Patient empowerment in hospitals

Eric de Roodenbeke - IHF
Patient empowerment is not an option

- The burden of disease calls for more empowerment
- The internet is providing finger tip information
- Person centered care is a recognized Policy priority
- Individuals request more decision making rights
In addition to volume the complexity of Multi-chronic conditions and the incidence at younger ages are adding pressure along with ageing population.
Patient empowerment is not an option ➔ e_patient

<table>
<thead>
<tr>
<th></th>
<th>% of adults who go online</th>
<th>% of internet users who look online for health information</th>
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Source: http://www.pewinternet.org/2013/01/15/information-triage/
e_patient is a reality for hospitals

Before, During...and After

Source: Google & Compete, Hospitals Study, 2012 - USA
Patient empowerment is not an option: Person centered care

Patient empowerment is not an option: health democracy

Stakeholder representation

Scrutiny
Making a difference

ACCOUNTABILITY

Rule of law

http://www.sochealth.co.uk/2013/07/23/democracy-for-health/
Patient’s role in health care

Two major trends in patient empowerment:

- **Patient is responsible of his/her health:** behavior must change!

- **Practitioners should develop a more equal relation with patients:**
  From providers and experts deciding on behalf
  To health advisors guiding people decisions
Major trend: patient is responsible: Healthy lifestyle

Campaign making people responsible... (guilty) of their health status ➔ change

Behavior change is not just about information. It is also a societal issue:

- Work & transportation
- Cost of healthy food
- Agro business options
- etc

Source: dreamstime.com
Major trend: improve patient practitioner interaction

- Show me respect and compassion
- Give me the necessary information
- Listen to me and my family
- Invite us to ask questions
- Have enough time for a meaningful conversation
- Discuss options, risks, benefits and costs
- Include us in decisions about my care plan
- Tell us the follow-up plan and who to contact with any questions or concerns

WHO is leading a campaign calling on international mobilization for changing patient practitioner relations:

→ It relies on good will

Working together for better care and a better experience
Patient-practitioner: From Interaction to Collaboration

National survey also reveals people see benefits in monitoring and sharing their health information between visits.

88% believe that working with their health care professional AS A PARTNER will help them manage and improve their overall health.

Health care as collaboration = Participatory Medicine

84% believe self-tracking their health data* & sharing it with their health care professional (HCP) between visits would help them better manage their health.

Believe that easily and accurately monitoring their bodies is important to ...

- 76% would use a clinically accurate and easy-to-use monitoring device:
- 81% are more likely to use device if their HCP recommended it.

Source: http://participatorymedicine.org/patients-overwhelmingly-want-partnership-with-their-clinicians/

This trend will grow in coming years with support of health professionals. Does it need to be formalized ....or just be considered as the regular practice?
Another perspective on patient empowerment

Facilities have a key role to play:

- Health education highly relevant during health related episodes
- Their mission is health: staff, patients & families to be involved at all levels and stages
- Patients are not just consumers but at the center of a process.

Patient empowerment is critical for executives & governing bodies:

Not individual goodwill BUT creating enabling conditions
Regulation for patient’s involvement in Hospitals.

IHF & IAPO surveyed 27 countries: regulation exist for patients’ involvement in about half of countries.

Patient involvement is a reality in most hospitals when regulation does not make patient involvement mandatory. Most countries have arrangements to allow them to participate:

- Meetings of patients’ organizations
- Patients’ rights groups
- Complaint tools (boxes, hotlines, etc.)
- Customer feedback systems (survey, etc.)
- Voluntary work
- Informational/educational activities, campaigns and conferences
- Involvement in specific organizations/groups (e.g., consumer organization, public complaints committees)
- Ad Hoc participation
Some country experiences

**France:** regulated in dominant public environment

**Hong Kong:** combination of regulation and facilitation in public environment

**Colombia:** Some regulation in private dominant environment

**USA:** Initiatives in a market dominant environment with significant regulations
France: regulation does not make it all

Regulation and initiatives

- Early 80ies: Patients Bill of rights
- 1996: Patients representative enter the hospitals’ boards
- 2002: Patients Rights Law that promote a “sanitary democracy”
- 2005: New laws that enlarge the powers of patients organizations
- 2012: French federation of hospitals calls for the presence of patients representatives at all levels of decision

Reality: Survey March 2012

- 80% of Hospitals have at least two patients representatives in their board
- 85% have a patient representative who has access to claims sent to hospital
- 23% of patients know the existence of patients organizations... but only 14% how to reach them
- 7% have a «house of patients» dedicated to patients organizations.
- In these hospitals, only 12% of in-patients are well informed on these «house of patients»

SOURCE: FHF - FÉDÉRATION HOSPITALIÈRE DE FRANCE
Patient Engagement in Hong Kong Hospital Authority

One of HA’s strategic foci (*Strategic Plan 2012-2017*):

‘Enhance Partnership with Patients and Community’

**Strategies:**
- Involve patient groups and community partners in care delivery
- Engage patients and community partners in service improvement
- Patient-centered approach in communication
Empowering patients on disease management & provide information on community resources

Establishment of platforms for patient leaders to advise on service planning and development

Regular communication with patients & patient groups

Collect feedback from patients and careers on patient experience and satisfaction

Patient representatives in Board and Committees

Contribute to specific projects (hospital strategic planning workshops, redevelopment)
Understanding Patient Empowerment in Colombia

Supportive trends
- Universal ($) coverage
- Explicit patient rights & responsibilities
- Informed consent
- Choice of providers
- Rising individual liberties

Reality is less bright
- Access and quality of care: challenges
- Limited information on care
- Limited choice for care
- Financial constrains on all sides
- No incentives to involve patients

- Surveys on patient knowledge of rights, expectations and satisfaction
- Statistics on complaints & congratulations
- Mandatory committees: Hospital ethics Research ethics Patient associations
- Quality (voluntary) accreditation system is including patient orientation
Example of patient empowerment in a US hospital

- From patient experience to patient engagement
- Transitioning the organizational culture not just a program
- Research linking patient engagement to financial impact
- Provide financial reimbursement for non-traditional encounters
- Provide physician education and training on patient engagement
- Use of technology to increase engagement especially for:
  - Access, Information, Care coordination, Communication & Population health
Assessment and Monitoring Tools: increase standardization and accuracy of data collection, in a wide array of settings, in real time

Interventions: e.g., prevention interventions; behavior therapies; self-learning and self-management tools (skills training, goal setting/tracking, behavior change), games

Therapeutic support for individuals, families, and clinicians

Engage patients and a care network of their choosing (e.g., decision support systems, social media)
Perspectives on Institutional patient empowerment

- The global trend is for an increased formal role of patients
- Growing acceptance of an institutional role for patients in healthcare organizations
- There are no regional trends on patient involvement: situation vary from a country to another and in some cases within a country
- **Major challenge**: patient participation should actually impacts the organization of service delivery to better respond to people’s needs
- Technology offers many promises but much remains to do
- Healthcare executive have a critical role to play: Enabling conditions and supporting factors.