

# What matters to me: Why it is imperative to include patients in assessing health systems performance

Kaisa Immonen  
Director of Policy European Patients' Forum

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@eupatientsforum

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



# Who am I?

- Director of Policy at European Patients' Forum, Brussels
- Co-chair of the Patients and Consumers Working Party at the European Medicines Agency
- Member of The BMJ Patient Panel (personal capacity)
- Member of ICHOM working group on general adult health, patient representative (personal capacity)
- No personal interests to declare
- EPF receives funding from a variety of sources, including the pharmaceutical industry. Details of EPF's funders, funding arrangements, and accounts are available on its website: <http://www.eu-patient.eu/About-EPF/Transparency/>



@KaisaBxl

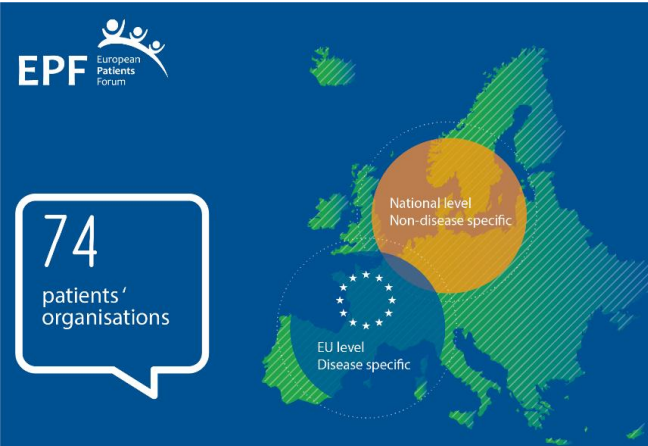
# What is EPF?

## European Patients' Forum

- Est. 2003
- Independent NGO
- Cross-disease umbrella patients' organisation
- 74 member organisations
- Focus: EU-level policy, projects, processes

*Vision:* “All patients in Europe have equal access to high quality, patient-centred health and related care”

*EPF is* the collective, influential patient voice in European health and related policies and a driving force to advance patient empowerment and patient access in Europe



# “What matters to you?”



# “What matters to you?”

We asked patients to describe good quality care in their own words...

“When doctors and other staff actually listen to what I am saying”

“Cooperation [between me and my health care professionals] means that I consult them on concerns and we find a solution to the problems together”

“... Listening to me, believing in my observations, giving me choices, helping me decide, taking care of other aspects of my life than the illness itself”

“understand my situation – social and psychological impact of disease”

“Being helped with the illness in a way that you yourself are an active participant”

“What is available through the healthcare system is not necessarily what the individual needs ... long-term holistic approach. Drugs are not the only remedy, we need psychological and behavioural measures as well“

“ With the head and with the heart”

“Patients’ Perceptions of Quality in Healthcare”  
[Report](#) of a 2016 survey conducted by EPF

# Patients describe quality of care...

We find that patients' definitions of quality do not totally fit with existing definitions

## Other aspects identified by patients not covered by WHO or EXPH

<p><b>The human face</b></p> <ul style="list-style-type: none"> <li>• Being cared for as a whole, as a person with context, not being treated as a diagnosis or a number, attention paid to psycho-social, mental and family aspects of illness together with physical aspects.</li> <li>• Empathy – professionals are able to put themselves in the patient's shoes</li> </ul>	<p><b>Communication and dialogue</b></p> <ul style="list-style-type: none"> <li>• Medical professionals communicate their reasoning and make patients understand; shared decision-making as standard practice; checking patient's understanding of what has been discussed and agreed, and a meaningful informed decision by patient; enough time to talk and reflect</li> <li>• Information to complement person-to-person encounter, provided in patient/lay-friendly language, format, presentation and easily accessible when you need it.</li> </ul>	<p><b>Improvement and learning culture</b></p> <ul style="list-style-type: none"> <li>• Learns from the past to see if anything could be done better for other patients; involves patients in feedback and improvement loop</li> </ul>
<p><b>Enabling and preventative</b></p> <ul style="list-style-type: none"> <li>• Guides the patient and minimises hassle with bureaucracy; being helped in a way that you yourself are actively involved; being accepted and welcomed as equal partner; family involvement especially if patient is in a vulnerable position</li> <li>• Having enough and the right support for effective self-care</li> <li>• Aiming to prevent further suffering and exacerbations</li> </ul>	<p><b>Integrated and co-ordinated</b></p> <ul style="list-style-type: none"> <li>• Understanding patient's situation, impact of the disease and social circumstances</li> <li>• Having the same doctor/other HCP who knows your history; knowing who is responsible for you</li> <li>• Multi-disciplinary teams organised around patient's /family's needs, taking a holistic approach, i.e. also non-medical needs</li> </ul>	<p><b>Trust and respect</b></p> <ul style="list-style-type: none"> <li>• Feeling that if one is in competent hands; relationship of trust with the professionals involved in your care</li> <li>• Being listened to and taken seriously; respect for the patient's choices; belief in patient's observations; taking patient seriously.</li> </ul>

