Why Patient Empowerment?

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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

Patient empowerment on the agenda

- Health systems face changes – chronic disease, ageing, technology, financial constraints – “the sustainability challenge”
- Healthcare often *not working for patients*
- The patient: from passive recipient to active <u>and equal</u> partner
- Informed patients are NOT cost-drivers – but part of the solution for sustainable patient-centred health systems
- Everyone agrees: patient empowerment = “good”…

  … BUT do we see it in the same way?
  … How to achieve it?

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 <u>not</u>: shifting responsibility on to patients inappropriately

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)

The EMPATHIE working definition

"An empowered patient has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being.

Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to:

- participate in decisions related to their condition to the extent that they wish to do so;
- become "co-managers" of their condition in partnership with health professionals;
- develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life."

This shows how empowerment (an intangible process) manifests itself in concrete action (involvement/participation).

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

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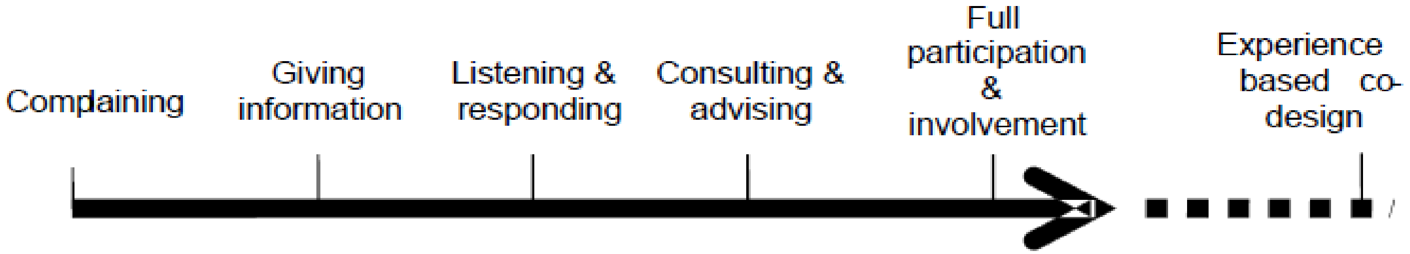

Complaining

Giving information

Listening & responding

Consulting & advising

Full participation & involvement

Experience based co-design

Bate and Robert (2006)

In conclusion

From doing things “to” the patient…

“I am the mos
important
member of my
care team”

… to doing things WITH the patient!

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