

The future of

- Healthcare conversations. Trends & Inspirations. •
- Where & How Romania fits in?

Conference 'Romania's Future of Healthcare'

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Health systems across Europe are confronting numerous challenges:

- ✓ Ageing populations
- ✓ Sustainable financing of healthcare
- ✓ Wide variation in clinical practice
- ✓ Emphasis on practical experience
- ✓ Significant public health problem

Better health can make a very important contribution to economic and social goals through:

- ✓ Longer working lives
- ✓ Greater productivity
- ✓ Reduced disability claims
- ✓ Better educational outcomes
- ✓ Reduced social exclusions

- Patients with Chronic Conditions continue to increase in numbers
- HCS cannot continue to focus on disease rather than the person – necessary steps include:
 - ✓ Involvement of patients to:
 - ✓ Adhere to treatment
 - ✓ Make behavioural changes
 - ✓ Self-management

IAPO's work on PCH focuses on the Rationale that:

PCH becomes entrenched in the minds of those working in HC and accepted in the same way as evidence-based care



Declaration on Patient-Centred Healthcare

Patient-centred healthcare is the way to a fair and cost-effective healthcare system

Health systems in all world regions are under pressure and cannot cope if they continue to focus on diseases rather than patients; they require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage. Patient-centred healthcare may be the most cost-effective way to improve health outcomes for patients.

To us, the International Alliance of Patients' Organizations, the essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective. By promoting greater patient responsibility and optimal usage, patient-centred healthcare leads to improved health outcomes, quality of life and optimal value for healthcare investment.

Patients', families' and carers' priorities are different in every country and in every disease area, but from this diversity we have some common priorities. To achieve patient-centred healthcare we believe that healthcare must be based on the following **Five Principles**:

1. Respect

Patients and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.

2. Choice and empowerment

Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

3. Patient involvement in health policy

Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives. See IAPO's Policy Statement at: www.patientsorganizations.org/involvement

4. Access and support

Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that all patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.

5. Information

Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture. See IAPO's Policy Statement at: www.patientsorganizations.org/healthliteracy

To achieve patient-centred healthcare at every level in every community, the International Alliance of Patients' Organizations is calling for the support and collaboration of policy-makers, health professionals, service providers and health-related industries to endorse these **Five Principles** and to make them the centre of their policies and practice. We call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

Definitions...

Definition and Principles of Patient-centred Healthcare (No definition available in non-western countries):

- *'A collaborative effort consisting of patients, patients' families, friends, the doctors and other health professionals...achieved through a comprehensive system of patient education where patients and the health care professionals collaborate as a team, share knowledge and work toward the common goals of optimum healing and recovery.'* (Grin, 1994).
- *'Heath care that is closely congruent with and responsive to patients' wants, needs, and preferences.'* (Laine & Davidoff, 1996).
- *'Placing patients at the centre of the system of care and developing good services that revolve around them'* (Mallett, 1996).

The Picker Institution (USA, Canada, Europe):

- *Informing and involving patients, eliciting and respecting their preferences;*
- *Responding quickly, effectively and safely to patients' needs and wishes;*
- *Ensuring that patients are treated in a dignified and supportive manner;*
- *Delivering well coordinated and integrated care. (Coulter, written communication, August 2004)*

The Picker Institute definition is based on the following elements outlined by Gerteis et al (1993): Respect for patients' values, preferences and expressed needs;

- *Coordination and integration of care;*
- *Information, communication and education; Shared decision-making and support for self-care;*
- *Physical comfort;*
- *Emotional support and alleviation of fear and anxiety; Involvement of family and friends;*
- *Continuity of care and smooth transition across service boundaries.*

US Agency for International Development USAD – Also the definition used by Europe

"patient-centred healthcare is, 'An approach to care that consciously adopts a patient's perspective. This perspective can be characterized around dimensions such as respect for patients' values, preferences, and expressed needs in regard to coordination and integration of care, information, communication and education, physical comfort, emotional support and alleviation of fear and anxiety, involvement of family and friends, transition and continuity." (USAID, 1999)

Definitions...

The Americas

Institute of Medicine (IOM)

Making health care more patient-centred

Many definitions but all on the same principles.

