

# “THE CHALLENGE OF ACCESS: THE KEY ROLE OF PATIENTS IN SECURING HEALTH SYSTEMS OF THE FUTURE”

Nicola Bedlington  
Secretary General

12 May 2016

Vienna

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

# Presentation Outline

- Background on EPF - How we work and what we do
- Gastein Health Outcomes 2015 and today's event
- Patient Empowerment and Patient Access - Hand in Hand
- Migration: inclusion and non-discrimination - How EPF plays a role
- Conclusions

# Who is EPF?



## Our Vision!

“All patients in the EU have **equitable** access to **high quality, patient-centred** health and social care.”



## Our Mission!

“To ensure that the patient community drives health policies and programmes that affect them.”

# Our Strategic Goals



Health Literacy



Healthcare Access and Quality



Patient involvement



Patient Empowerment



Sustainable Patients' Organisations



Non-discrimination

Three „take aways“ from EHFG 2015:

- **Health literacy:** Citizen empowerment and patient-centered approach
- **Value of innovation:** Deeper cooperation across different levels and stakeholders – access to medicines and innovation → transparency, solidarity and trust
- **Migration:** „This is not a refugee crisis, this is a reception crisis.“

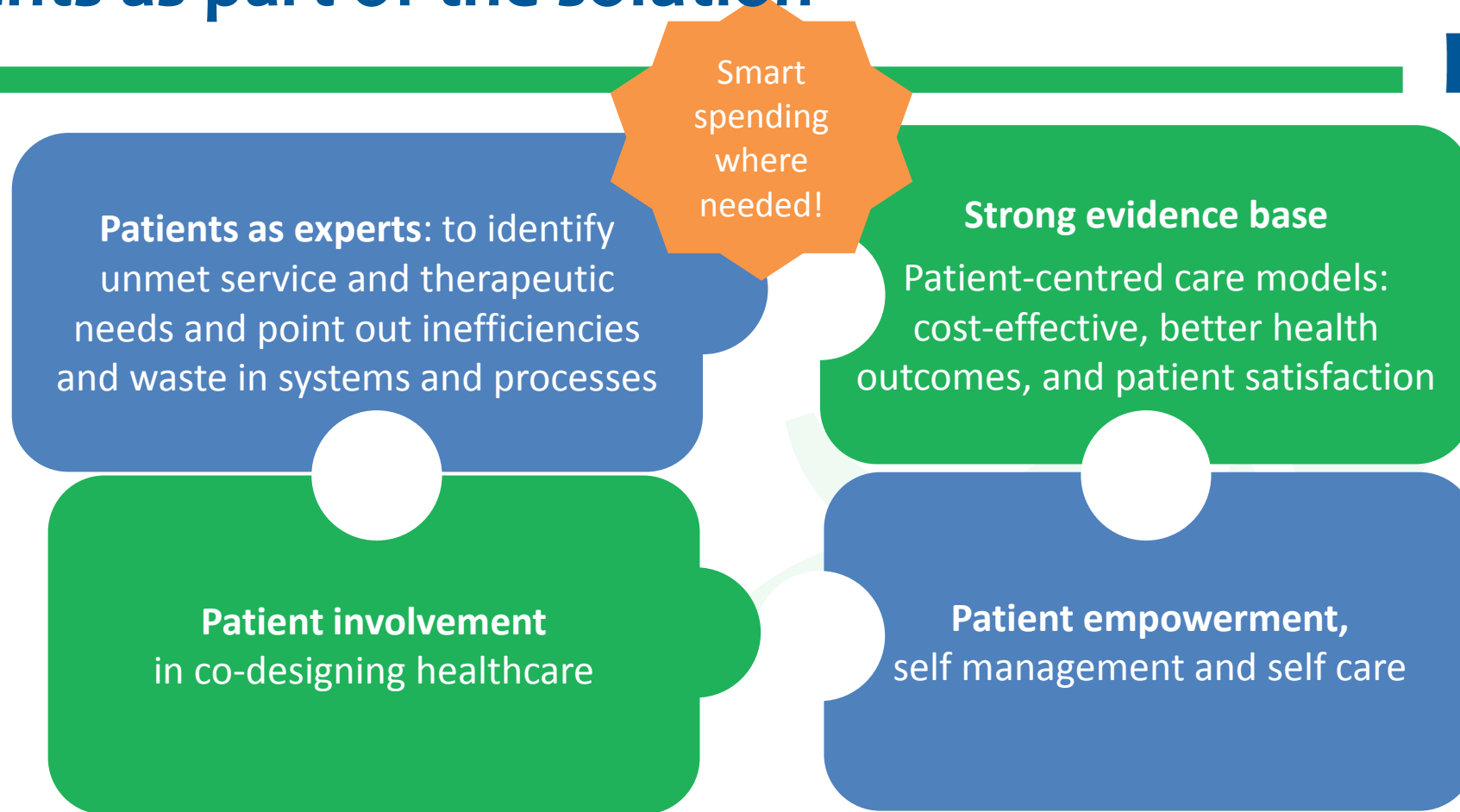
The aim of this event is to discuss these outcomes from a national Austrian perspective.



# PATIENT ACCESS AND PATIENT EMPOWERMENT

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# Patients as part of the solution



➔ **Health literacy**, the right skills and competencies for all the players, including patients, and an enabling environment



- The level of health literacy is diverse between population groups, which contributes to health inequalities
- 56,4% of Austrians have an inadequate or problematic health literacy level (2012)
- Although many initiatives take place, health literacy needs to be strengthened in Austria
  - Strengthening citizens' health competence is one of the ten main health targets (Austrian Federal Ministry of Health)

- EDUCATION
- EXPERTISE
- EQUALITY
- EXPERIENCE
- ENGAGEMENT



→ Patients prescribe **E<sup>5</sup>** for Better Health Systems!

