Online tools for the screening and diagnosis of dementia: aging, tech, ethics?

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John K Friesen Conference
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A familiar scenario

Unfortunately, There’s No Field Of Science That Deals With The Brain

BUT I Can Give You A Pamphlet For A Cult

Pew Research Internet Project 2012, Kitchens et al., 2014, Robillard et al., In Press, 2015
Roadmap

- Online health information matters
- Self-assessments for Alzheimer disease
- Tackling the ethical challenges
Every demographic group is engaging online.

Internet use by age group, 2000-2012

% of American adults age 18+ who use the internet

- 18-29
- 30-49
- 50-64
- 65+

Pew Research Internet Project 2012
Internet users seek health information

search queries in the next 60 seconds

80% of Internet users seek health information online

Do I have Alzheimer’s?

Google Canada

Pew Research Internet Project 2012
Internet users self-assess their health

35% of US adults turn to the Internet to establish whether they or someone they know suffer from a medical condition
Online health information matters

Online health information poses ethical challenges

- Who benefits from online health information?
- Who is harmed by online health information?
- Is the online consent process valid for everyone?
- How can we safeguard users’ privacy?
- How can we mitigate conflicts of interest?
Online self-assessments

What is the quality of freely accessible online tests for Alzheimer disease?
## Quality of online tests for Alzheimer disease

<table>
<thead>
<tr>
<th>Objective</th>
<th>Methods</th>
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<tbody>
<tr>
<td>Evaluate the quality of freely accessible online tests</td>
<td>Information mining</td>
</tr>
<tr>
<td>Criteria:</td>
<td>Expert panel review</td>
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<tr>
<td>1) Scientific validity</td>
<td></td>
</tr>
<tr>
<td>2) Human-computer interaction items</td>
<td></td>
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<tr>
<td>3) Ethics items</td>
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</tbody>
</table>

2X

- NPT
- Clinician
- HCI Specialist
- Ethicist
**Test characteristics (N=16)**

<table>
<thead>
<tr>
<th>Type of host</th>
<th>News, not-for-profit, academic, commercial, entertainment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monthly traffic to host</td>
<td>200 – 8.8M</td>
</tr>
<tr>
<td>Estimated time to completion</td>
<td>2 – 60 min</td>
</tr>
</tbody>
</table>
| Test administration | Self (13)  
Proxy (3) |
| Types of questions | Questionnaire (6)  
Performance (10) |
| Possible outcomes | 2 or 3 categories (9)  
Continuum (3)  
Pass/fail (2)  
Fail (1)  
None (1) |
The scientific validity of online tests is poor.
Take-home message

Most tests do not provide useful information about cognition or dementia
Online tests do not adhere to ethical norms

- **Conflict of interest**
- **Consent**
- **Privacy**

Expert rating

- Clinician
- Ethicist
- HCI
- NPT

Robillard et al., In Press, 2015
Take-home message

Some tests are potentially harmful because the online environment does not require high ethics standards
Good tests, bad tests?

An ‘F’ for Online Dementia Tests

Neurology Now
December/January 2013 Volume 9(6) p 30–32

Most Online Tests For Alzheimer's Disease Fail On Scientific Validity, Reliability And Ethical Factors

Don't Trust Online Tests For Alzheimer's Disease
Tackling the ethical challenges

• Who benefits from online health information?
  – Broad reach, high quality, readability, usability

• Who is harmed by online health information?
  – Wording, presentation, complementarity

• Is the online consent process valid for everyone?
  – Testing, empirical evaluation

• How can we safeguard users’ privacy?
  – Clear terms of agreement, best practices

• How can we mitigate conflicts of interest?
  – Transparency, education
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