According to the Institute of Medicine (IoM), patient-centeredness is:

- *"providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions". Coordinated and integrated care; and treating patients in a dignified way (particularly in the context of long-term care).*

Patient Empowerment - a specific component of patient-centred care - Involvement of patients in health care decision-making, and viewing patients as a key partner in the co-production of health care (alongside medical professionals and policy makers).

National Health Council (NHC)

'Patient-centred care is quality health care achieved through a partnership between informed and respected patients and their families, and a coordinated health care team.'

The NHC also defined three principles of 'patient-centred care':

- *Patients and their families manage their health care in partnership with a coordinated health care team that recognizes, respects and acts upon their goals, needs, values, preferences, cultural wishes, and/or other factors identified by patients and their families.*
- *Patients and their families receive evidenced-based, cost-effective quality care that maximizes health, alleviates discomfort and is safe and free from avoidable errors.*

Patients and their families have the ability to obtain and understand health information and services, and make appropriate health decisions. (NHC, 2004)

Provide a framework describes decisions of PCH

WHO "General Principles of Good Chronic Care", 2009

1. Develop a treatment partnership with your patient
2. Focus on your patient's concerns and priorities
3. Use the 5 A's: Assess, Advise, Agree, Assist, Arrange
4. Educate patient on disease and support patient self-management
5. Organize proactive follow-up

6. Involve "expert patients," peer educators and support staff in your health facility
7. Link the patient to community-based resources and support
8. Use written information registers, Treatment Plan, treatment cards and written information for patients to document, monitor, and remind
9. Work as a clinical team
10. Assure continuity of care



EU Health programme 2014-2020

High Quality VS Poor Quality



- The development of tools to help Member States improve quality of care is a key objective of the EU Health Programme, 2014-2020.²⁸ **Quality of care** is a priority area for the EU Expert Group on Health System Performance **Assessment**, as well as a major theme in the development of international health care indicators at the OECD.
- **Health care quality: effectiveness, safety, and patient-centredness / responsiveness.** Effectiveness and safety both reflect outcomes of care: effectiveness concerns the extent to which health care interventions actually improve the health of patients; safety focuses on the prevention of medical errors and adverse events (e.g. hospital-related infections). **Patient-centredness / responsiveness is not an outcome per se**; it concerns the way in which care is delivered – e.g. whether it **is attentive to patients' needs, preferences, and expectations**.
- Patient-centred outcomes may be based upon clinical, mortality, administrative or patient-reported data – the key point is that they reflect outcomes **that patients themselves consider to be meaningful and relevant**.

Tools to improve Quality and Sustainability

- ✓ Health care outcome measures decision
- ✓ Health System Performance Assessment (HSPA)

Outcome measures of 4 types

- ✓ Clinical
- ✓ Mortality
- ✓ Administrative
- ✓ Patient reported data
 - ✓ PROMS
 - ✓ Involving patients in the selection of outcome measures for use in quality in proven indicators

PATIENT-REPORTED OUTCOME MEASURES (PROMs)

PROMs can be both **generic** and medical condition-specific. For many medical conditions both a generic and condition-specific PROMs may be used.

Generic PROMs focus on general aspects of a patient's health, and are used across a variety of conditions. Examples of generic PROMs include the EQ-5D and SF-36 - both include questions on:

- physical functioning / mobility (e.g. walking or cycling);
- symptoms (such as pain and fatigue);
- psychological well-being (e.g. anxiety / depression);
- the ability to perform normal day-to-day activities (e.g. shopping / cleaning);
- social well-being (e.g. at work, family, sports).

Condition-specific PROMs examples:

- the Asthma Quality of Life Questionnaire
- the Oxford Hip Score (for hip replacements)
- the Burn Specific Health Scale
- the Health of the Nation Outcome Scales (used in psychiatric care)
- and the PTSD checklist (for post-traumatic stress disorder).

