Telemedicine on the internet

Telemedicina e e-Saúde

2016/17

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References

- Sources are indicated by [RefSource] where the complete citation will be at the end
- Insite citations will be From: CitationSource
Telemedicine and the internet

Internet Usage

WORLD INTERNET USAGE AND POPULATION STATISTICS
NOVEMBER 15, 2015 - Update

<table>
<thead>
<tr>
<th>World Regions</th>
<th>Population (2015 Est.)</th>
<th>Population % of World</th>
<th>Internet Users Latest Data</th>
<th>Penetration (of Population)</th>
<th>Growth 2000-2015</th>
<th>Users % of Table</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>1,158,355,663</td>
<td>16.0 %</td>
<td>327,145,889</td>
<td>28.2 %</td>
<td>7,146.7%</td>
<td>9.8 %</td>
</tr>
<tr>
<td>Asia</td>
<td>4,032,466,882</td>
<td>55.5 %</td>
<td>1,611,048,215</td>
<td>40.0 %</td>
<td>1,309.4%</td>
<td>48.1 %</td>
</tr>
<tr>
<td>Europe</td>
<td>821,555,904</td>
<td>11.3 %</td>
<td>604,147,280</td>
<td>73.5 %</td>
<td>474.9%</td>
<td>18.1 %</td>
</tr>
<tr>
<td>Middle East</td>
<td>236,137,235</td>
<td>3.3 %</td>
<td>123,172,132</td>
<td>52.2 %</td>
<td>3,649.8%</td>
<td>3.7 %</td>
</tr>
<tr>
<td>North America</td>
<td>357,178,284</td>
<td>4.9 %</td>
<td>313,867,363</td>
<td>87.9 %</td>
<td>190.4%</td>
<td>9.4 %</td>
</tr>
<tr>
<td>Latin America / Caribbean</td>
<td>617,049,712</td>
<td>8.5 %</td>
<td>339,251,363</td>
<td>55.0 %</td>
<td>1,777.5%</td>
<td>10.1 %</td>
</tr>
<tr>
<td>Oceania / Australia</td>
<td>37,158,563</td>
<td>0.5 %</td>
<td>27,200,530</td>
<td>73.2 %</td>
<td>256.9%</td>
<td>0.8 %</td>
</tr>
<tr>
<td>WORLD TOTAL</td>
<td>7,259,902,243</td>
<td>100.0 %</td>
<td>3,345,832,772</td>
<td>46.1 %</td>
<td>826.9%</td>
<td>100.0 %</td>
</tr>
</tbody>
</table>

NOTES: (1) Internet Usage and World Population Statistics updated as of November 15, 2015. (2) Click on each world region name for detailed regional usage information. (3) Demographic (Population) numbers are based on data from the US Census Bureau, Eurostats and from local census agencies. (4) Internet usage information comes from data published by Nielsen Online, by the International Telecommunications Union, by GfK, by local ICT Regulators and other reliable sources. (5) For definitions, disclaimers, navigation help and methodology, please refer to the Site Surfing Guide. (6) Information in this site may be cited, giving the due credit and placing a link to www.internetworldstats.com. Copyright © 2001 - 2015, Miniwatts Marketing Group. All rights reserved worldwide.
The Internet

- Source of medical information
- "As physicians, we, too, use the Internet daily. Doctors now routinely consult the Web in search of diagnoses.”
- “In 2006, two Australian specialists tested the diagnostic accuracy of Google searches by entering symptoms and signs from 26 published case records."
  - “Google searches revealed the correct diagnosis in 15 (58%, 95% confidence interval 38% to 77%) cases.”

The Internet still

After evaluating a 16 year old water polo player who presented with acute subclavian vein thrombosis, one of us (HT) started to explain that the cause of the thrombosis was uncertain when the patient’s father blurted out, “But of course he has Paget-von Schrötter syndrome.” Having previously googled the symptoms, he gave us a mini-tutorial on the pathophysiology hypertrophy of the neck muscles leading to dynamic compression of the axillary vein at the thoracic inlet—leading to thrombosis) and the correct treatment of the syndrome.

From [GOOGLING]
However

"On the Internet, nobody knows you're a dog."

Cartoon by Peter Steiner from page 61 of July 5, 1993 issue of The New Yorker (Vol.69 (LXIX) no. 20)

The Internet

- Trust worth issues

- Educate vs. ban
  - prudent gathering of info
  - careful evaluation
The Internet still

everything could be found on the web if only one knew the correct search terms.

From [GOOGLING]

Searching with Google may help doctors to formulate a differential diagnosis in difficult diagnostic cases.

From [GOOGLING]

See here for search terms used.

The Internet still

GP's associated Internet use with issues of patients’ “power and control” in health care and particularly within the primary-care consultation. They felt that when patients used the Internet it was often to check up on them (i.e. the GPs), especially regarding medication, and that this was frightening.

