PATIENT EMPOWERMENT IN HEALTHCARE ORGANIZATIONS

Eric de Roodenbeke, PhD
CEO, International Hospital Federation
Patient empowerment is not an option

• The burden of disease calls for more empowerment

• The internet is providing finger tip information

• Individuals request more control and autonomy

• Health care is under much pressure: patients are key to solutions
Patient empowerment is not an option

Global burden of diseases
Patient empowerment is not an option

Internet provides all health related information

“More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google.”
Patient empowerment is not an option: e_health

Common words used to describe E-Patients based on October 2010 Google search:

- "e-patient"
- "Internet patient"
- "health seeker"
- "cyberchondriac"

"E-Patient" is a term used to describe individuals who use the Internet and other tools to seek out, share and sometimes create information about health and wellness.

61% American adults who have gone online to find health information.

51% People with chronic conditions who go online to find health information.

42% Adults who say they have or someone they know has been helped by following medical advice or health information found on the Internet.

66% Internet users who look online to find information about a specific disease or medical problem.

84% Women conduct research online for others more often than men.

77% The recently diagnosed who turn to online sources for health information first.

66% Internet users rely on search engines two-thirds of the time when researching health and medical information.

51%* U.S. adults who rely on social media for medical content.

35% E-Patients with a favorable view of social media communications efforts by health nonprofits or charities.

51% E-Patients with a favorable view of social media communications efforts by pharmaceutical companies.

37%* E-Patients who want news or information about medical conditions or diseases via social media.

60%* E-Patients who are interested in two-way dialogue with health organizations via social media.

38%* E-Patients interested in seeing advertising on social media.

10 Million adults use a cell phone to find health information.

12%* E-Patients interested in seeing advertising on social media.

Source: www.pathoftheblueeye.com – visualisation Enskepos LLCC
Patient empowerment is not an option: people at center of care

WHO strategy on Person centered and integrated health 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 empowerment is not an option: healthcare under pressure

- Need and demand are both growing at high pace
- Fiscal space limits growth of healthcare public expenditures
- Global economy and competition are limiting private expenditures on healthcare (employment and revenues)
- Innovation is creating increased uncertainty on care models
- Structural tensions: Human resources & access to capital
- Complexity of organizations with multiple professional cultures and high level of independence
- Nature of services: more “merit good” than pure private

⇒ Need to optimize allocation of resources and increase efficiency of production: people are key for solutions
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 makes it all!

Campaign are most often making people responsible... (guilty) of their health status and calling for change:

Reality is far more complex and 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 and international mobilization on changing patient practitioner relations:

⇒ this relies on good will

Working together for better care and a better experience
Another perspective on patient empowerment

• It is not about individual good will but about enabling conditions and obligations

• Facilities have a key role to play:
  • Health education highly relevant during health related episodes
  • Their mission is health: staff, patients & families should be involved at all levels and stages
  • Patients are not just consumers but at the center of a process involving them.

• Patient empowerment is a critical issue for healthcare executives and governing bodies: it impacts relevance and efficiency of service provision.

• Technologies can enable institutional changes and the approach on patient’s health.

➔ Patient is a stakeholder in health care
IHF-IAPO survey

• **AIM OF THE SURVEY:** provide a general overview of the trend of patient involvement in hospitals on a national level

• **RESPONDENTS:** Completed questionnaires were submitted by 34 organizations, 17 of which are members of the IHF

• **27 COUNTRIES:** Argentina, Australia, Austria, Bulgaria, Cameroon, Canada, El Salvador, France, Germany, Greece, Guatemala, Hong Kong, Hungary, Indonesia, Israel, Korea, Nigeria, Pakistan, Philippines, Poland, South Africa, Switzerland, Taiwan, Thailand, the Netherlands, the United Kingdom and the United States

• **NO DISCREPANCIES** were found among the answers provided by both IHF and IAPO’s members from Australia, Israel, Nigeria and South Africa
Regulation for patient’s involvement.

In half of surveyed countries regulation exist for patients’ involvement.
Nature of arrangements for involvement

- Ad Hoc participation
- Seating in governing body
- Seating in formal committee
- Participation to Technical/Advisory Group
- Regular Meetings
... And some additional modalities

• Patient counselling (both inside and outside the hospital)

• Patient advocacy

• Guardianship legislation (ombudsman,....)

• NGOs having office in hospital

• Representatives of the communities

• Volunteers
Nature of patient representation

**Disease Specific Organization**

**General Patient Organizations**

**Consumer’s Association**
Modalities for involvement

In 75% of Countries there are opportunities for patient involvement when no formal arrangement is in place:

• 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 private free market environment
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: “White Book” of the French federation of hospitals that call 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
France: how to explain the gap ?

