says that she can come in at 9 am, noting the practice’s evening hours. She also suggests that Ginny could do some self-assessment on the NHS Direct website, with assistance from one of the practice nurses if she desires. Ginny walks up to a telephone appointment with a practice nurse later that day. She views that her mole looks and feels much like the descriptions and photos on the website. The practice nurse is confirming and offering to book Ginny directly into the dermatology clinic. Although slots are available tomorrow, Ginny has a ticket to play for a big meeting with Bronson in London on Wednesday, so she selects a convenient time on Thursday evening. Ginny sends an email to concentrate – more stories from well-intentioned friends and help (rules 1-5).

Ginny turns up at the dermatology clinic, and is seen about five minutes after her appointment time. The nurse notes this delay and apologies. The dermatologist diagnoses the mole and tells Ginny that she should have the biopsied in about three days. He asks, with her about her concerns while removing the mole. Noting that she is a computer user, he prints out addresses of websites where she can read more. He provides her with the clinic’s e-mail address, where she can send questions when they occur to her. Her bribery that she may not always be able to personally answer all emails, but that someone from the practice team will always respond. "And, of course, there is always the old-fashioned way of ringing us," he mentions (rules 6, 7).
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.

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)
Skin Cancer (malignant melanoma)

Introduction

A malignant melanoma is a serious tumour that develops in skin cells called melanocytes. Malignant melanomas are the most common type of skin cancer in both men and women, with a peak incidence between the ages of 30 and 60 years. The cancer can occur in any part of the body in anyone at any age. Malignant melanoma is the most common cancer to kill in the United Kingdom.

Types of melanoma

There are two main types of melanoma:

1. Superficial spreading melanoma
2. Lentigo maligna melanoma

Both types of melanoma can occur at any age.

Causes

The main cause of malignant melanoma is exposure to the sun. People who spend a lot of time in the sun are more likely to develop melanoma.

Diagnosis

Diagnosis of malignant melanoma usually involves a skin biopsy. If the biopsy shows that the melanoma has spread to other parts of the body, a CT scan or magnetic resonance imaging (MRI) may be used to check for metastatic disease.

Treatments

The treatment for malignant melanoma depends on the stage of the cancer at the time of diagnosis. Early-stage melanoma is treated with surgery, while advanced-stage melanoma may require chemotherapy, immunotherapy, or targeted therapy.

Prognosis

The prognosis for melanoma depends on the stage of the cancer at the time of diagnosis. Early-stage melanoma has a better prognosis than advanced-stage melanoma. The survival rates for early-stage melanoma are high, while the survival rates for advanced-stage melanoma are low.

Prevention

To reduce the risk of developing malignant melanoma, it is important to protect your skin from the sun. You can do this by wearing sunscreen, avoiding sunburn, and seeking shade when possible.
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

- Buzbybee: 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
### 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

### Most viewed
**(Aug 2008)**

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>126. Sarcoidosis</td>
<td>575. AIDS</td>
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<tr>
<td>271. Bipolar disorder</td>
<td>611. Oxycodone</td>
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<tr>
<td>292. Pneumonia</td>
<td>618. Psychology</td>
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<tr>
<td>367. Magnesium stearate</td>
<td>635. Multiple sclerosis</td>
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<tr>
<td>388. Schizophrenia</td>
<td>654. Cancer</td>
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<tr>
<td>431. Tramadol</td>
<td>665. Meningitis</td>
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<tr>
<td>445. Asperger syndrome</td>
<td>751. Lyme disease</td>
</tr>
<tr>
<td>501. Tuberculosis</td>
<td>756. Pregnancy</td>
</tr>
<tr>
<td>515. Autism</td>
<td>771. Down syndrome</td>
</tr>
<tr>
<td>548. Circumcision</td>
<td>784. Gout</td>
</tr>
</tbody>
</table>
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

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
- thrombocytopenia, essential ["idiopathic thrombocytopenic purpura"]
- fragile X syndrome
- urticaria, cholinergic
- anemia, hereditary nonspherocytic hemolytic ["glucose-6-phosphate dehydrogenase deficiency"]
- achalasia
- melorheostosis
- trismus pseudocamptodactyly syndrome ["MYH8"]
- Frey's syndrome
- mantle cell lymphoma
- psoriasis
- Townes Brocks syndrome
- Setleis syndrome [no article]
- anemia, Fanconi
- VACTERL Association [no article]
- urticaria, cholinergic
- Weismann Netter Stuhl syndrome [no article]
- anemia, Fanconi
- chromosome 18q- syndrome [no article]
- thrombocytopenia, essential ["idiopathic thrombocytopenic purpura"]
- trismus pseudocamptodactyly syndrome ["MYH8"]
- Frey's syndrome
- Townes Brocks syndrome
- anemia, Fanconi
- VACTERL Association
- urticaria, cholinergic
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

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

Editors

- 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:
χ²(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 + 3s
- 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
- Qualified healthcare professional: 47
- Broadly qualified (HCP or biomedicine qualification): 94
- Any science qualification: 144
- Graduate (or undergraduate student): 194
- No degree: 1
- Among those with some personal info – not stated: 143
- 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).
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 age-related health and vision problems
  - 3 unrelated articles edited by someone who is blind

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)

- “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

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

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