<http://www.eu-patient.eu/globalassets/policy/quality-of-care/epf-position-paper-on-quality-2017-final-version.pdf>

# Patients value “humanity” in care

Human aspects are at the core of what is important to patients

- Being cared for as a person, not a diagnosis or number
- Being treated with empathy, kindness and respect
- Holistic approach that “treats” psychological, emotional social, mental and family aspects of illness as well as physical ones
- High “technical” quality should be there in any case



# Patient empowerment – why is it needed?

- “Health systems need to change. Patients need to take more responsibility...”
- BUT... patients are often “blocked” in their interactions with the system – professionals, organisations & services
- Healthcare environments can be very *disempowering*

“Many of our patients may be feeling scared or even frightened witless when, for us, it’s just another day at work...”

– Dr Patricia Cantley, [BMJ](#) blog

“How differently I might have felt ... if doctors and nurses empathised more instead of calling me a word I didn’t feel; if they’d explained what a test was for and why I needed it, and apologised if they could see I was upset.”

– Sophie Lyons, “[Be brave](#)”, BMJ WYPIT series\*

\* *What your Patient is Thinking*





# Patient empowerment – is it complicated?

“A multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important”

Collectively, “a process through which communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs”

(EPF [Patient Empowerment Toolkit](#))



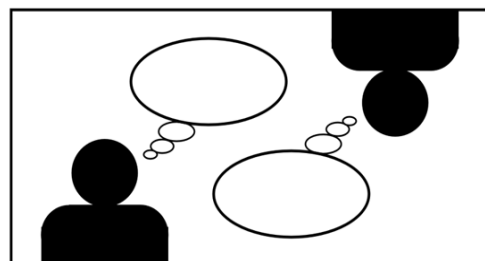
## 3 facets of empowerment

[EMPATHIE \(2014\)](#)

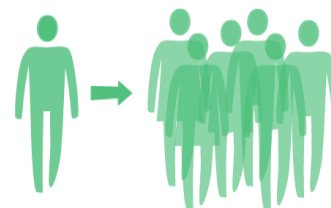
- Health literacy
  - Information, education, tools...
- Self-management
  - Skills, behaviours, self-efficacy, support...
- Shared decision-making
  - Relationship, decision-aids, communication, HCP skills & attitudes...



A process: non-binary, non-linear



Cannot be imposed from top-down



Relational, realised in interactions

# Shared decision-making is key to empowerment

## Shared decision-making: the pinnacle of person-centred care

“Patients should be educated about the essential role they play in decision making and be given effective tools to help them understand their options and the consequences of their decisions. They should also receive the emotional support they need to express their values and preferences and be able to ask questions without censure from their clinicians. Clinicians, in turn, need to relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners — learning, in other words, how to ask, “What matters to you?” as well as “What is the matter?”

- Barry and Edgman-Levitan, 2012

# Is the patient in the room?

“Decisions can’ be shared if conversations aren’t”

“When a panel of experts has come to a decision it’s hard to even question it, let alone row back on it ... it doesn’t endear you to your clinicians. Nor does asking to attend the multidisciplinary meetings at which your case is discussed, to get an understanding of the rationale for decisions. A recent request I made was met with surprise and a sharp, ‘No, we are not set up to include patients.’ When I declined chemotherapy that was recommended by a consultant I’d never met before (on the basis of a discussion about my case that I didn’t even know was taking place), his conclusion, incorrectly, was that I lacked the will to live.”

