



National Patients'
Organisation

Национална пациентска организация

www.npo.bg



The uniqueness of the patients' expertise
and the patient organization of the future.

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What do you mean by Patient involvement?

Patient involvement?

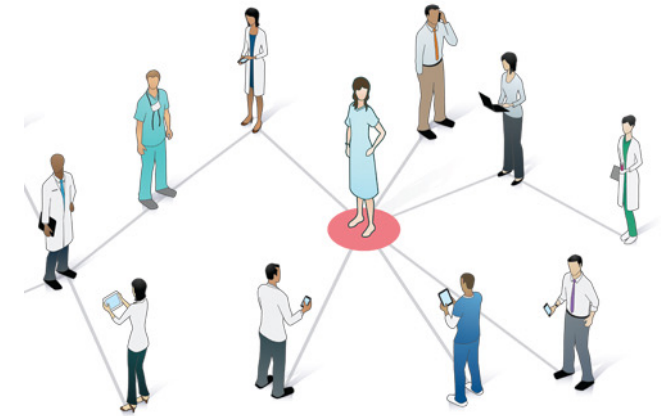
Even the greatest idea could fail if it does not match the patients' needs.



Shift: To/with the patients

🌐 Shift from doing things TO the patients to doing things better WITH patients:

- ✓ From disease-centred to patient- and family-centred approach
- ✓ Combining self-management with well-integrated professional support
- ✓ Lack of awareness and recognition of patient empowerment



🌐 For a sustainable healthcare system all measures taken should be:

- designed, agreed, tested, implemented and evaluated **with patients.**

Patient Centricity



Patient involvement...

...but why?

There are 3 main foci around
role and expertise of the
patients.

If utilized and nourished
properly they could solve three
major issues.



1. Patients' expertise is unique

Learning by experiencing:

Patients are the only stakeholder with detailed knowledge on the entire healthcare system:

- administration
- gaps
- barriers
- potential solutions

Patients have specific expertise on:

- the day-to-day use of medicines
- what it is to live with specific disease

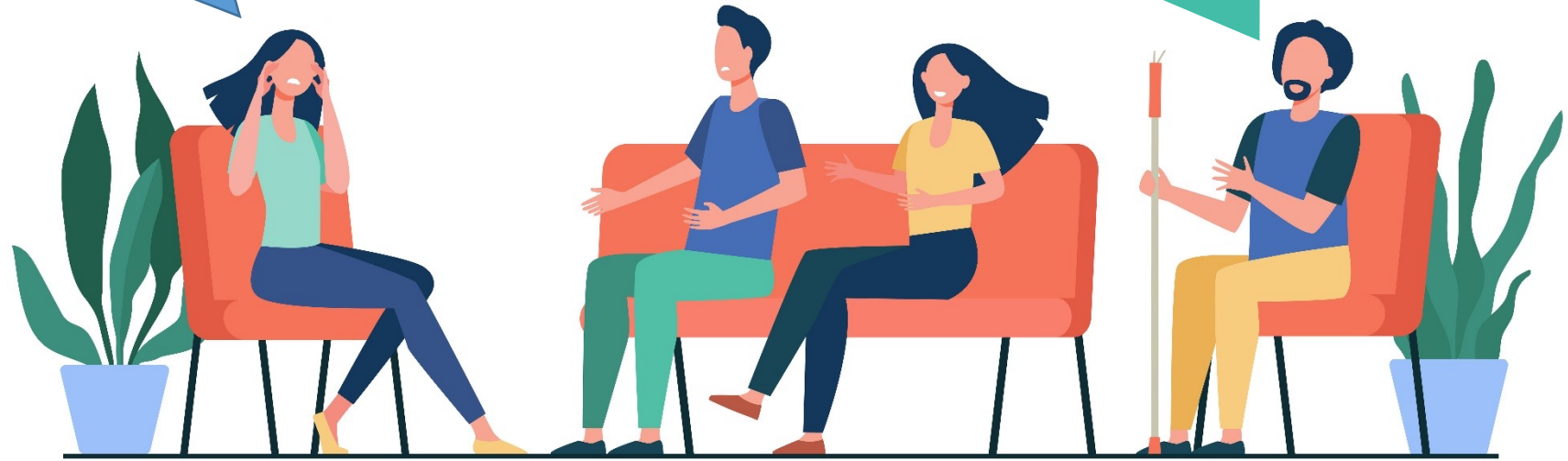


"You learn about thousands of diseases. I only focus on what is wrong with ME! Now which one of us do you think is the expert?"

