

# **Patient Perspective**

### Transparency and person-centred measures

Valentina Strammiello- Director of Programmes European Patients' Forum





## **Person-centred care**

## EHMA 2023

Patient-centred care: "Providing care that is respectful of and responsive to individual patient preferences, need, and values, and ensuring that patient values guide all clinical decisions." (IOM, 2001)

**Person-centred, coordinated care**: aims to achieve the outcomes that matter for each individual patient

- Personal goals & preferences
- Shared care planning, shared decision-making
- Being seen as a person, not a diagnosis or number
- Holistic approach psychological, emotional social, mental and family aspects as well as physical problem





## **Quality of healthcare**

### • WHO 7 dimensions of quality

- Effectiveness Does healthcare actually improve patients' health?
- Safety Prevention of medical errors and adverse events
- Patient-centredness / responsiveness Is care delivered in accordance with patients' needs, preferences and expectations?
- Timeliness
- Integration
- Equity
- Efficiency





EHMA 2023



## **Quality of healthcare**

How outcome measurement can help improve quality

- Performance monitoring and transparency
  - ✓ Identification of best practices, facilitate patient choice
  - ✓ Incentivise providers to improve quality
- Inform policies and recommendations aimed at improving health care quality and efficiency
  - ✓ At organisational level, e.g. by tracking variation in outcomes
  - ✓ At system level (international) learning, benchmarking
  - ✓ Targeting investment towards high-value care
- Making healthcare more patient-centred
  - Supporting HCP-patient communication and shared decision-making
  - Involving patients in the selection of outcome measures for quality improvement initiatives





Measure the Patient Experience!



## Patient Empowerment

"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."

3 dimensions:

- Health literacy
- Information / education
- ICT tools

1.

- Systems navigation...
- 2. Self-management
  - Skills, behaviours, self-efficacy
- emotional support...
- 3. Shared decision-making

OWN CHOICES

Relationship

(EPF PE Toolkit)

- Decision aids
- Communication
- HCP skills, attitudes...



EHMA 2023



# Good design & training is critical to ensure quality

- Consider involving patients in training and design of programme
- Especially communication strategies & materials
  - ✓ People with lived experience of risk behaviours
  - ✓ People from various backgrounds including lower health literacy
- Ethical caution: patients' expertise should be recognised and involvement should not be exploitative (e.g. reducing people to "a story" with no other input)
  - Community liaisons for marginalised or excluded groups
  - ✓ Patient organisations can represent their communities



EHMA 2023

**#EHMA2023** 



# Patient organisations: untapped potential

- POs can be your valued partners in implementing programme
- Peer support to patients is a core function mentoring, counselling, legal & financial support, self-management education...
- POs can disseminate messages on policy, education, evidence... but also help design programmes so they work better for patients
- Consider "referral" of patients to relevant patient organisations and communities for support
- Consider involving POs in trainings, providing feedback & evaluation on BRIEF programmes





## **H2O IS A REVOLUTIONARY INITIATIVE AIMING TO STRENGTHEN HEALTH CARE IN EUROPE**



HEALTH OUTCOMES

Setting-up data observatories...

... creating a learning community...

... and driving cultural change





patient-centric pan-European & Setting-up national observatories with the aim of engaging patients and connecting providers, ultimately different stakeholders equipping with the necessary data to improve patient care

Building a community of patient-centric and outcomes-driven organizations based on transparency and trust

Changing mindset and behaviors towards adoption of value-based health care and patient empowerment

# **BENEFITS FOR PATIENTS**

- ✓ Join and contribute to a community that empowers and encourages patients to take better control of their health information and supports data-driven decision making.
- Track the health measures that impact their care decisions, and better discuss their thoughts and preferences in individual consultations with their physician or other health care professional.
- ✓ Have an integrated view of their health information at hand, enabling them to refer to it during a visit to any health care professional, regardless of the setting.
- Benchmarking with other patients: better understand the general burden of disease, compare how their experience and measures compare to those of other patients with the same condition, and assess the quality of care that the patient receives compared to others.
- Potentially have access to higher quality of care, thanks to evidencebased advocacy and decision making







## Thank you!

Author/Presenter's contact details

