

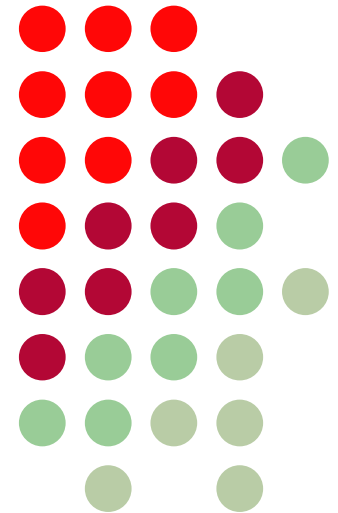
Patients mailing lists: a responsible resource

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Internet and health

- Health issues:
 - a major motivation for Internet consultation
 - Proliferation of websites and diversity of producers
 - Proliferation of services and activities
- An important concern for professional people
 - Quality, quantity and uses of information: toward the chaos and the confusion?
 - Question on the impact on the relationships with patients
 - An uncertain responsibility
- Mailing lists
 - “closed”: imply a subscription
 - =>anonymity is quite infrequent
 - No necessary skill (a very simple tool)
- Publications
 - M. Akrich et C. Méadel, « Engagements et participations des collectifs électroniques. Les nouveaux militants de la santé », *Hermès*, n°47, 2007.
 - M. Akrich, C. Méadel et C. Rémy, “Building collectives via the web? Information and mobilization on cancer websites”, Conference *Virtually informed*, Vienna, January 2008.
 - M. Akrich et C. Méadel, « Prendre ses médicaments / prendre la parole : les usages des médicaments par les patients dans les listes de discussion électroniques, *Sciences sociales et santé*, vol.20, n°1, 2002, pp 89-116.

Three kinds of agency

- Support
- Collective Action
- Knowledge production

Knowledge production

- A wide range of sources
 - From scientific and medical knowledge
 - To Personal accounts: self-centred to general issue
- Mixing up to produce an original knowledge
- Developing a valuable information
 - Esquivel, Adol, Meric-Bernstam, Funda et Bernstam, Elmer V, "Accuracy and self correction of information received from an internet breast cancer list: analysis of posting content", BMJ, 2006, 10, 1136.

Collective action

- An ambivalent mechanism :
 - no well defined position or clear agenda
 - A reluctance to act as a structured group
- A fuzzy and labile identity
- A (possible) political action.
- => Patients mailing lists as laboratories for information and convictions

Which regulation. An example: The Eurordis Charter

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- A collaborative (but distant) work
 - Fifteen “experts”: seven e.health group managers, two medical webmasters (physicians; the hoster of the site), and specialists of medical information or discussion lists.
- A normative approach
 - “The aim of this Charter is to propose guidelines to regulate patients’ email discussion lists. The Charter specifies the correct rules of community life for this type of exchanges”

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http://www.eurordis.org/article.php3?id_article=1018

Issues for regulation

- The crucial role of moderators to maintain the group and protect the members
- Content status linked to the definition of the groups' policy
- Relationships with clinicians: respect and distance

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Mailing lists for rare diseases:
<http://www.medicalistes>.

To conclude: relevance and value of the health mailing groups

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- The mailing lists are places
 - Information is debated, opinions are confronted, discourses and arguments are elaborated
 - Common tools are possibly constructed - exploiting the specific resources provided by the medium - which « equip » and transform individuals
- And the mailing lists are specific organizations
 - With a fussy and labile identity
 - An informal commitment (which could be huge however)
- Eventually, their debates can impact existing organizations, but indirectly or tangentially.