Patient empowerment: Vision for the future

Chair
Kathleen Gallant, International Federation of Psoriasis Associations (IFPA) and Rebecca Johnson, IAPO

Speakers
Kaisa Immonen-Charalambous, European Patients Forum (EPF)
Robinah Kaitiritimba, Uganda National Health Users/Consumers Organisation (UNHCO)
Leigh Manasco, LIVESTRONG

@IAPOtweets  #GPC2014
www.facebook.com/internationalallianceofpatientsorganizations
E3: Patient empowerment: A vision for the future

Kaisa Immonen-Charalambous
Senior Policy Adviser, European Patients’ Forum
Equity and quality – fundamental values in healthcare

**Equity** = “the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically.” (WHO)

**Quality** = effectiveness; efficiency; accessibility; acceptability/patient-centredness; equity; safety (WHO 2006)

**EPF Strategic Goal 2: Healthcare Access and Quality.**
To contribute to improvements in health systems that enable equitable access to sustainable and high-quality healthcare designed and delivered to meet patients’ and informal carers’ needs at all levels of care, embracing innovation in all its forms.” ([EPF Strategic Plan 2014-2020](https://epfinternational.org/))

- Economic argument: “health = wealth”
- Ethical argument: health is a fundamental right and a value in itself

Quality AND access go hand in hand
Patient empowerment / involvement

**Patient empowerment** = a *process* that helps patients *gain control* over their lives, increasing their capacity to act on *issues that they themselves define as important*; a process through which patients individually *and* collectively are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take action to meet those needs. (Adapted from European Union Network on Patient safety & Quality of Care, PaSQ, 2012)

*(Meaningful) patient involvement* = patients take an *active role* in *activities or decisions that will have consequences for* the patient community, *because of* their specific knowledge and relevant experience as *patients*. The involvement must be planned, appropriately resourced, carried out, and evaluated as to its outcomes, impact and the process itself, according to the values and purposes of *all* participants. (Adapted from EPF project “Value+”, 2009)
Health systems need to change

European health systems face a sustainability challenge

- Acute/hospital vs. chronic/long-term/community
- Financial constraints
- From a patient’s perspective: health systems are unable to cope because they do not meet patients’ needs
- Must “do more with less” – too simplistic
- Often the system challenge has to do with the way healthcare is delivered and services organised – e.g. fragmentation of health and social care, lack of coordination
- Chronic disease requires holistic, patient/family-centred approach, long-term monitoring + self-management by patients/families
- So instead: invest adequately, spend more effectively, “do better”.
Individual and collective empowerment

**Individually:**
- Patients/families are able to become “co-managers” of their condition and participate in decisions related to their health/care according to their capacity and wish to do so.

**Collectively:**
- **Provider level:** patients (individually and) collectively play a role in improving healthcare services for all patients by contributing their specific experiences as learning and educational tools to inform (re-)design of services.
- **Policy level:** patient organisations contribute to shaping the healthcare system through their involvement in healthcare policy-making.
- **Community:** peer support, voice in public debates.

**Vision:** patients as “co-producers” of well-being and integral actors in the health system.

**What PE is not about:** consumerization; shifting responsibility inappropriately; blame.
Individual and collective empowerment

**Individually:**

- Shared decision-making
- CDSMP
- Reporting & learning systems
- Provider choice

**Collectively:**

- Patients’ representation on hospital boards, national authorities
- Patient organisations involvement in research
- Patient organisations influencing policy: local, national, European, global
- Patient (online) communities

Click on the logos for hyperlinks
2009: **EU Council Recommendation on Patient Safety**

2. Empower and inform citizens and patients by:

(a) **involving patient organisations** and representatives in the development of policies and programmes on patient safety at all appropriate levels;

(b) **disseminating information** to patients on:

(i) patient safety standards which are in place;

(ii) risk, safety measures which are in place to reduce or prevent errors and harm, including best practices, and the right to informed consent to treatment, to facilitate patient choice and decision-making;

(iii) complaints procedures and available remedies and redress and the terms and conditions applicable;

(c) considering the possibilities of **development of core competencies** in patient safety namely, the core knowledge, attitudes and skills required to achieve safer care, for patients.
Diagnosis:
Acute Pulmonary Pain
Resulting from
Pneumonoultramicroscopic-silicovolcanoconiosis

The offices of
Heath L. Iteracy, M.D.
“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”
What needs to happen to realise empowerment?
Who should do it?
Contact Us

website to find out more:

www.eu-patients.eu
6th Global Patients Congress
Better access, better health:
A patient-centred approach to universal health coverage

