

Patient organisation perspective

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@eupatientsforum

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

EPF European Patients Forum The logo for the European Patients' Forum, featuring three stylized green human figures in a dynamic pose above the acronym EPF and the full name "European Patients Forum".

About EPF



European Patients' Forum

- Independent, non-governmental umbrella founded in 2001

Our members

- 74 National patient coalitions & EU disease specific organisations

We strive to be the collective, influential patient voice across diseases in European health/related policies and advance patient empowerment and equitable access to high-quality, patient-centred care in Europe, for all patients by driving change in policy and practice



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

EPF's Strategic Goals 2014-2020



Health Literacy



Healthcare Access
and Quality



Patient involvement



Patient
Empowerment

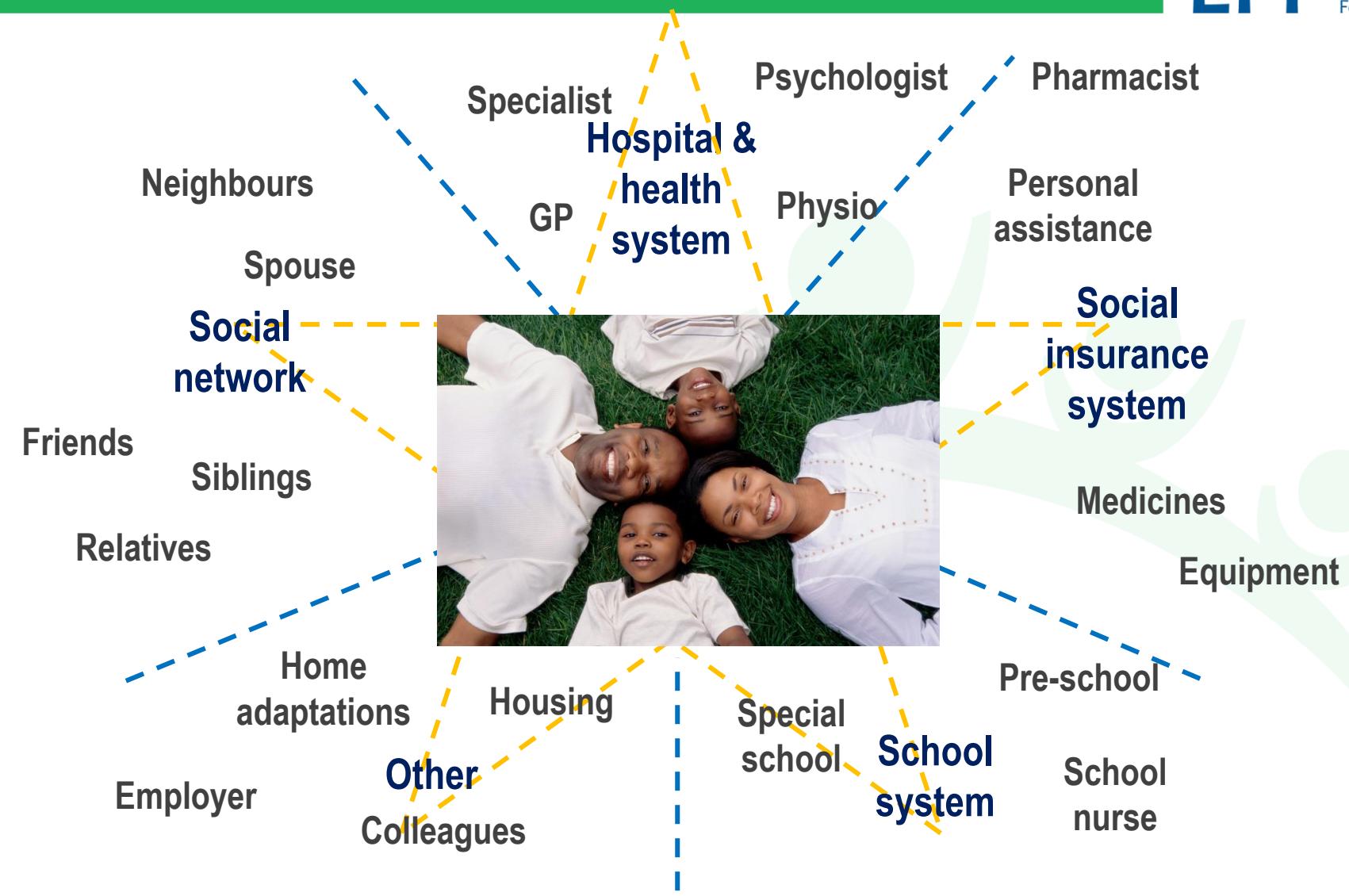


Sustainable Patients'
Organisations



Non-discrimination

Patients' needs at the centre of integrated care



Chronic conditions: a challenge to healthcare

Long-term, holistic, integrated management

1 in 4 adults: long-term condition or disability

80% of people 65+: at least one chronic condition



Coordination of care
Multidisciplinary teamwork
Collaborative care
Empowering practices
Supporting self-management
Advocacy
Navigation

...



Task shifting & sharing – the future?

Accessibility, effectiveness and efficiency of healthcare

“Task shifting” identified as a potential area to improve quality & sustainability of our health systems (European Commission, 2019) → enhance role of nurses, pharmacists...