- Tessa Richards, Senior Editor, [BMJ](#) 2018

# The 10 fundamental principles of empowerment

The Patient's [Charter](#) on Patient Empowerment (2015)

1. I am more than my health condition

2. I am empowered to the extent I wish to be

3. I am an equal partner in all decisions related to my health

4. I have the information I need in an easily understandable format, including my own health records

5. My health professionals and our health system actively promote health literacy for all

6. I have the ongoing support I need to manage my own care

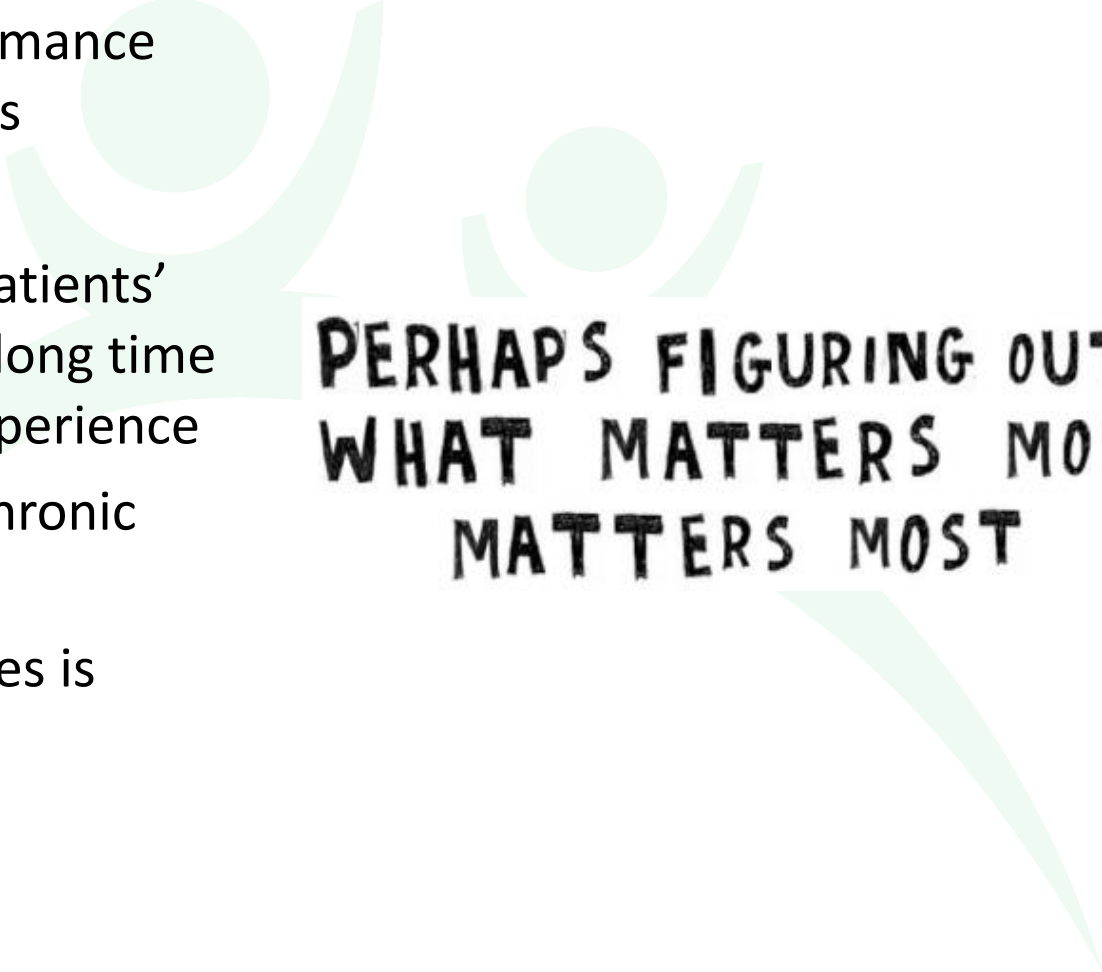
7. My experience is a vital measure of healthcare quality

8. I can participate in evaluating and co-designing healthcare services so they work better for everyone

9. Through patient organisations, my voice becomes part of a bigger, united voice

10. Equity and empowerment go hand-in-hand - I want a fair deal for all patients

- Indicators used to measure health systems performance often do not reflect what matters most to patients
- Clinicians may *think* they know, but they don't
- Measures mostly designed for “episodes” – but patients' journey moves across & between services over a long time  
→ need for different ways of assessing patient experience
- Gaps for patients with complex or/and multiple chronic conditions
- Dichotomy of “clinical” vs “quality of life” outcomes is outdated?



