



# E-health and the changing role of the patient:

## What will the future bring?

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*"Nurse, get on the internet, go to SURGERY.COM, scroll down and click on the 'Are you totally lost?' icon."*

## Content

- 1. E-health: What it is, and what it isn't**
- 2. E-patient: The changing role of the patient**
- 3. My dreams for 2020**

## **1.E-health**

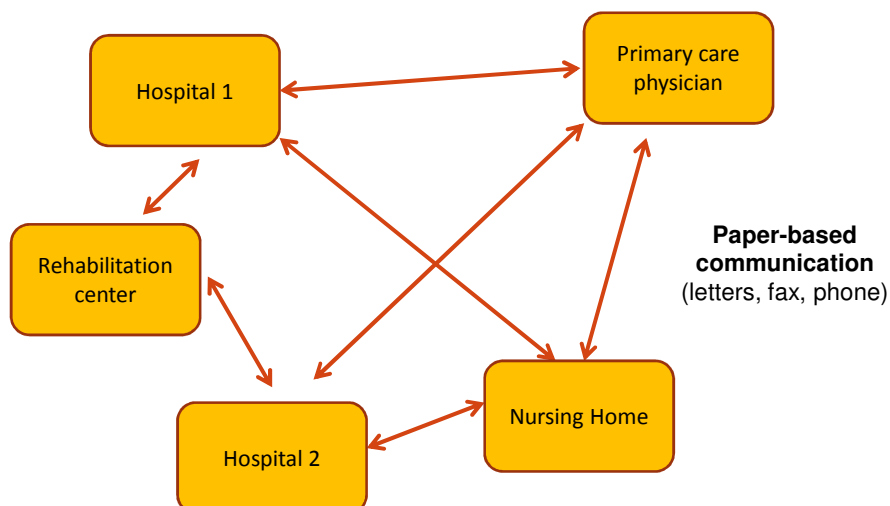
### **What it is, and what it isn't**

## E-health: What is it?

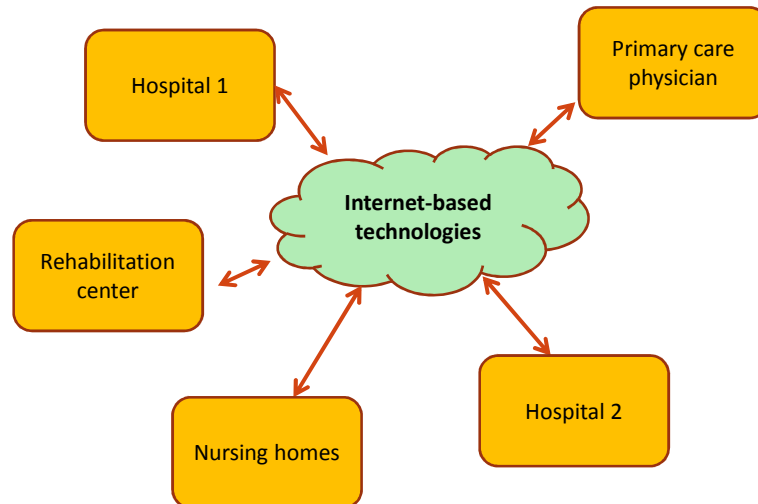
“E-health is the use of emerging information and communication technology, especially the Internet, to improve or enable health and healthcare.”

(Eng T. The e-health Landscape – a terrain map of emerging information and communication technologies in health and health care. Princeton NJ: The Robert Wood Johnson Foundation; 2001. <http://www.hetinitiative.org/media/pdf/eHealth.pdf>)

## Communication before „e-health“



## Communication after „e-health“



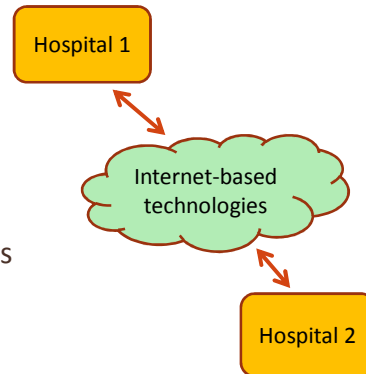
## E-health scenarios

- Scenarios for internet-based communication:
  - Business-to-business communication
  - Business-to-consumer communication
  - Consumer-to-consumer communication