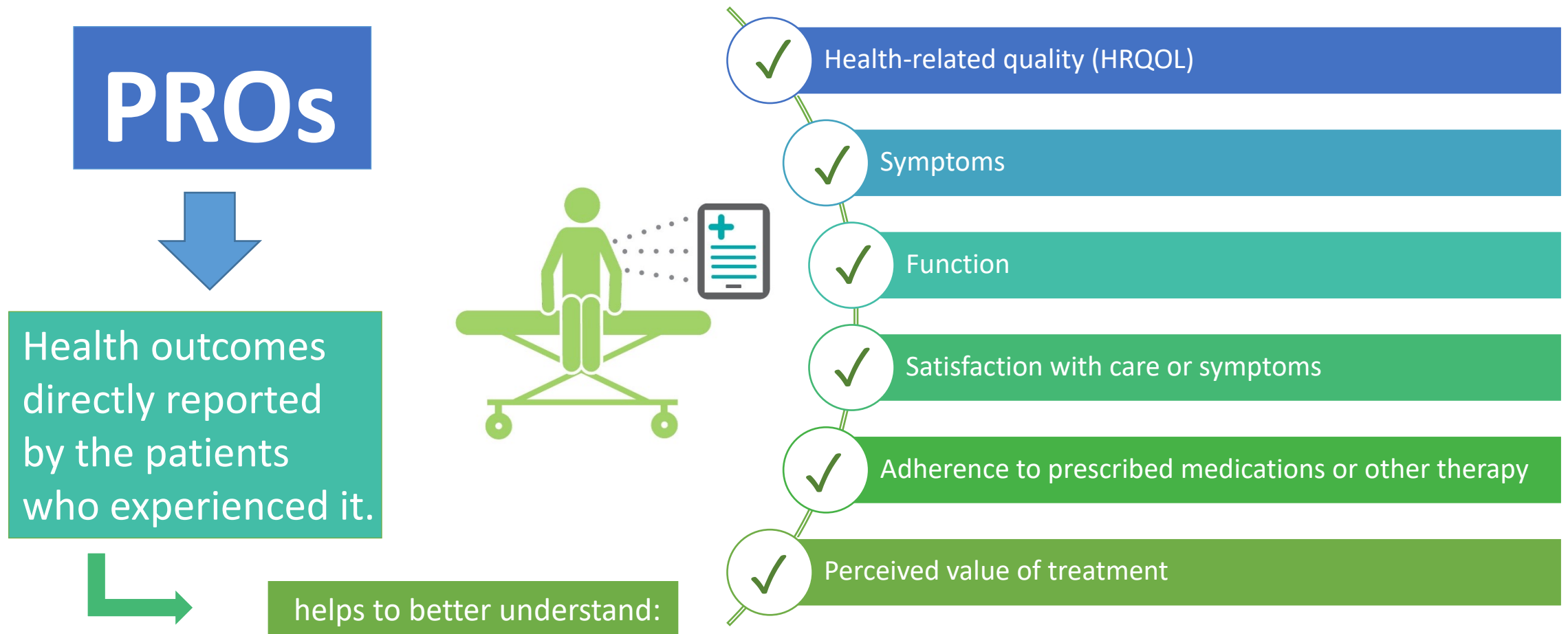
2. Patient communities

Patients know
the target
groups!

Could help to reach
marginalized
communities.



3.1. Patient reported outcomes (PROs)



3.2. Real-World Data/Evidence (RWD/RWE)

Real-world evidence is the clinical evidence regarding the usage and potential benefits or risks of a medical product derived from analysis of RWD.

RWE can be generated by different study designs or analyses, including but not limited to, randomized trials, large simple trials, pragmatic trials, and observational studies



Six areas where RWE provides advantage

Why Oncology needs to be even more patient driven?





The technology of change

Technology is not a barrier

It is amplifier of a positive change.

Digital patient empowerment:

- Education and training
- Health dossier & patient diary
- Patient groups & organisations



The technology of change

The patients' communities
& organisations of
the future?

What are the challenges?





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Thank you!

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CEE
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