29–31 March 2014 • Macdonald Berystede Hotel, Ascot, UK
Session Outline

• Welcome and introduction to the session
• Presentation, Kaisa Immonen-Charalambous, European Patients Forum (EPF)
• Presentation, Robinah Kaitiritimba, Uganda National Health Users/Consumers Organisation (UNHCO)
• Presentation, Leigh Manasco, LIVESTRONG
• Questions for the speakers
• Discussion: what are the principles of patient empowerment globally?
• Concluding remarks
• Close

#GPC2014
Empowerment as a pre-requisite for participation and improving quality- Uganda’s case

Robinah Kaitiritimba

Executive Director, Uganda National Health Users/ Consumers Organisation(UNHCO)
Session Outline

• About UNHCO
• Empowerment
• Tools for empowering people
• Voices
ABOUT UNHCO

UNHCO is a not for profit Non Governmental Organization (NGO).

The logo presents the three ‘Ps’ strategy,
- Policy maker
- Provider
- Patients

It was formed to provide a platform for health consumers and users of health care to institutionalize their voices to participate in creating and sustaining an effective health care delivery system.
EMPOWERMENT

- Empowerment is a pre-requisite for the Rights Base Approach – RBA
  “expression of assets and capabilities of poor people to participate in, negotiate with, and hold accountable the institutions that affect their lives”
- Components of empowerment
- Change, improve capacity of people.
- Create enabling environment
- Provide information, skills, legal framework, assets to take charge & address vulnerability.
- Effective, informed participation of marginalised people/groups in planning, implementation and monitoring to influence services to meet their needs.
ADVANTAGES OF EMPOWERING PATIENTS.

- Gives patients a more realistic appreciation of providers’ and own situation.
- Increased trust, builds partnership between patients and health workers.
- Informed patients respond more effectively to treatment, recover more quickly (WHO).
- Improved compliance, promoting patient responsibilities.
- The right to choose reduces the burden of the health worker and increases patient responsibility for their own health.
- Balanced partnership between health workers and user of services for a common goal.
- Strengthening health worker professional conduct, ethics, quality, accountability.
“For safe care to be achieved, patients must be centrally involved in the process and advocate for their own safe care.”

-WAPS
Tools for participation

- Legal and policy framework e.g. Patients Charter, sector plans and strategies
- Mechanisms/fora for feedback and redress at service points
- Information for empowerment, engagement and action
- Collective action for Advocacy
- Research on patient issues - the ‘demand side’
- Coordination, bringing people together to form a critical mass-Stakeholder engagements,
- Working with the Media
PS MOH, WHO health rights desk officer, Civil Society Advisor DFID, chairperson UHRC participating in Health Rights day
"If they give me panadol (2x3), I take two and when the pain disappears I keep the rest for the children."

• “For many years they gave me septrin and my condition got worse. They did not know I was allergic to sulphur.”

• “I have been to so many hospitals, I have decided to come home and wait for my day. They have never told me what my sickness is.”

• “I can not ask patients to wash their hands, my own hands are not washed because there is no water here.” health care worker

• “I do not want patients to waste my time, I look at the line through the window and all I do is call out-next, next, next”
Contact Us

Please visit our website to find out more:

[www.unhco.or.ug]

Tel: +256-414-532123
Fax:
Email: rkitungi@unhco.or.ug
Website: www.unhco.o.ug
Patient-centered advocacy: Keeping the patient voice at the core of what we do

Leigh Manasco
Rebekkah Scheer, MIA
LIVESTRONG Foundation
The LIVESTRONG Foundation began as an organization identifying a gap:

A glaring lack of programs and services to help people navigate their cancer experience.
So, we started talking to those most affected by a cancer diagnosis – patients, their caregivers, and health care teams.
Navigating a cancer diagnosis can be overwhelming.
Cancer impacts nearly every aspect of your life.
Stigma surrounding cancer is pervasive.
People fighting cancer need to be better supported.
“While health care reform must occur in broad strokes, we must work to keep in mind the daily experiences of the patient with cancer.”

-Dr. Yousuf Zafar and Dr. Amy P. Abernathy, Duke Cancer Institute
Family & Friends

Social Media

LIVESTRONG at the YMCA

Self and Direct Navigation
Thank you!

Leigh Manasco leigh.manasco@livestrong.org
Rebekkah Scheer rebekkah.scheer@livestrong.org
Questions
Discussion: What are the principles of patient empowerment globally?
Conclusions
Contact Us

Please visit our website to find out more:

www.patientsorganizations.org

Tel: +44 20 7250 8280
Fax: +44 20 7250 8285
Email: info@patientsorganizations.org

www.facebook.com/internationalallianceofpatientsorganizations

@IAPOtweets  #GPC2014
6th Global Patients Congress

Better access, better health:
A patient-centred approach to universal health coverage

29–31 March 2014 • Macdonald Berystede Hotel, Ascot, UK