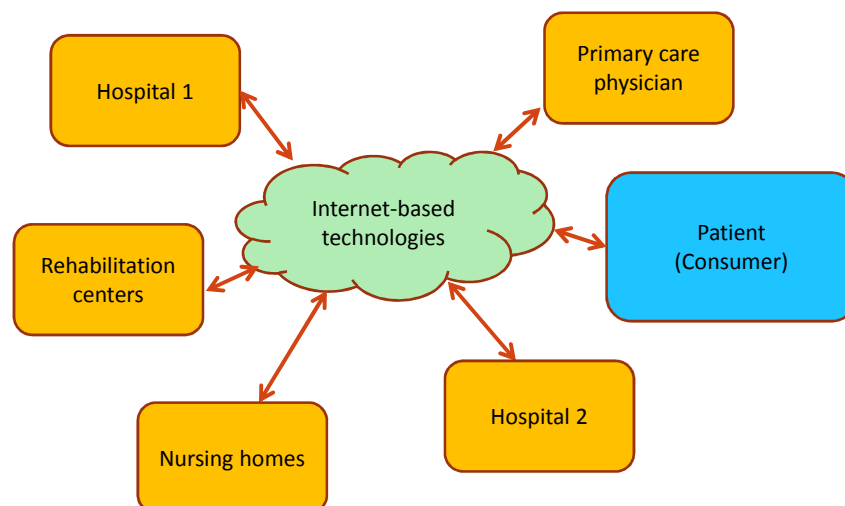
## Business-to-business communication

- **Business-to-business:** exchange of information between health care organizations

- Exchange of referral information
- Exchange of discharge letters
- Teleconsultation
- Telepathology
- Telesurgery
- National electronic health records
- .....



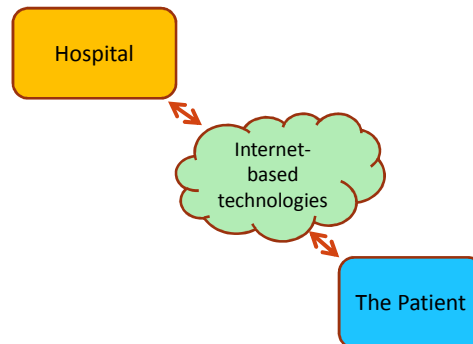
## Communication after „e-health“



## Business-to-consumer communication

- **Business-to-consumer:** exchange of information between health care organizations and their patients

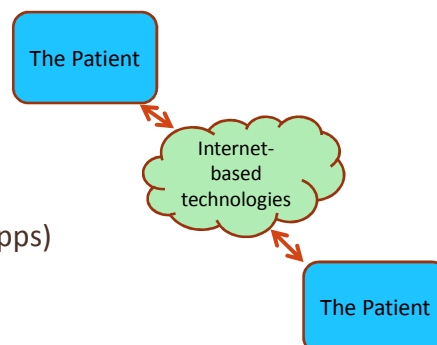
- Appointment scheduling
- Secure messaging
- Medication refills
- Telemonitoring
- Tele-Education
- Patient portals
- E-visits
- ...



## Consumer-to-consumer communication

- **Consumer-to-consumer:** documentation and exchange of information between patients and for patients

- Social networks
- Internet support groups
- Personal health records
- Mobile health
- Quantified self
- Health games (educational apps)
- ...



## E-health: News ways of communication

- Summary: E-health is about news ways of communication, about sharing of information
  - Between health care organizations and their patients
  - Between patients
- *But is e-Health only about “communication”?*
- **E-Health is also about cooperation and collaboration!**

## E-health: News ways of thinking

E-health is

“not only a technical development, but also  
 a state-of-mind, a way of thinking, an attitude,  
 and a **commitment for networked, global thinking,**  
 to improve health care locally, regionally, and  
 worldwide by using information and communication  
 technology.”