PERHAPS FIGURING OUT  
WHAT MATTERS MOST  
MATTERS MOST

- Objective” measures of performance – cost, length of stay, certain clinical parameters – often prioritised because *easy* to measure...
- ... or they have been used for a *long time*
- ... or professionals are *comfortable* measuring them
- ... or the measures are well *validated*
- But do they reflect what matters to the patient – or do they “recycle” old “system” priorities?
- To measure person-centredness, values and principles of person-centred care must be operationalised into person-centred practices – which can be then evaluated
- Shift in discourse: from “patient-reported” to *patient-prioritised and co-designed* outcome measures

## PROMs have many uses!

- Check the impact of having a condition or different treatments on the quality of life of patients
- Compare different treatment options
- Looking at outcomes from other similar patients g
- Patients find such information useful for informed, shared decision-making



# “Integrated” = person/family-centred, coordinated

“Integrated care”, “care pathway” = systems perspective

“well coordinated”, “patient journey” = patient perspective

www.nationalvoices.org.uk/



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# A note on language

Words aren't everything... but sometimes they expose paternalistic attitudes, lack of respect, a "listening gap"

*"Integrated care  
Patient pathway  
Non compliant patient  
Poorly controlled diabetic  
Multimorbid  
Patient failed therapy  
Sufferer  
Being under the care of...  
Confined to a wheelchair  
Difficult patient!..."*



***"Care that is well co-ordinated  
Joined-up care  
My journey  
Am I achieving my goals?  
Treatment isn't working for me  
Person living with diabetes  
Partner in research  
Freed by a wheelchair!  
Empowered patient..."***



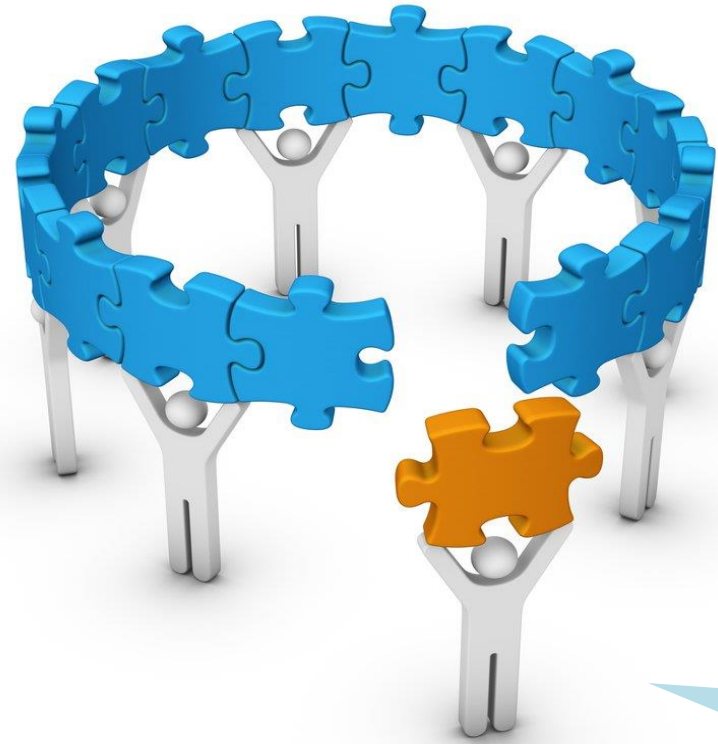
<http://blogs.bmj.com/bmj/2017/04/07/tessa-richards-words-that-annoy-phrases-that-grate/>

# From “patient-centred” to... “partnership”?

Patient-centred care...



“Doing to”



Partnership / collaborative / team

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

“Doing with”

# EPF Congress: exploring involvement



“Organised by EPF, this is the first European Congress on patient involvement developed by and with the European patient community”

“For everyone in healthcare and policy who wishes to understand the benefits of and potential of patient involvement and enhance the quality of their own work”

## Advancing *meaningful* patient involvement

A path to effective health systems

12-14 November 2019, Brussels

[www.epfcongress.eu](http://www.epfcongress.eu) #EPFCongress19

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