Enhancement



Substitution



Innovation

Towards high + harmonised standards



Quality of professionals' training is key

- Up-/reskilling efforts related to redistribution of tasks → changes to health professionals' education – including basic and CPD
 - Patients deserve equally high standards of care regardless of where in EU they live
 - Patient safety must not be compromised
- Commission 2019 report: skill mix innovation should be accompanied by *active involvement of patient and professional organisations*

Key areas for professional training

Training to support chronic disease management

- Chronic conditions require long-term, holistic, integrated approach
- Adapted for people with multiple health problems
- Awareness of best practices in (multiple) chronic disease care
- Effective integration & coordination of care
- Support for patients' self-management
- Adherence support

Training for person-centred care

- Training in “soft” skills – shared decision-making, communication, health literacy, empathy...



Transparent quality for patients

Transparency on quality standards, including professional training

- Health systems should be more transparent to patients around quality and safety of care → accountability, trust
- Include transparency of qualifications for different specialities, national CPD requirements
- More convergence of standards & guidelines
- Benchmarks / key indicators for monitoring quality
- 2011 Cross-border healthcare directive included provisions on transparency of safety and quality standards – but implementation lacking so far



Patients in professional education

- Although still limited, increasing interest
 - Increasing “pockets” of good practice
 - Guidelines, some governmental policies (e.g. INVOLVE, British Medical Association, NHS in UK)
 - Research showing positive effects and calling for more examples
- Ultimate goal of education is teaching professionals how best to help patients
 - Obvious role for patients BUT this has always been very passive... time to change!



Key findings and recommendations on
*Education and training in patientsafety
across Europe Work of the Education
and Training in Patient Safety Subgroup of the
Patient Safety and Quality of Care Working Group
of the European Commission*

Core needs are common

Patients value “human” aspects of care highly

- Empathy, respect, dignity
- Holistic approach
- Continuity, not fragmentation
- Good communication & engagement

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

“understand my situation – social and psychological”

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

- Different levels of patient involvement in different curricula (*nursing* and social work leading)
- Team effort from professionals & educators needed for involving patients meaningfully



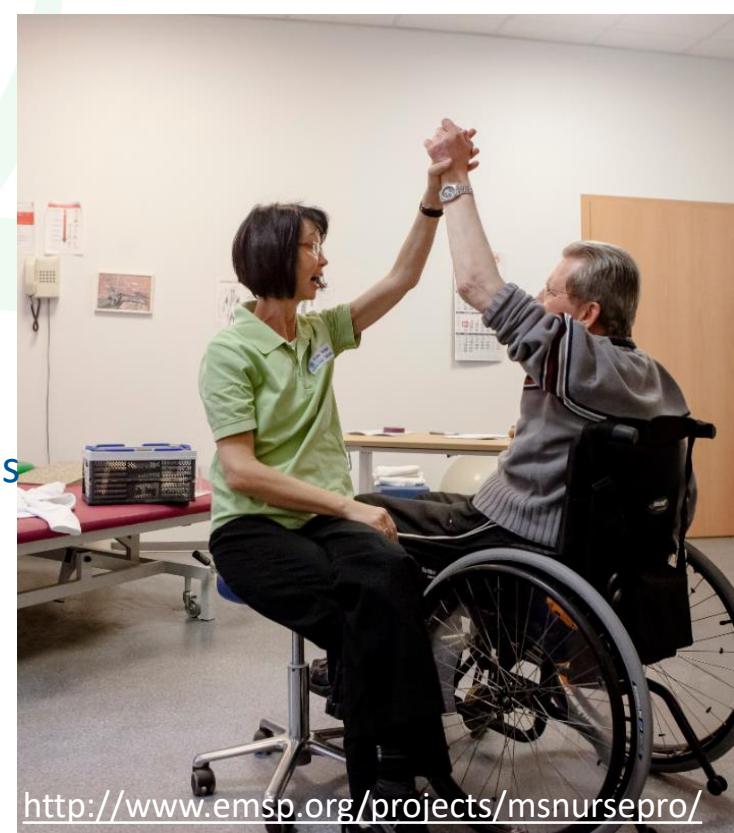
www.eu-patient.eu/globalassets/policy/quality-of-care/quality-survey-report.pdf

Example: Patient-centred training

... for high-quality specialist nursing

Patient organisation – European MS Platform – co-designed “MS Nurse Professional” with specialist nurses

- Accredited online training tool → consolidate standards of MS nursing care across Europe.
- 7,000+ MS nurses enrolled 2012-2019
- Six accredited online training modules:
Understanding MS, Clinical presentation, Diagnosis and assessment, Treatment, Care and support, Rehabilitation
- Available in several languages
- Co-production between patients and nurses



<http://www.emsp.org/projects/msnursepro/>

EPF recommendations

- Integrate common “core competences” into professional training and curricula
 - New roles and skills (co-ordination, coaching, patient advocacy...)
 - Integrated, coordinated (multiple) chronic disease management – collaborative teamworking
 - Identify best practices that exist now
 - Agree minimum training requirements & common principles → modules can be developed to be integrated in professional training at different levels
 - Embed aligned training curricula in all MS
- Promote patients’ involvement in professional training



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