G. Eysenbach, What is e-Health, 2001,  
<http://www.jmir.org/2001/2/e20/>

## E-health: New role of the patient

**Encouragement**

**Empowerment**

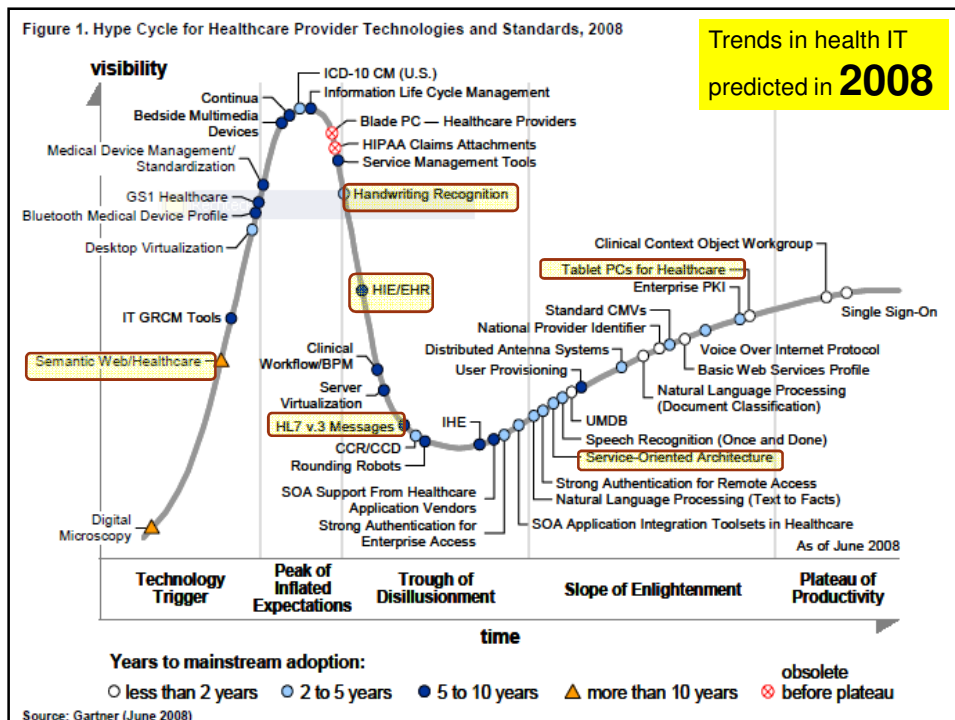
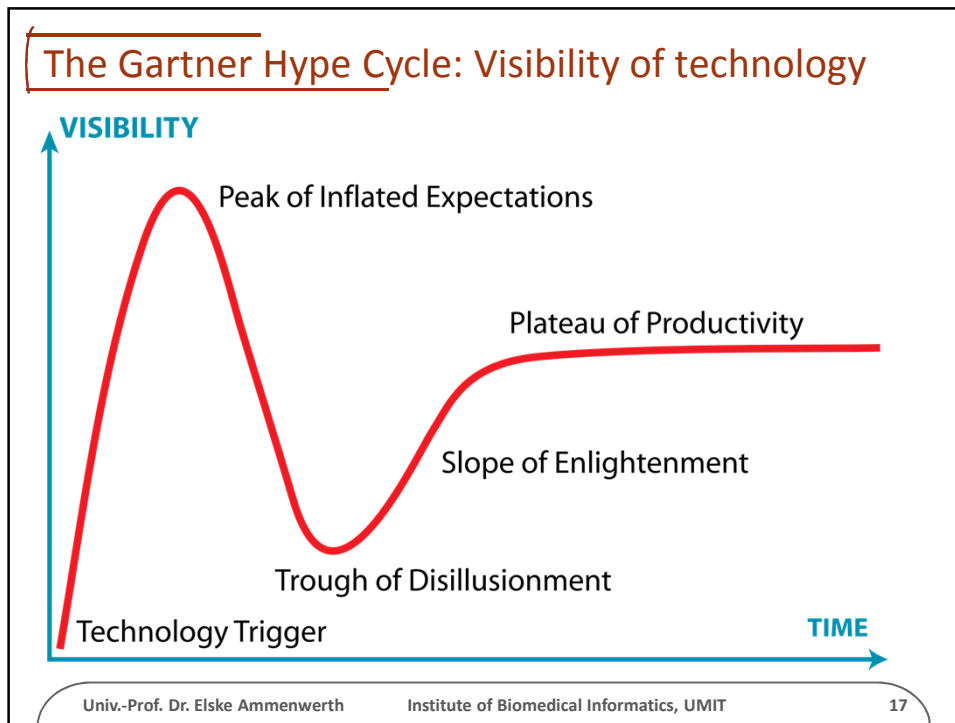
**"... a new relationship  
between the patient and health professional,  
towards a true partnership, where decisions are  
made in a shared manner.."**