Practice of PCH and outcomes

- Patient- centeredness as the strongest predictor of:
- Health outcomes and Efficiency of HC
- Patient-satisfaction
- Engagement at task-orientation
- Reduction in anxiety
- Quality of life improvements
- Doctor satisfaction
- Increase in efficiency – fewer diagnosis teams, fewer unnecessary references



NHS (England) Outcomes Framework



■ Reducing premature mortality:

- from the major causes of death
- in people with mental illness
- in children
- in people with a learning disability

■ Enhancing quality of life for people with long-term conditions:

- Employment of people with long-term conditions
- Employment of people with mental illness
- Health-related quality of life (HRQoL) for carers
- HRQoL for people with three or more long-term conditions (under development)

■ Helping people to recover from episodes or ill health or following injury:

Health gain as assessed by patients for elective procedures

Recovery of mobility / walking after hip fracture

Improvement in activity / lifestyle following stroke

■ Treating and caring for people in a safe environment and protecting them from avoidable harm:

deaths and severe harm attributable to problems in health care

The five E's of patient empowerment

European Patients' Forum Campaign on Patient Empowerment

- **Education** Patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.
- **Expertise** Patients self-manage their condition every day so they have a unique expertise on health care which needs to be supported.
- **Equality** Patients need support to become equal partners with health professionals in the management of their condition.
- **Experience** Individual patients work with patient organisations to represent them, and channel their experience and collective voice.
- **Engagement** Patients need to be involved in designing more effective health care for all, and in research to deliver new and better treatments and services.

Genuine patient quotations

- ✓ *"My doctor is not a specialist in thalassaemia treatment and I sometimes feel he should know more."*
- ✓ *"Staff should be well trained in cannulation and should realise that our veins are precious to us!"*
- ✓ *"I sometimes have to wait 4 hours for my transfusion which is boring and frustrating."*
- ✓ *"I would love to have combination treatment but don't know if it is appropriate for me."*
- ✓ *"I would like to have regular cardiology appointments and bone density scans but don't know if I should ask about this."*
- ✓ *"The most helpful thing my doctor does is listens to what I say and is honest with me."*

UKTS, 2016

Patients' Perspective on PCH

UKTS, 200-2016



- Access to patient-centred care
 - “out of hours” treatment
 - Continual provision of updated, clear information on:
 - ✓ Disease-specific issues
 - ✓ Policies’ development / changes
 - ✓ Participation in clinical trials
 - ✓ Clinical trials’ results
 - ✓ New / upcoming advances
 - Psychosocial support
 - Active patient involvement and integration in decision-making

Access to holistic care, based on UK standards / TIF protocol (evidence-based)

- Access to all “authorized” for the disease treatment drugs – innovative/generic
- Access to “off-label” drugs, if and when scientific evidence for benefit is demonstrated
- Access to appropriate multidisciplinary care

The UK Thalassaemia patients' experience and success (UKTS)



UKTS achieved involvement in:

- Government-related bodies
 - ✓ Specialized commissioning
 - ✓ CRG (Clinical Reference Group)
 - ✓ NHR (National Haemoglobinopathy Registry)
 - ✓ NICE (National institute of Clinical Excellence)
 - ✓ NHS Blood & Transplant
 - ✓ NHS Antenatal & Newborn Screening Program
- Government organizations set up to support
 - ✓ APPG (All Party Parliamentary Group)
 - ✓ UK Forum (United Kingdom Clinical Forum)
 - ✓ Peer Review of treatment Centres

• Furthermore, UKTS achieved involvement in:

- The education of health professionals and policy makers on the patients' perspective by:
 - ✓ Presence at conferences local / national / International
 - ✓ Attendance and presentations in workshops
 - ✓ Lecture presentations
- The preparation and adoption of standards of care for Thalassaemia: (Standards for the care of children and adults with Thalassaemia in the UK)
- Developing and evaluating as well as publishing patient questionnaires so as to establish the patients views
- Developing of patients' and clinicians educational workshops / conferences

Greek/ Cyprus Thalassaemia Associations, actively involved in decision-making at the national/ regional/ central level: Government and HPs (1980-2016)



