

Littératie en Santé

Recherches, Pratiques et Systèmes

1<sup>ères</sup> Journées Francophones

# Internet et littératie en santé

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13 & 14  
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Lyon - France

## Internet & health literacy

*What are we talking about?*

Internet & health...  
E-health?

*E-santé?*

Digital health?  
*Santé numérique?*  
*Santé connectée?*

- ✓ Internet information?
- ✓ Telemedicine?
- ✓ M-health?
- ✓ Communication technologies?
- ✓ Social media?
- ✓ Smart objects?

Health...  
✓ services?  
✓ treatments?  
✓ care?  
✓ promotion?

Of...  
✓ Patients?  
✓ Professionals?  
✓ Health insurers?  
✓ Decision makers?

E-health literacy?

*Littératie en e-santé?*  
*Littératie en santé digitale?*

« Capacité des individus à repérer, comprendre, évaluer et utiliser des informations utiles pour pouvoir fonctionner dans le domaine de la santé et agir en faveur de leur santé »

## Internet & health literacy

*What are we talking about?*

- Evolution in internet & health literacy related studies?
  - **First phase:** Early 2000's, advent of the internet as a public source of health information. Studies on
    - ✓ Quality of health information and information seeking techniques (in response to professionals' fears => need to intervene?)
    - ✓ Sense making, and consequences, of information seeking practices from non professionals (social sciences studies)
    - ✓ Online communities
    - ✓ *Content and organisation of internet space*
  - ⇒ **Academic and professional concerns about what the « public » can do with health information. Trend is to control, even restrain, access to online health sources.**
  - ⇒ **Literacy (as defined early) is therefore not a primary question in this context**

- Evolution in internet & health literacy related studies?
  - **Second phase**: Mid 2000's to early 2010's, reinsurance about the impacts of the internet on the health of information seekers.
    - Social studies tend to show
      - ✓ Information seeking in echo to everyday concerns around health and illness
      - ✓ Informed patients as an opportunity to an improved patient-doctor relationship
    - On the side of professionals, context is changing
      - ✓ Health democracy => place and word to the patient (health care system user)
      - ✓ Unstoppable progress of communication technologies
      - ✓ Health care system rationalisation
      - ✓ Patient education

## Internet & health literacy

*What are we talking about?*

- Evolution in internet & health literacy related studies?
  - **From early 2010's**, the question of the Internet and what people do with it, is abandoned (*by social scientists*) in favour of
    - ✓ Medical studies about e-/Internet interventions in the perspective of improving health care
    - ✓ Psychologists in the exploration of enhanced competences via Internet-based devices and/or interventions
    - ✓ Health promotion professionals and scientists facing the risk of excluding vulnerable groups from health promotion actions

⇒ **Internet & health studies make place to literacy studies**

⇒ **Emergence of the question of « differences » between groups**
  - **Mid 2010's to date**, growth of literacy studies, focus on social disparities, HL measuring tools...
    - ⇒ **Surprisingly, social sciences are rather absent... except for endorsing a more critical position** (Del Rio Carral, 2017)

## Internet & health literacy: *2 questions...*

- 1) From Internet & health studies in the 2000's, what are the lessons that could contribute to the development of current e-HL studies?
- 2) What can qualitative research bring to current studies in e-health literacy?

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## 1) From Internet and health studies: *What are the lessons?*

- Technology
- Information online sources
- Quality information
- ...

From the question  
of « acces to »

To the question of  
« uses »

- Health and well-being information seeking
- Social networking
- Expertise building
- Illness self-management

## 1) From Internet and health studies: *What are the lessons?*

- Does the person rightly understand the searched and/or provided information ?

From the question of  
« understanding »

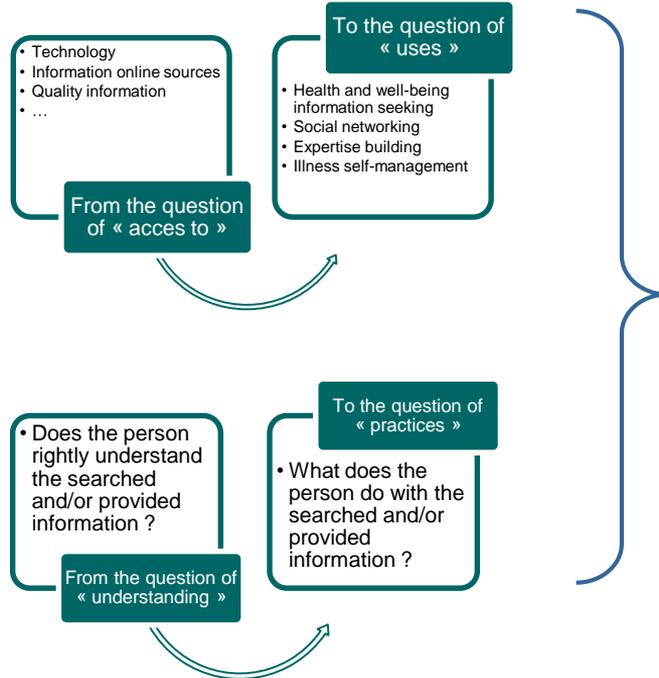
To the question of  
« practices »