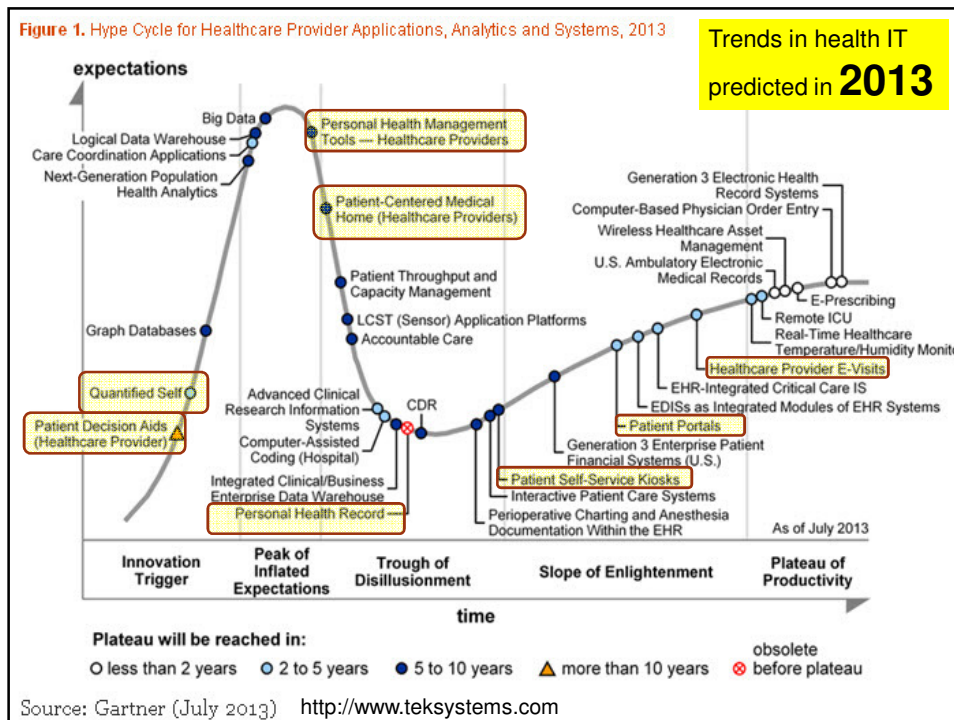
G. Eysenbach, What is e-health, 2001, <http://www.jmir.org/2001/2/e20/>

## 2. E-patients

**The changing role of the patient in e-health**







## Gartner hype cycle

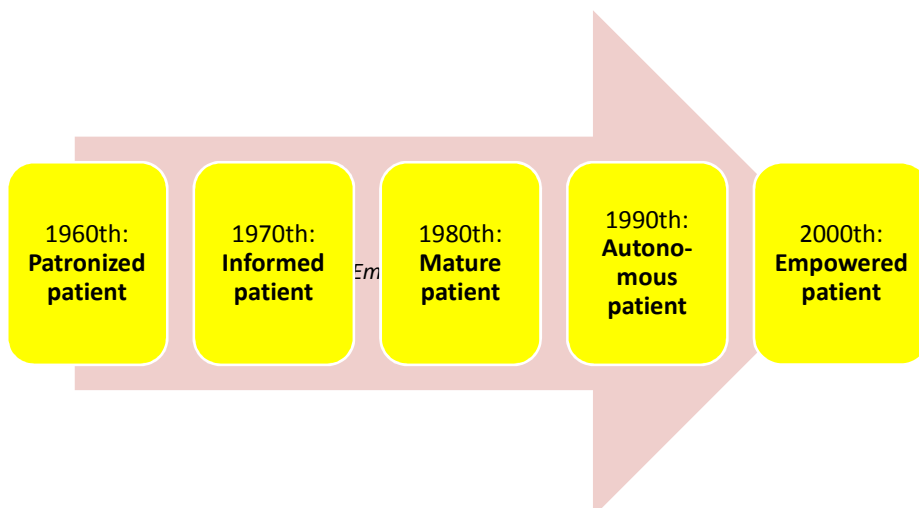
- Clear shift from technology-centred view (2008) to patient-centred (or consumer-centred) view (2013)
- *Does this reflect a new role for the patients and a trend towards patient empowerment?*

## Patient empowerment

- Based on a philosophy which views humans as having the **right and ability to choose by and for themselves**.
- Patients are **responsible for their choices** and the consequences of their choices.
- Patients are able to make autonomous, informed decisions, within a **true partnership** between patient and health care professional.

Anderson RM et al. Patient Empowerment: Myths and Misconceptions. Patient Educ Couns. 2010; 79(3): 277–282.  
 Aujoulat I et al. Patient empowerment in theory and practice: Polysemy or cacophony? Patient Educ Couns 66 (2007) 13–20.