Greece

1. Μεταγγίσεις και όλες τις εξετάσεις στα Δημόσια Νοσοκομεία ΕΝΤΕΛΩΣ ΔΩΡΕΑΝ για όλους τους θαλασσαιμικούς.
2. Φάρμακα αποσιδήρωσης EXJADE - FERRIPROX - DESFERAL και αναλώσιμα υλικά για τόσους κάνουν αποσιδήρωση με Desferal ΕΝΤΕΛΩΣ ΔΩΡΕΑΝ. Δεν υπάρχει περιορισμός για την επιλογή φαρμάκου. Συνταγογραφεί ο θεράπων ιατρός ότι νομίζει
3. ΕΝΤΕΛΩΣ ΔΩΡΕΑΝ τα φάρμακα που λαμβάνονται για αντιμετώπιση επιπλοκών της νόσου. Για παράδειγμα αν κάποιος παίρνει φάρμακα για την καρδιά, ή το θυροειδή, ή άλλες ενδοκρινολογικές επιπλοκές, ή για την ηπατίτιδα, ή για διαβήτη είναι όλα δωρεάν. Ακόμα και η αντιβίωση δίνεται δωρεάν χωρίς συμμετοχή όταν ο θαλασσαιμικός έχει κάνει σπληνεκτομή.
4. Για οποιαδήποτε εξέταση που γίνεται σε ιδιωτικά νοσοκομεία ή κέντρα (MRI, DEXA, αιματολογικές εξετάσεις, ακτινογραφίες, κλπ) ο θαλασσαιμικός πληρώνει 15% συμμετοχή στην τιμή της εξέτασης. Για παράδειγμα αν κάποιος κάνει MRI σε ιδιωτικό κέντρο για εξέταση σε καρδιά και ήπαρ πληρώνει συμμετοχή 75 ευρώ. Η εξέταση μπορεί να γίνει έως και 2 φορές το χρόνο.
5. Οι θαλασσαιμικοί που τελειώνουν τις σπουδές σε ιατρική σχολή και σε οποιοδήποτε παραϊατρικό επάγγελμα διορίζονται αμέσως σε δημόσιο νοσοκομείο της επιλογής τους.
6. Μπαίνουν με ειδικό (ευνοϊκό) καθεστώς στα Πανεπιστήμια για να σπουδάσουν σε όποια σχολή επιθυμούν.
7. Μετά από 15 χρόνια εργασίας σε οποιοδήποτε επάγγελμα στο Δημόσιο ή Ιδιωτικό τομέα, ο θαλασσαιμικός μπορεί να συνταξιοδοτηθεί με πλήρεις αποδοχές σαν κανονική σύνταξη γήρατος.
8. Όλοι οι θαλασσαιμικοί λαμβάνουν οικονομική ενίσχυση από το κράτος (επίδομα) που φτάνει τα 360 ευρώ το μήνα
9. Μπορούν να αγοράσουν αυτοκίνητο χωρίς να πληρώσουν τελωνειακούς δασμούς και απαλλάσσονται από τα Τέλη Κυκλοφορίας

Cyprus patients' success story: official involvement and engagement – by law, April 2016

Ε.Ε. Παρ. Ι(Ι)
Αρ. 4563, 22.4.2016

Ν. 46(Ι)/2016

Ο περί της Διαδικασίας Διαβούλευσης Κρατικών και Άλλων Υπηρεσιών σε Θέματα που Αφορούν Ασθενείς Νόμος του 2016 εκδίδεται με δημοσίευση στην Επίσημη Εφημερίδα της Κυπριακής Δημοκρατίας σύμφωνα με το Άρθρο 52 του Συντάγματος.