# Patients' Charter on Patient Empowerment

- 10 core principles from patients' perspective
- Co-developed with EPF members
- What really matters for patients



Objective: promote action and culture change “on the ground” in the healthcare environment

**Patients prescribe E<sup>5</sup> for Better Health Systems**

## Dissemination strategy:

- Will be made available in most EU languages
- Distributed to EPF members and associates
- Ensure local coverage

Objective: patient organisations “own” the Charter, make it theirs

- Orphan Medicinal Products Regulation
- Advanced Therapy Regulation
- Pharmacovigilance Directive
- Revised Clinical Trials Regulation
- Upcoming Data Protection
- Directive on Patients' Rights in Cross Border Healthcare

*Leading **patient organisations** influenced all of this legislation.*

***Patient engagement** is also crucial in effective **implementation**, through EMA and at national level*

## EPF Preliminary Statement

- Distributed in advance on Informal Health Council 15 April – ongoing discussions
- Key concerns regarding current pricing models – which contribute to inequities
- A patient perspective on the ‘value’ of innovation
- Core principles for the pharma industry, and political decision-makers to ensure equitable access to treatment based on need, not means, + long-term sustainability of our health systems

- Some of the main challenges for Austria
  1. high-priced medicines
  2. cost pressure in cases involving broad indications
  3. „life-style“ medicines
  4. relationship between cost and benefit
- Patients' voice is not heard in regulatory or access processes
- Time to market: short time span until innovations become available on the Austrian market, but access to innovation is not equally distributed

# The Patient Access Partnership

## The Access Partnership

**Working towards a European Partnership for equity of access to quality healthcare**



A multi-stakeholder partnership with patients, healthcare professionals, healthcare industries, and health experts, and key decision makers

### Objectives

- Join forces to **measure, map and explore solutions to overcome inequities**, based on individual and collective expertise
- To put the issue higher on **the EU political agenda**



# A patient led campaign on access 2017

Huge disparities across the EU and within countries, austerity measures have widened the gap

Patients face multiple, concrete barriers to access, yet the European approach is focusing primarily on health determinants

“Healthcare coverage is universal or almost universal in all Member States” (EC, 2014)  
≠ not our experience

**Economic imperatives are overshadowing** the cost of health inequalities, which is both financial and human



# Our main theme: The road to universal access in the EU by 2030

- UN sustainable development goals in health : **universal health coverage by 2030**
- To show that we are still far from it... regardless of whether it is
  - the population covered
  - the type of services
  - or the proportion of costs that patients pay
- To define **concrete steps that need to be taken by 2030** to be on the right track
- A **long term vision** where equity of access becomes a reality



# MIGRATION, NON-DISCRIMINATION AND INCLUSIVENESS

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- Rapid increase of migrants: +10,6% in 2015 (Statistics Austria, 2016)
- In principle healthcare is accessible for migrants, however following challenges exist:
  - Low level of health literacy
  - Intercultural communication with health personnel
  - Unmet needs for psychosocial support → start of new initiative (CARE, 2016)

# Patients and discrimination: the picture today

- Strong link between discrimination and health inequalities
- Patients stigmatised and discriminated because of **disease**: e.g. HIV
- **Age** also a factor of unmet need and stigma: both for older and younger patients.
- **Gender**: Inequalities in research, gender labelling of diseases



Conference on rights and needs of older patients, 2011 Warsaw



Europe meets young patients, 2013 Brussels

- **Mental health:** Denial of adequate examination, lesser monitoring of physical conditions
- **Disabled people:** denial of treatments because of assumptions on quality of life and access related barriers
- **Sexual orientation:** Status of the partner?
- **Ethnicity:** Stigma
- Strong evidence that some groups like the **Roma people** and **undocumented migrants** face barriers to access, and exclusion

- EPF position “health for all” defines principles we stand for + recommendations for decision makers in 5 domains:
  - Right of access and equal treatment for all
  - Right to be protected from discrimination based on health status
  - Right to respect and to dignity in healthcare facilities
  - Right to information and support
  - Right of “vulnerable” groups to participate in non-discrimination policies



# EPF's work on migration with partners

- Joined the Fundamental Right Platform of the EU **Fundamental Rights' Agency** in 2011
- Collaborated with 11 NGOs on a common statement on discrimination in healthcare sent to MEPs in 2014
- Joint NGO statement to the Council on the migrant crisis in June 2015 to call on Member States to challenge migration policies that undermine public health objectives





- Developing internal EPF **roadmap** to define concrete actions to improve inclusiveness
- Aim: structured **cooperation** with organisations representing groups potentially vulnerable to discrimination
- An initiative driven by EPF members with expertise and interest in this area
- Direct **dialogue** between key **NGOs**
- To identify **synergies** between the patient movement and NGOs fighting discrimination



# Areas of synergies

## -migrants' rights to healthcare

- Promoting the right of undocumented migrants **to full access to healthcare**, and raising awareness of barriers they face legally and in practice.
- Exploring the link between undocumented migrants status and experience with **mental health**, promoting access to mental health care
- **Older undocumented migrants and disabled undocumented migrants:** promoting access to health and social care
- **EPF's work on transition to adult care:** include the rights of child migrants to keep their entitlement to healthcare into adulthood

# Conclusions

- Patient Empowerment, and Patient Access inextricably linked
- Multi-stakeholder collaboration – shared learning – thinking and doing things differently.
- ‘Full circle’ approach – the national dimension is vital
- Moving towards an EU framework on non-discrimination on the grounds of health status

Health literacy



Value of innovation



Migration



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[info@eu-patient.eu](mailto:info@eu-patient.eu)

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