## Patient empowerment



Nagel G. Patientenkompetenz. Krankenhauspharmazie 2005;26:128-33.

## Patient empowerment

- A **process of communication and education** in which
  - knowledge and power are shared between patient and healthcare provider, and where
  - patients are enabled to act autonomously.
- **Evidence** shows:
  - Patients want to be empowered
  - Empowered patients show better clinical outcome
  - Patients are getting active and demanding

Aujoulat I et al. Patient empowerment in theory and practice: Polysemy or cacophony? Patient Educ Couns 66 (2007) 13–20.



## E-patients

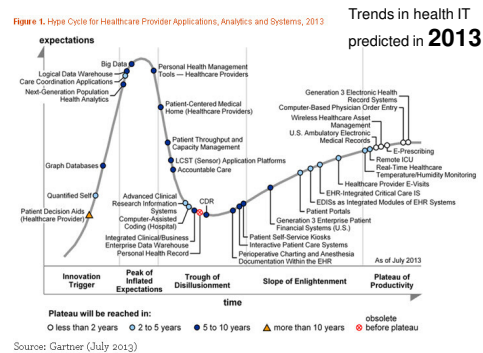
**E-patients** describe individuals who are

- equipped,
  - enabled,
  - empowered and
  - engaged
- in their health and health care decisions.

Ferguson T. e-Patients. 2007. [http://e-patients.net/e-Patient\\_White\\_Paper\\_with\\_Afterword.pdf](http://e-patients.net/e-Patient_White_Paper_with_Afterword.pdf)

## „Equipment“ for E-patients

- Internet-based information resources
- Social networks
- Internet-based patient support groups
- Personal health records
- Mobile health tools
- Quantified self
- Patient portals
- ....



## Patient portals: Definition

### Patient portal:

Provider-tethered applications that allow patients to electronically **access his health information** that is documented and managed by a health care institution

Patient portals are **owned and administered by health care institutions**

Ammenwerth E et al. The Impact of Electronic Patient Portals on Patient Care: A Systematic Review of Controlled Trials. J Med Internet Res 2012;14(6):e162.

## Patient portals: Levels of functionality

### Level 1:

**Access to clinical data from the electronic patient record of that hospital**

(such as lab results, discharge letters, medication)

### Level 2:

**Communication between patient and healthcare institution**

(such as appointment scheduling, secure messaging, e-Visits)

### Level 3:

**Disease-specific functionalities as part of disease management programmes**

(such as personal reminders, guidelines, educational material, self-documentation)

## Patient portals

Home Messages Appointments Medications Forms Insurance Statements My Health

Dorothy Watson

Quick Links

Request an Appointment Refill a Medication Request a Referral

9 Appointments

Date / Time	Location	Provider	Patient
Fri, Jul 06 2012 @ 9:45 AM	North Avenue	Lisa Campbell	Dorothy Watson
Wed, Jul 11 2012 @ 9:00 AM	Main Street	Lisa Campbell	Dorothy Watson

Medications

Name	Start Date	Prescribed By	Source
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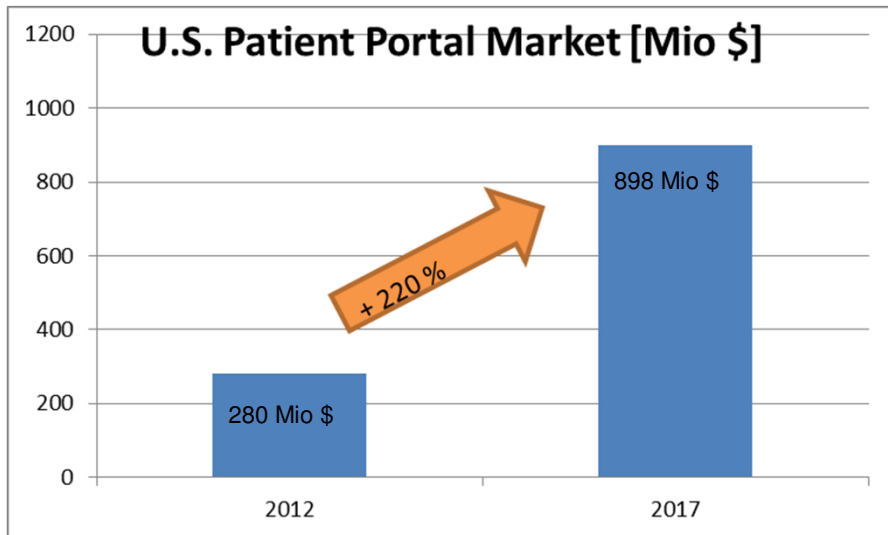
Practice Pages