Αριθμός 46(Ι) του 2016

ΝΟΜΟΣ ΠΟΥ ΠΡΟΝΟΕΙ ΓΙΑ ΤΗ ΔΙΑΔΙΚΑΣΙΑ ΔΙΑΒΟΥΛΕΥΣΗΣ ΚΡΑΤΙΚΩΝ ΚΑΙ ΑΛΛΩΝ ΥΠΗΡΕΣΙΩΝ ΣΕ ΘΕΜΑΤΑ ΠΟΥ ΑΦΟΡΟΥΝ ΑΣΘΕΝΕΙΣ

- Προοίμιο. Επειδή κρίνεται επιβεβλημένη η σταδιακή ένταξη των οργανωμένων συνόλων των ασθενών στις διαδικασίες λήψης αποφάσεων που αφορούν θέματα ασθενών και
- Επειδή η ένταξη αυτή προσπαθεί την εκπαίδευση και κατάλληλη προετοιμασία των εκπροσώπων των ασθενών, για την οποία απαιτείται χρόνος που στο παρόν στάδιο δεν υφίσταται, προτείνεται η θεσμοθέτηση σε πρώτο στάδιο της διαβούλευσης κάθε υπηρεσίας που ασκεί δημόσια εξουσία για θέματα που αφορούν ομάδες ασθενών με την Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων στις περιπτώσεις εκείνες που δεν προβλέπεται από ειδικό νόμο η συμμετοχή οργανωμένων συνόλων των ασθενών στα κέντρα λήψης αποφάσεων.
- Η Βουλή των Αντιπροσώπων ψηφίζει ως ακολούθως:
- Συνοπτικός τίτλος. 1. Ο παρών Νόμος θα αναφέρεται ως ο περί της Διαδικασίας Διαβούλευσης Κρατικών και Άλλων Υπηρεσιών σε Θέματα που Αφορούν Ασθενείς Νόμος του 2016.
- Ερμηνεία. 2.-(1) Λέξεις ή όροι που δεν ερμηνεύονται στον παρόντα Νόμο έχουν την έννοια που τους προσδίδεται από τον περί της Κατοχύρωσης και της Προστασίας των Δικαιωμάτων των Ασθενών Νόμο.
- 57 του 1972
85(Ι) του 1997. (2) Στον παρόντα Νόμο, εκτός αν από το κείμενο προκύπτει διαφορετική έννοια -
- «Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων» σημαίνει το σωματείο με το όνομα «Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων», το οποίο ιδρύθηκε στις 30 Οκτωβρίου 1986 και λειτουργεί δυνάμει του περί Σωματείων και Ιδρυμάτων Νόμου.
- «υπηρεσία» σημαίνει οποιαδήποτε δημόσια υπηρεσία, αρχή, υπουργείο, κρατικό όργανο, ημικρατικό οργανισμό, νομικό πρόσωπο ή οργανισμό δημοσίου δικαίου και οποιοδήποτε άλλο όργανο που ασκεί δημόσια εξουσία και περιλαμβάνει κάθε όργανο τοπικής αυτοδιοίκησης.
- Υποχρεωτική διαβούλευση με την Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων. 3.-(1) Η Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων καθιερώνεται ως κοινωνικός εταίρος του κράτους σε θέματα που αφορούν ασθενείς.
- (2) Κάθε υπηρεσία η οποία πρόκειται να αποφασίσει για θέματα που αφορούν με οποιοδήποτε τρόπο άμεσα ή έμμεσα ομάδες ασθενών διαβουλεύεται προτού αποφασίσει σχετικά με την Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων.
- (3) Για τους σκοπούς του εδαφίου (2), η υπηρεσία ζητά από την Παγκύπρια Ομοσπονδία Συνδέσμων Πασχόντων και Φίλων να υποδεικνύει τον εκπρόσωπο ή τους εκπροσώπους της σε κάθε περίπτωση.

Patient Engagement is important to all Stakeholders along the treatment pathway



Good Patient Engagement has many potential benefits



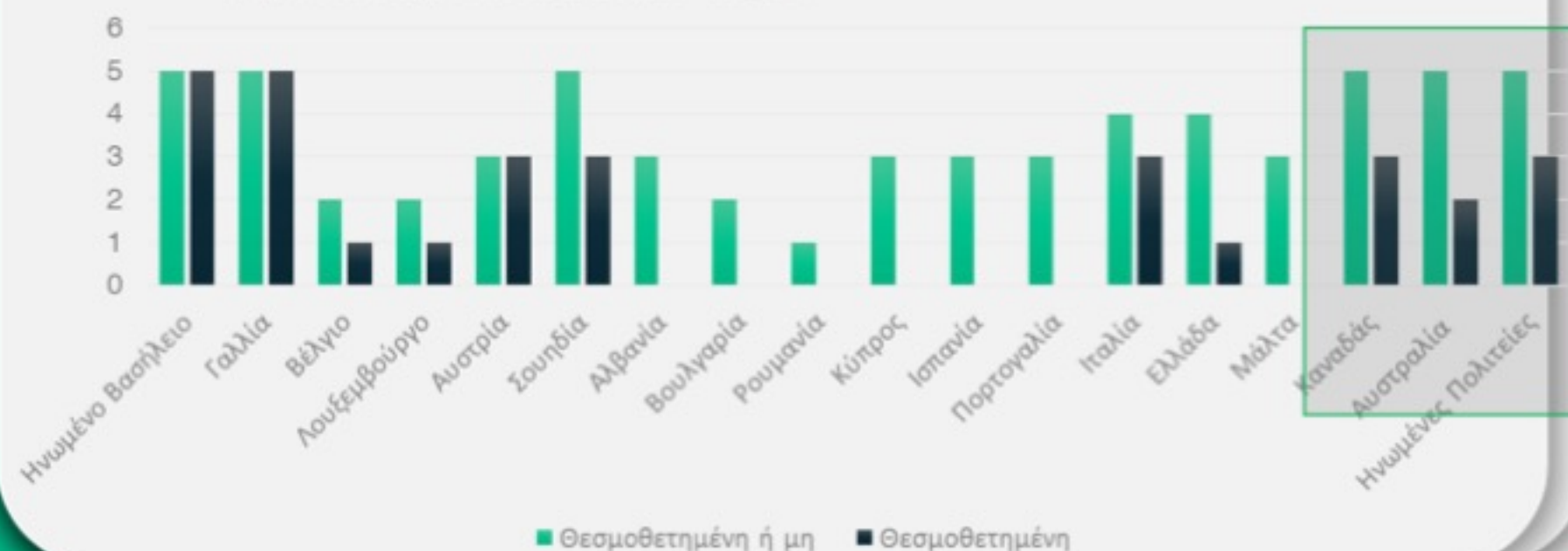
International Alliance of Patients' Organizations