From [DIVIDE]

Patients, on the other hand, described their use of the Internet as a means of creating a favourable impression during their consultation.

One GP said: ‘The Internet – yes, it’s fine. As long as we’re still in control.’
Positive testing bias

- If $P$ then $Q$ implies querying for:
  - $P$ and $Q$ (*modus ponens*)
  - And
  - not $Q$ with not $P$ (*modus tollens*)

- People tend to search online only for $P$ and $Q$ (if given the hypothesis “if $P$ then $Q$”)
  - And get results for confirming evidence, specially if (not $Q$) is expressed by $R$
  - Which means that search results do not include the expression $R$

From [PosTestKayhan]

Positive testing bias – Exp1

- Experiment 1: test positive hypothesis:
  - “coffee is associated with hypertension risk”
  - DB with 4 confirming, 3 disconfirming and 30 noise
  - From 20 participants, 17 hypothesis is valid and 3 invalid
    - These 3 said confirming papers evidence’s not convincing

From [PosTestKayhan]
Positive testing bias: Exp2

- Experiment 2:
  - Recommendation system: proposed searching for the “not” term
  - “Did you search for coffee and low blood pressure?”
  - Incorporation system: incorporating the “not” term in the results for the positive search
  - 20 participations to each system
  - In rec system none clicked the recommendation
  - In inc system 15 saw the disconfirming evidence

Positive testing bias: results

<table>
<thead>
<tr>
<th>Selected decision</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No debiasing technique (Experiment 1)</td>
</tr>
<tr>
<td>Hypothesis is valid</td>
<td>17 (85%)</td>
</tr>
<tr>
<td>Hypothesis is invalid</td>
<td>3 (15%)</td>
</tr>
<tr>
<td>Total</td>
<td>20 (100%)</td>
</tr>
</tbody>
</table>
The wave is changing...

- There’s a new trend to empower the patient
- Set the focus on the patient
- e-patients.net
- epatientdave.com
- Society for participatory medicine
- Intel’s People Centred innovation
- Wellocracy
**Phrasebook [Patient Journey]**

<table>
<thead>
<tr>
<th><strong>Patient</strong></th>
<th><strong>Doctor</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem ➔ Resource</td>
<td>Clinician ➔ Service provider</td>
</tr>
<tr>
<td>Recipient ➔ Co-creator</td>
<td>Knowledge provider ➔ Sparring partner</td>
</tr>
<tr>
<td>Cost ➔ Investment</td>
<td>Fire extinguisher ➔ Preventer</td>
</tr>
</tbody>
</table>

**Nurse**

| Care provider ➔ Health helper | Carer ➔ Adviser | Practitioner ➔ Trainer |

**Quantified Self**

- Movement of people that do continuous self-monitoring of daily-life
- Objective of the group is “to help people get meaning out of their personal data”.
- Personal data
  - EEG, ECG
  - Activity levels, mood, blood O$_2$
  - Food intake, air quality
  - Cognitive
- Several tools for doing this
An ounce of prevention is worth a pound of cure,

- Benjamin Franklin
HON

- Health on the Net Foundation
- “promotes and guides the deployment of useful and reliable online health information, and its appropriate and efficient use”
- Created in 1995
- In 2002, recognized as a non-governmental organization and granted special consultative status with the United Nations Economic and Social Council
- Several tools developed for assessing/providing reliable sources

HONCODE Principles

- Principle 1: Authority
  - Give qualifications of authors

- Principle 2: Complementarity
  - Information to support, not replace

- Principle 3: Confidentiality
  - Respect the privacy of site users

- Principle 4: Attribution
  - Cite the sources and dates of medical information

- Principle 5: Justifiability
  - Ability to back claims

- Principle 6: Transparency
  - Accessibility, provide valid contact details

- Principle 7: Financial disclosure
  - Provide details of funding

- Principle 8: Advertising
  - Clearly distinguish advertising from editorial content

Source: [http://www.hon.ch/](http://www.hon.ch/)
HON Code Accreditation Process

1. Web publisher submits a request to be accredited and to obtain the right to display the HONcode seal
2. The Web publisher fills in an online questionnaire
3. The HONcode review team conducts a thorough evaluation of the website
4. According to findings, website is:
   - accredited
   - accredited under condition to modify/add some statement on the website
   - not accredited
5. If accredited, a unique HONcode seal is granted
6. Each website is re-evaluated each year
7. The accredited website is integrated into the database of HONcode accredited websites, HONcodeHunt

HONCode

• Principle:
  • “The request for accreditation is usually backed by the willingness to improve”

• Toolbar available for
  • Accreditation status
  • Search for compliant
Tools

- Search only HONcode Certified sites: HONCodeHunt
- HONCode site evaluation form
- Targeted search engine
  - Wrapin
    - Search for terms and sources of information regarding terms of sites
    - Uses the results from Marvin