<http://www.intelichart.com/patient-portal-overview>

## Patient portals: Adoption

- **57%** of U.S. health care organization are offering a patient portal (KLAS, 2012: Patient Portals 2013: On Track for Meaningful Use?).
- **36%** of U.S. patients have access to their records via a patient portal (Accenture, 2013: Survey on Patient EMR Access).
- Meaningful Use Stage 2 requirements are **accelerating patient portal adoption in the U.S.** (KLAS, 2012: Patient Portals 2013: On Track for Meaningful Use?).

## Patient portals: Market



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Frost & Sullivan 2013. <http://www.frost.com/prod/servlet/press-release.pag?docid=285477570>

## Patient portals: Austria

<https://www.patienten-portal.kages.at/>

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## Patient portals: Austria

### eRöntgenpass

Im eRöntgenpass erhalten Sie Informationen über alle radiologischen Untersuchungen, die Sie in den LKHs der KAGes erhalten haben und die dabei aufgetretene Strahlenexposition. Derzeit sind im eRöntgenpass Untersuchungen seit 01.01.2014 enthalten.

### Befundabruf (geplant)

Über diese Anwendung wollen wir Ihnen in Zukunft die Möglichkeit anbieten, Ihre persönlichen ambulanten Befunde, stationären Entlassungsbriefe und Radiologiebefunde abzurufen.

### Buchung von Ambulanzterminen (geplant)

Über diese Anwendung wollen wir Ihnen in Zukunft die Möglichkeit anbieten, für ausgewählte Terminambulanzen Termine zu reservieren.

<https://www.patienten-portal.kages.at/>

## Patient portals: Adoption

- *Why is adoption of patient portals so low in Austria and other countries?*
- Concerns by health care professionals?
- Data security concerns?
- Costs are too high?
- Impact is unclear?

## Impact of patient portals

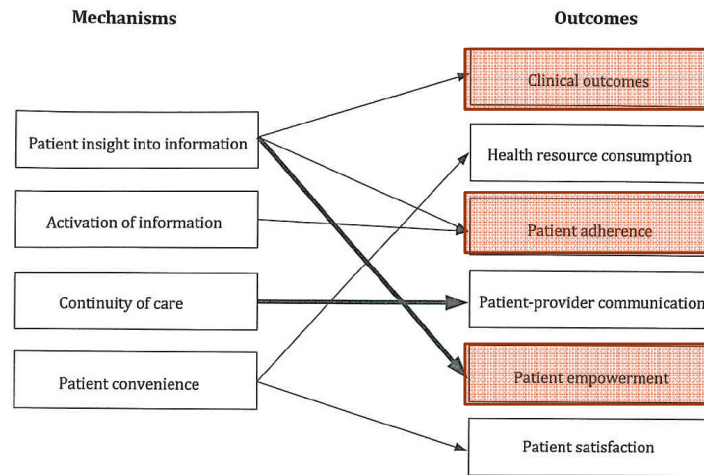


Figure 2 Hypothesized links between mechanisms and outcomes. The thin arrows signify that at least 50% of authors hypothesized that a given mechanism produced a given outcome. The thick arrows indicate that this was the case for at least 75% of authors.

Otte-Trojel T et al. How outcomes are achieved through patient portals: a realist review. J Am Med Inform Assoc. 2014 Jul-Aug;21(4):751-7.

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## Patient portals: Impact

- Systematic review **2012**: Four controlled impact studies on patient portals, not sufficient evidence