- What does the person do with the searched and/or provided information ?

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## 1) From Internet and health studies: *What are the lessons?*



- **Linking individual action to social context**
- **Thinking about capacities rather than competences**
- **Considering resistance practices**
- **Approaching media technology as a perfectly integrated component of social world (domestication)**

## 2) Qualitative research and e-HL studies: *What added value?*

- **Qualitative health research?** “Any type of research, conducted in the field of health, implementing methods of data collection and analysis methodologies [*providing*] access to the **in-depth understanding** of the phenomenon investigated” (Kivits et al.,2016)
  - In Internet studies, the focus was on the “making sense of” seeking health information practices in relation to
    - ✓ An evolving media environment (internet-based)
    - ✓ The everyday life (with or without illness)
    - ✓ The relationship with health professionals
    - ✓ Patients’ expectations and experiences (necessarily, various...)

*Sociology of Health & Illness Vol. 25 No. 6 2003 ISSN 0141-9889, pp. 589-607*

**‘Ignorance is bliss sometimes’: constraints on the emergence of the ‘informed patient’ in the changing landscapes of health information**

**Flis Henwood<sup>1</sup>, Sally Wyatt<sup>2</sup>, Angie Hart<sup>3</sup> and Julie Smith<sup>4</sup>**

## 2) Qualitative research and e-HL studies: *What added value?*

### ■ **Qualitative health research ?**

- In e-HL studies, the focus could be better put on the **social appropriation of medical / health information**, meaning
  - ✓ The integration of the information into an everyday environment (from behavior change to deliberate ignorance)
  - ✓ The reception context that cannot be limited to socio-economic characteristics, but needs to be considered in its temporal, social and practice dimensions (L. Quéré)
- Today, qualitative studies in e-HL seem to be focused
  - ✓ on difficulties (and opportunities) in using internet, apps, e-monitoring, telemedicine services...
  - ✓ on users' perceptions of the e-health offers

Quick search on  
pubmed

« ehealth literacy AND  
qualitative research »  
51 occurrences...

J Med Internet Res. 2013 Feb; 15(2): e27.

PMCID: PMC3636295

Published online 2013 Feb 11. doi: [10.2196/jmir.2428](https://doi.org/10.2196/jmir.2428)

PMID: [23399720](https://pubmed.ncbi.nlm.nih.gov/23399720/)

Measuring Actual eHealth Literacy Among Patients With Rheumatic Diseases: a Qualitative Analysis of Problems Encountered Using Health 1.0 and Health 2.0 Applications

Monitoring Editor: Gunther Eysenbach

Reviewed by Michael Stelfox and Efrat Neter

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## 2) Qualitative research and e-HL studies: *What added value?*

- **Qualitative health research ?**
  - More generally, qualitative approach could help
    - ✓ Better conceptualizing but also providing empirical highlights on underlying and central notions in HL

Autonomy

Capacities

- ✓ Exploring information reception contexts
- ✓ Anchoring digital environment in the social world

### To conclude...

*Internet, HL and Social sciences:*

*Where shall we go?*

- Towards an **anthropology of information practices**
  - Highlighting
    - ✓ Contextual components of literacy (not necessarily linked to health and / or illness...)
    - ✓ information « poaching » => *braconnage* (de Certeau)
    - ✓ Notions of autonomy (limits ? interpretation ?) and capacities (concrete expressions in the social world ?)
  - Contributing to
    - ✓ Evaluation and adjustment of existing HL interventions
    - ✓ Measuring and quantitative approaches of HL
    - ✓ The understanding of production mechanisms of social inequalities in HL
  - Based on qualitative methods
    - ✓ Ethnographic observations
    - ✓ Narrative interviews (*récits de vie*)

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