

# E Patient

## A Step Towards Empowerment in the Field of Rare Diseases



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### Introduction

Health is today the number 1 use of Internet.  
 E patients are health consumers who use the internet to gather, share, produce information about a medical condition of particular interest to them.  
 Health social networks are becoming an important entity of influence in the medicine of the future, as they are generated bottom-up rather than top-down, by patients.

### The E Patient experience

E patients are increasingly active in their care and are demonstrating the power of the Participatory Medicine or Health 2.0 / Medicine 2.0 model of care.

They are

- equipped,
- enabled,
- empowered,
- engaged,
- equals,
- emancipated and experts.

Analysis of our Rare Disease E Community via Facebook showed some influence areas and new skills development similar to other studies (GER E Patient study, fig 1 and fig 2).

#### Influence Areas

- peer definition, discussion on diagnosis, symptoms, every day life as a patient
- treatments and treatment alternatives
- choosing and ranking (reputation) of doctors, hospitals and other treatment and care persons and institutions
- pros and cons for medication, side effects, alternatives.

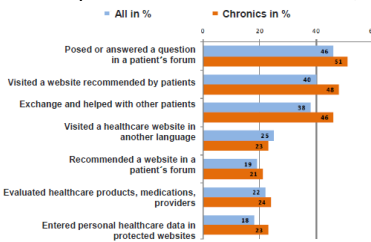


Figure 1: Patient communication activities

#### Development of New skills

Our Community member informs himself and others, connects, collaborates, participates, finds and gives personalized and optimized orientation and evaluation, changes attitudes, behaviour, decisions on outcomes, contact or non-contact to stakeholders, generates a digital demand that is not fulfilled by today supply, prefers patient made content, communities over institutional sources, compares and spreads treatment guidelines and perceives digital healthcare as highly relevant and useful.

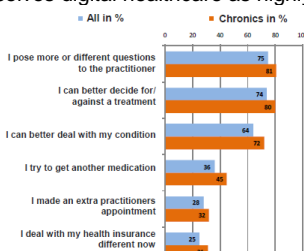
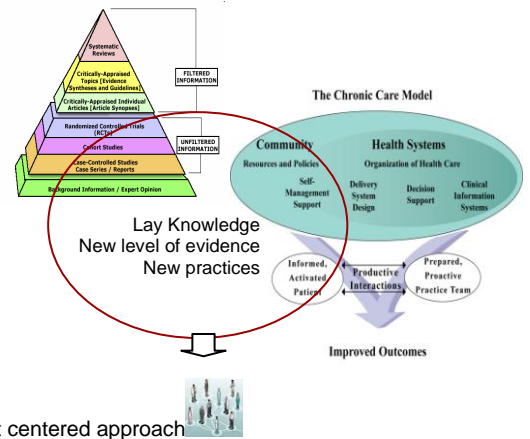


Figure 2: Patient's attitudes

### E Patients, Health Social Networks and Models of Care

Health Social E Networks the missing link from the level of evidence towards a patient centered (personalised) medicine

- expert patient and Wiki tools will provide an additive level of evidence
- engaged patient will be in the center of medical co-decision
- peer to peer and community interactions will enrich the patient centered model of care.



patient centered approach

### Perspectives

#### 1. E Patient and Health social media will Challenge the healthcare system

Healthcare System	Social Media
Control of knowledge and access by authority and institutions. Centralized intermediation	Information is free, peer production "Wisdom of Crowds", Decentralized disintermediation
"reform" is linear, very slow, interest-focused and dictated	Non-linear Innovation "on the fly", "open innovation"
"risk averse", filter then share	"risk taking", share then filter
Proprietary product knowledge, firm-based, patented	Open source, product transparency "commons-based peer-production"
Closed network, strong ties, "B2B"	Open network, "Strength of weak ties", C2C
Regulated supply, no price economy	Deregulated and increasing demand, Economy of awareness and relevance

Mindest: system made, "healthcare online is dangerous"

Mindest: liberal and heterogenous, "healthcare online works"

- #### 2. and Reshape patient participation
- peer and community collaborations versus medical professionals and decision makers
  - going mobile via smart solutions
  - promoting innovation and new practices
  - co-acting of medical decision, prescriptions, health provisions, research...
  - providing outcomes via patient reported information

### Conclusion

E patients are increasingly active in their care and are demonstrating the power of the Participatory Medicine or Health 2.0 / Medicine 2.0 model of care. Decisions makers should encourage a process whereby patients play an increasingly important role in the management of their health, and social networks in a community health and outcomes research perspective. Success will rely on new business model based on the absence of commercial value on the "patient community" ownership of medical data.  
 Development of an E Patient multimedia secured and interoperable 2.0 platform by patients' communities is needed.