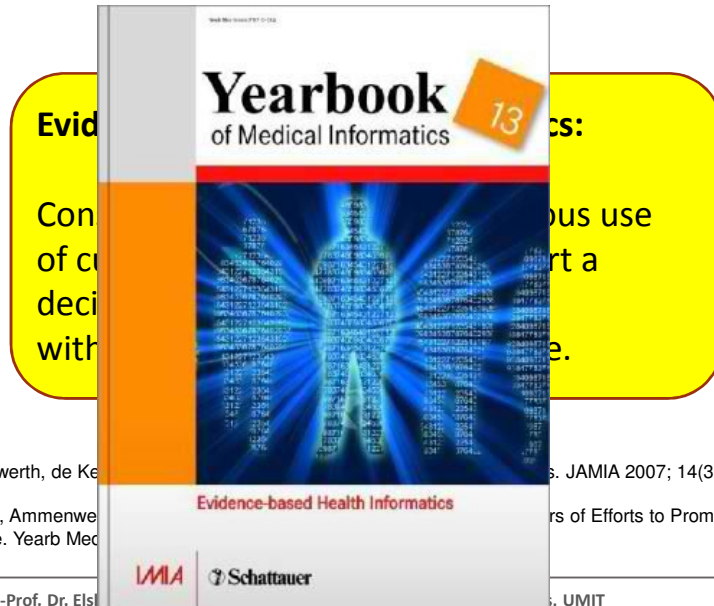
Ammenwerth E et al. The Impact of Electronic Patient Portals on Patient Care: A Systematic Review of Controlled Trials. J Med Internet Res 2012;14(6):e162.

- Systematic review **2015**: Update of Ammenwerth review, still not sufficient evidence

Kruse CS et al. The Effect of Patient Portals on Quality Outcomes and Its Implications to Meaningful Use: A Systematic Review J Med Internet Res 2015;17(2):e44

- Overall, **limited evidence** on impact of patient portals!

## Evidence-Based Health Informatics



## Patient portals: Challenge of evaluation

- Patient portals are so-called “complex interventions”:
  - Very **heterogeneous** intervention.
  - Very **different level of functionalities and content**.
  - Different **groups of patients** targeted.
  - High degree of **self-organization** over time.
  - Variability of **outcomes**.
  - Multiple **mediator variables** affecting outcome.

## Patient portals: Challenge of role change

- **Role of health care professional** is essential for patient empowerment and thus for impact of patient portal
- “If the **underlying relationships** between clinicians and patients **are not fundamentally transformed**, professional interventions will not empower patients!”

Ferguson T. e-Patients. 2007. [http://e-patients.net/e-Patient\\_White\\_Paper\\_with\\_Afterword.pdf](http://e-patients.net/e-Patient_White_Paper_with_Afterword.pdf)

## Patient portals: Success

**Success of patient portals** will not come from specific functionality, but from

“successfully communicating the idea that **patients can effectively manage their own illness.**”

Ferguson T. e-Patients. 2007. [http://e-patients.net/e-Patient\\_White\\_Paper\\_with\\_Afterword.pdf](http://e-patients.net/e-Patient_White_Paper_with_Afterword.pdf)