Marvin The crawler

- Web crawler
- Uses MeSH thesaurus and other medical dictionaries
- Detection of medical and health related Web pages
- Semi-automatic selection of most relevant health and medical Web pages
- Several languages processed
  - English, French, Spanish, Italian, German, Portuguese, Danish, Dutch
HON Code: Automatic assessment

- Machine learning algorithms (see [HONWRAPIN])
- Several languages (English, French, Spanish, Italian)
- Give results according to the HONCode criteria
  - Authenticity, complementary, advertising, etc

HON Code: Automatic assessment – results

- From [HON-PRES2]:
  - Globally results are very good for Privacy and Attribution_Ref
  - Good for Complementarily, Transparency, Sponsorship and Advertising
  - Small confusions between Sponsorship and Advertising
  - Small confusions between Authority and Reference
  - Confusions between Justifiability and Complementarity

- Informative 65% whereas general purpose was 59%
- Reliable 72% whereas general purpose was 41%
New Tools

• **HONSelect**: search HONCode validated sites by MeSH Term

• **Khresmoi**: partnership with HON for showing results
  • “Khresmoi for Everyone is a search engine for online health information.”

others
• URAC:
  • Accreditation company for health institutions
  • Also does web-site accreditation.

• Discern: is a questionnaire which can be used to judge the reliability of a publication as a source of information about treatment choices.

• NETSCORING was developed to provide a set of criteria that can be consistently used to assess the quality of health information on the Internet. There are 49 criteria which fall into eight categories: credibility, content, links, design, interactivity, quantitative aspects, ethics, and accessibility.

From [EUROQC]

EU – Quality criteria for Health related websites

“The purpose of the eEurope 2002 action on Quality Criteria for health-related Websites was to encourage the adoption of a common set of basic quality criteria for such sites. The issue of whether and how these criteria might be implemented at European level was not within the terms of the action.”

From [EUROQC]
EU – Quality criteria for Health related websites

• In addition to community law
  • Which include “medical advertising”, “data protection”, “defective products”, etc.

EU – Quality criteria for Health related websites
- Criteria

• Transparency and Honesty
  • (HON: Authoritative, Transparency)

• Authority
  • (HON: Attribution)

• Privacy and data protection
  • (HON: Privacy)

• Updating of information
  • (HON: None)

• Accountability
  • (HON: Some aspects on Transparency)

• Accessibility
  • (HON: Some aspects on Transparency)

[EUROQC]
notes

Some points

• Health workers should have internet access
• Health workers should have/be provided training for assessing internet information
• Health workers should be knowledgeable on sites of his/her area
  • Societies driven
• Government should periodically peer-review their contents for accuracy

Adapted from [AUTHUTIL]
Some points (cont.)

- Treatment facilities should provide accurate information
- Quality standards should be applied
  - Enforced/re-assessed externally
- Information on practitioners should be accessible on the web
- Patient satisfaction surveys on the quality of information
- Consumer, patient, public education on information evaluation

Briefly other uses
As a tool

• **Online disease Management**
  - Register data, reminders, analysis
  - Ex.: Sugar Stats (diabetes), ChartMyself (several symptoms to be recorded), MedHelp (several tracking tools)

• **Administration stuff**
  - Repeat prescriptions, make appointments
  - Ex.: EmisAccess (UK), PDS/Área do Cidadão do SNS

• **Support groups**
  - Ex.: MDJunction list

Social networking

• **Cure together**
  - Acquired by 23andMe

• **Patients Like Me**

  • Enables sharing, searching, comparing symptoms, treatments, health data
  • “Learn from others experience”
  • Different business models associated
    - Sending advertisement for clinical trials on behalf of drug makers, book and product sales (CureTogether)
    - Selling non-identified/aggregated data (PatientsLikeMe)
As online EHR

- Examples:

  - Microsoft Health Vault
  - Google Health

Where next?

Jeff Livingston, an obstetrician and gynaecologist in Irving, Texas, said his 10-doctor practice has about 600 Facebook fans and more than 1,500 Twitter followers. They not only use the social networking service to communicate through text messaging, but can read and comment on postings about birth control, breast feeding and a variety of other health care topics.

From *E-health and Web 2.0: The doctor will tweet you now*  
Computer World, May 20, 2010
End of Telemedicine on the internet

(hope not 😞)

References

- [HON-PRES] Celia Boyer “Health On the Net Foundation: assessing the quality of health Web page all over the world”, presentation
References

- [PosTestKayhan] Varol Onur Kayhan, Seeking health information on the web: Positive hypothesis testing, International Journal of Medical Informatics, Volume 82, Issue 4, April 2013, Pages 268-275, ISSN 1386-5056

Acronyms

- HON – Health On the Net
- MeSH – Medical Subject Headings
- UMLS – Uniform Medical Language System