

Why Patient Empowerment matters in Patient Safety

Robert Johnstone
Board Member, European Patients' Forum

EPF Conference “Patient and Family Empowerment for Better Patient Safety”

8 November 2016, Brussels

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”

What do we mean by empowerment?



Why patient empowerment?

“The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare.”

Alma Ata Declaration – Principle IV (1978, WHO)

“All EU health systems ... aim to involve patients in their treatment, to be transparent with them, and to offer them choices where this is possible... to offer individuals information about their health status, and the right to be fully informed about the treatment being offered to them, and to consent to such treatment. All systems should also be publicly accountable and ensure good governance and transparency.”

Council Conclusions on common values and principles in European Union Health Systems, 2006

EPF definition of empowerment

“Patient empowerment is *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 JA-PaSQ, 2012)

- A process – non-binary, non-linear
- Cannot be imposed from top-down – needs changes at all levels
- Individual but also collective (patient community)

Aspects of empowerment

- Vision: patients as “co-producers” of well-being
- Self-awareness, confidence, health literacy, coping skills to manage impact of illness in everyday life
- Participation in health-related decision-making *to the extent that patients wish*
- Being recognised by professionals as a key partner in care
- What it is not: shifting responsibility on to patients inappropriately



Can patient empowerment improve safety?



Patients can help improve safety

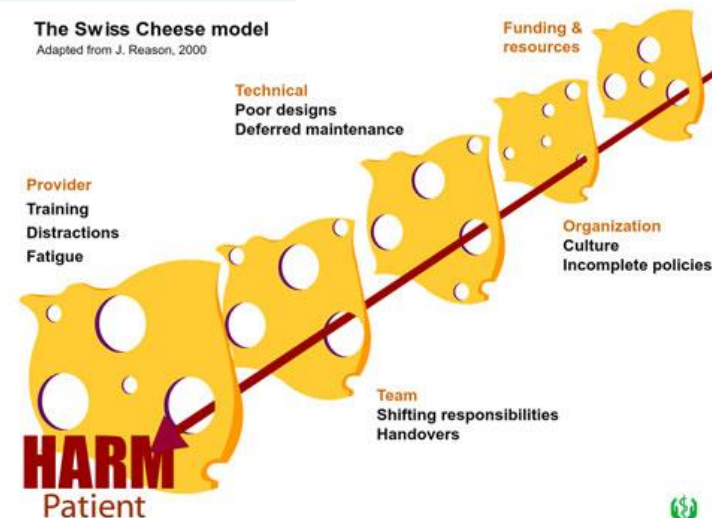
Safety = a key aspect of quality

Patient-centredness = a key aspect of quality

Individual patient's experience of his/her healthcare “journey” = rich resource of information about gaps and failures in the system

Need support and empowerment:

- ➡ *Information that is understandable*
- ➡ *Health literacy skills*
- ➡ *Professional who listen and encourage*
- ➡ *Patient-friendly environment*
- ➡ *Self-management support*



Patient: the last “barrier”

“When I read through my medical record, I noticed two mistakes.”

“When I received a new glucose monitor, I noticed the readings were not right. I noted all the readings comparing the old and new monitor ... Finally the nurses agreed there was a problem with the new brand of monitors.”

“If I can be working in partnership with clinicians I could have much more success at avoiding mistakes. Clinicians are full of good intentions and highly trained, **but they are never going to be as committed to me and my health and wellbeing as I am.**”



Patient safety = patients' business (also)



At the collective level:

- Patient organisations – role in informing & educating patients and health professionals
- Effective advocacy through access to the community
- Involvement in co-designing healthcare services to make them more patient-centred & meet real-life needs and preferences of patients
 - Important to involve patient organisations at policy level
 - International, EU and Member States

Patient safety = patients' business (also)

Important caveats:

- Respect patients' willingness to get involved – or not
- Do not over-estimate patients' capacity to get involved
- Patients in vulnerable situation – no shifting of burden of “responsibility” on them
- Patients already observe much – healthcare staff need to listen more, take their views seriously
- Is it possible to be empowered if the system is not functioning optimally?

Appropriate support and enabling environment is key

What more needs to happen?



Patient safety = EU policy priority?

What is the issue?

★ Types of adverse events

Healthcare-associated infections (HAI):

are directly responsible for **37 000** deaths / year

contribute to a further **110 000** deaths / year

cost hospitals over **€5.4 billion** / year

Medication-related errors

Surgical errors

Medical device failures

Errors in diagnosis

Failure to act on the results of tests

★ Patients think they can be harmed

EU citizens who think that **patients could be harmed by hospital care**

53%

57% - 100%
50% - 56%
0% - 49%

★ **91%**
of **STAKEHOLDERS** think
patient safety is an issue

Source: EC infographic, 2014

Culture change!

- Empowered patients seen as a threat by some professionals
- Balance of power needs to change – professionals need to accept this
- Recognise patients as experts in their care
- Focus on education and training for professionals
- Patient involvement a “sine qua non” of health system design.



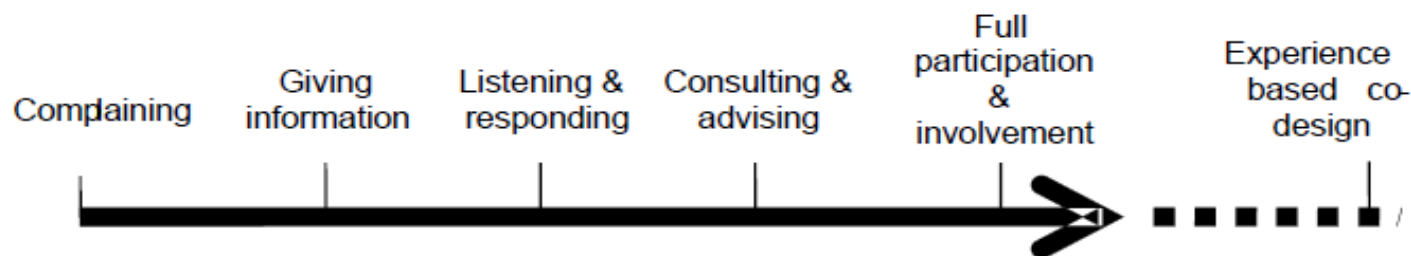
“You have to learn about thousands of diseases, but I only have to focus on fixing what’s wrong with ME! Now which one of us do you think is the expert?”

Designing care around patient needs

- Only the patient sees the whole journey
- **Patient involvement → services that meet the real needs of patients**
- Patient experience is NOT only patient satisfaction surveys
- Involve patients in assessing, planning, designing, implementation, continuous evaluation & improvement !
- Involve patient organisations at provider and policy level



illustrations of.com #5886



Bate and Robert (2006)

In conclusion

From doing things “to” the patient...



"I am the most important member of my care team"

... to doing things WITH the patient!

THANK YOU FOR YOUR ATTENTION!

Follow us on Social Media!



/europeanpatientsforum



/eupatient



/eupatientsforum



eu-patient.eu/blog

More information

www.eu-patient.eu

info@eu-patient.eu

“ A STRONG PATIENTS' VOICE TO
DRIVE BETTER HEALTH IN EUROPE ”