Companies in the future are going to be paid on patient outcomes rather than on just selling prescription drugs.
Joseph Jimenez, CEO Novartis, 2014

Συμμετοχή (Θεσμοθετημένη ή όχι) οργανισμών ασθενών στο χώρο της υγείας (σε πέντε επίπεδα)

Πέντε επίπεδα συμμετοχής

- Συμμετοχή στη χάραξη στρατηγικών, πολιτικών, νομοθεσιών, συστάσεων
- Συμμετοχή στον προγραμματισμό δραστηριοτήτων προς επίτευξη των πιο πάνω
- Συμμετοχή στην εφαρμογή συγκεκριμένων δραστηριοτήτων (που αναπτύσσουν αλλά και να αξιοποιούν την εμπειρογνωμοσύνη και τις δεξιότητες των ασθενών
- Συμμετοχή στη διαδικασία αξιολόγησης των προγραμματισμένων δραστηριοτήτων
- Συμμετοχή στον προσδιορισμό και την ιεράρχηση προτεραιοτήτων καθώς και στην κατανομή των διαθέσιμων πόρων.



Attributes of patient-centered primary care practices (IoM - one of the six aims of quality)

1 *Superb access to care:*

2 *Patient engagement in care:*

3 *Clinical information systems*

4 *Care coordination:*

5 *Integrated, comprehensive care and smooth information transfer across a fixed or virtual team of providers:*

6 *Ongoing, routine patient feedback to a practice*

7 *Publicly available information on practices:*

Improving Care Pathways



Health systems need to be well organised and to function in ways that ensure patients receive the treatment and care they need. Care pathways can offer a number of benefits. They enable the best evidence-based medicine and effective new technologies to be adopted in local practice. Other potential benefits of care pathways include:

- reducing / eliminating practices shown to be less effective
- providing support for the management of care and decision-making
- ensuring that patients receive clinical interventions and assessments that are appropriate and timely
- reducing unnecessary variations in treatment for particular conditions
- improving information about the goals and likely outcomes of treatment
- improving communication between the professionals involved and the patient
- ensuring decisions are made with the full involvement of patients
- ensuring integration of care between the different parts of the health system - primary and secondary care services, in-patient and community care (even health and social care)
- reducing duplication of work and wastage of resources
- avoiding the possibility of gaps in service



Barriers...



- Structure of the Healthcare System:
- Under-funding
- Low staffing
- Low morale
- In many countries to day additionally
- Lack (services) of medicines
- Hospital equipment
- Restricted opportunities to train and educate healthcare teams on improving the care of patients

Strategies and tools for engaging patients

- Supporting patient self-management
- Supporting patients' shared decision making
- Strengthening patient peer-to-peer support
- Supporting patients' families and carers

Strategies and tools for empowering populations

- Protecting people's rights and fostering shared responsibilities
- Enabling populations' informed choice
- Strengthening health literacy
- Supporting community development