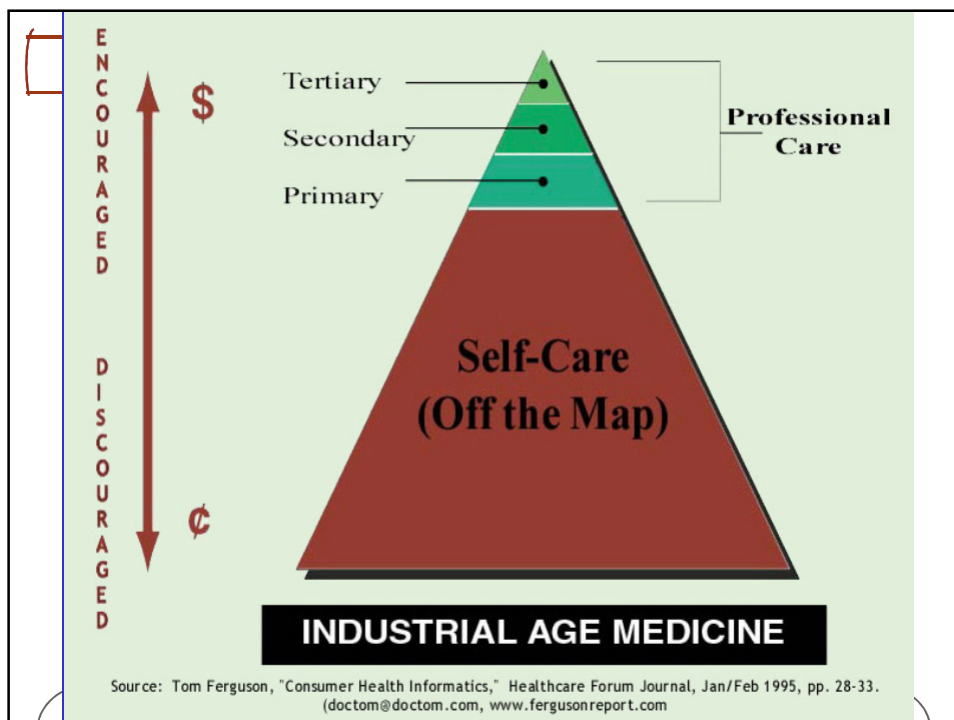
## E-patients: Summary

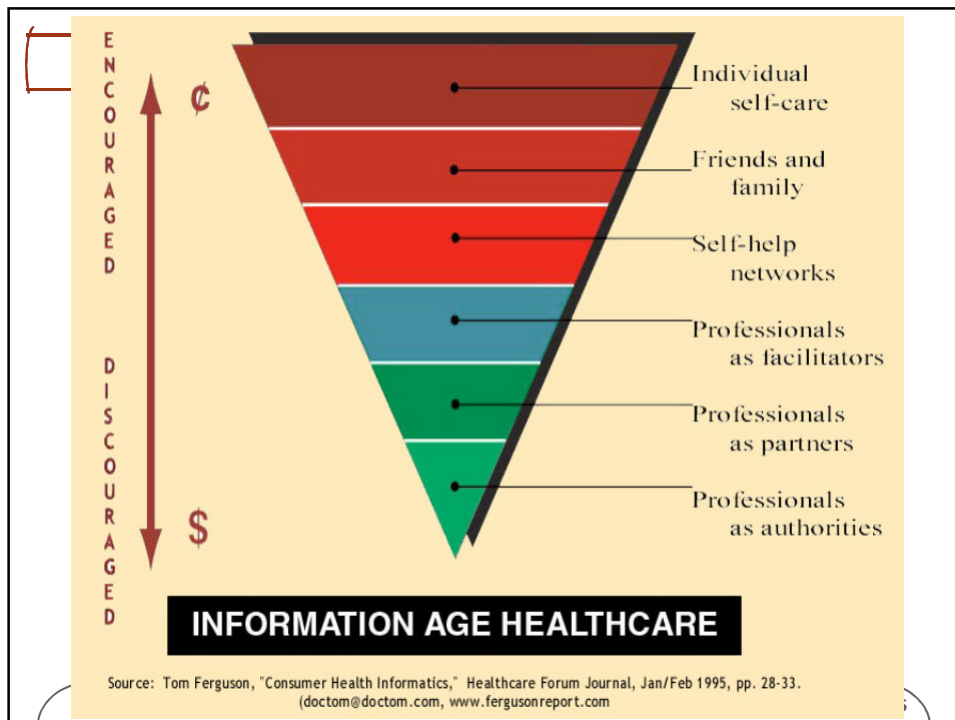
- Patient portals and other e-health interventions aimed at improving patient safety may only show impact
  - When **health care professionals** are willing to engage in a **true partnership** with the patient and to give up power
  - When **patients** are willing to take over **responsibility** for their own health management
- We need **more evidence** on mechanism and on impact of e-health interventions.

## 3. My dreams for 2020

## E-health in the year 2020

- We should not talk so much about **technical, legal or financial issues** when dealing with e-Health:
  - Interoperability and standards,
  - data integration,
  - data protection,
  - accreditation and certification,
  - and reimbursement ...
- ... but we should talk about a **new organization of health care**





Thus, in 2020 e-health should ...

... enable patient-centred management of health and care

... support coordination of health, social, informal and self care

... respond to needs of patients & families

... support patient empowerment and true partnership

... be based on evaluation and evidence

## Conclusion

1. E-health is not about technology, it is **about people and power**.
2. E-health can support a **paradigm change in health care**, with the patient more in the center.
3. E-health should support **self-care and informal care** more than professional care
4. **Patient empowerment** and patient engagement will be the key to high-quality health care.
5. **E-health** can support this, but change in **mindset** is needed.

„The key question we must ask is not what technology will be like in the future, but rather what **we** will be like.“

Sherry Turkle, MIT



Cited from: Ferguson T. e-Patients. 2007. [http://e-patients.net/e-Patient\\_White\\_Paper\\_with\\_Afterword.pdf](http://e-patients.net/e-Patient_White_Paper_with_Afterword.pdf)



## Further information

**eHealth summit 2015:** Vienna, 18. – 19. June 2015

[www.ehealthsummit.at](http://www.ehealthsummit.at)

**ENI: Nursing & Social Care Informatics 2015:** Hall, 28.-29. Sept. 2015

[www.kongress-eni.eu](http://www.kongress-eni.eu)

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