• Patients’ associations are mostly related to specific pathologies

• A general council (CISS) has been created after the rise of AIDS and chronic diseases but not much activities except formal meetings

• Internet initiatives in France: Scopesante.fr and Hopital.fr.... but not enough communication to all citizen about them.

• Patients’ organizations are not well organized at national level and do not reach out actively in a coordinated approach.

SOURCE: FHF - Fédération Hospitalière de France
Patient Engagement in Hong Kong Hospital Authority (HA)

• 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-centred approach in communication
Cluster Level: where care is actually delivered

- Patient education and empowerment activities
- Communication with patients & patient groups
- Enabling access to patient group information
Head Office Level: Where care delivery is organized

- Empowering patients and careers 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
Board Level: where policy and strategy is decided

- Patient representatives serve in **Board and Committees** (e.g. HGCs or other meetings) to advise HA on needs and service feedback
- Contribute to **specific projects** (hospital strategic planning workshops, redevelopment consultation)
Understanding Patient Empowerment in Colombia

<table>
<thead>
<tr>
<th>Supportive trends</th>
<th>Reality is less bright</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Universal ($) coverage</td>
<td>• Access and quality of care challenges</td>
</tr>
<tr>
<td>• Explicit patient rights &amp; responsibilities</td>
<td>• Limited information on care</td>
</tr>
<tr>
<td>• Informed consent</td>
<td>• Limited choice for care</td>
</tr>
<tr>
<td>• Choice of providers</td>
<td>• Financial constrains on all sides</td>
</tr>
<tr>
<td>• Rising individual liberties</td>
<td>• No incentives to involve patients</td>
</tr>
</tbody>
</table>

- 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
What is in place for patient empowerment in a US hospital?

Current practices

- Culture of Patient-Centered Care
- **Patient Bill of Rights**
- Patient Education
  - Documentation
  - Direct interaction
- Family Advocacy Committees
- Hourly Nurse Rounding
- Teach Back Discharge instructions
- **Care Coordination** (limited but evolving)
- Follow-up Discharge Calls
- **In-Patient Surveys** (CMS)
- Outpatient and Ambulatory Surveys

In **BOLD** mandatory measures
What is in place for patient empowerment in a US hospital? Significant room for improvement

Percentage of Physicians and Patients Agreeing with the Following Statements About Compassionate Care

<table>
<thead>
<tr>
<th></th>
<th>Physicians</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassionate Care is Very Important to Successful Medical Treatment</td>
<td>76%</td>
<td>85%</td>
</tr>
<tr>
<td>Most Health Care Professionals Exhibit Compassionate Care</td>
<td>78%</td>
<td>54%</td>
</tr>
</tbody>
</table>

Source: Advisory Board

Impact

Today’s Imperative: Stopping the Bleed
- Reduce patient “defections” due to problematic provider, staff relationships
- Enhance care team coordination, follow-up to prevent patient confusion, frustration
- Accommodate patient demand for convenient service

Tomorrow’s Mandate: Enhancing Care Value
- Elevate the patient voice in shared clinical decision making
- Identify, educate, and activate high-risk patients; proactively monitor lower-risk populations
- Deliver right services at right time and place, based on patient need

Source: Advisory Board
What is in place for patient empowerment in a US hospital?

Institutional & Policy Opportunities

• Shift focus from patient experience to patient engagement
• Focus on transitioning the organizational culture not just a program
• Provide research linking patient engagement to financial impact
• Lobby for supporting governmental policies and incentives
• 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
Perspectives on patient empowerment

• The role of patients remains limited in many countries
• 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 impact the organization of service delivery to better respond to people’s needs
• Technology offers many promises but much remains to do.
Promise of Applying Technology to Patient Empowerment

Technology offers considerable promise for impacting the spectrum of health and wellness: assessment, prevention, treatment, recovery support, and care coordination

- **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)
Promise of Applying Technology to Patient Empowerment

- **Reach:** Offer great promise for enabling the widespread dissemination of evidence-based interventions targeting health behavior.

- **Quality:** Deliver care with fidelity, ensuring delivery of empirically-supported care

- **Personalization:** Responsive to each individual’s profile of needs, preferences, culture, level of cognitive functioning, etc.

- **Engagement:** Offer the potential to enable individuals (and optionally an extended support network) to play leading roles in their own care management
Science of Behavior change. Several key scientific principles transcend “disorder” or “diagnosis” and focus on increasing an individual’s personal and social resources that support and reinforce healthy, goal-directed behavior and reduce self-defeating behavior.

- Activate behavior change based on an individual’s preferences/values
- Solve problems and overcome obstacles to effective behavior change
- Teach skills and provide guidance in the execution of behavior change
- Maintain the user’s motivation to change
- Facilitate user’s communication with their social support network
The liquid hospital: Play an active role in putting patient in drivers’ seat
THANK YOU

Contact: info@ihf-fih.org
WWW.IHF-FIH.ORG