PATIENTS AND EU HEALTH POLICY: SETTING THE SCENE

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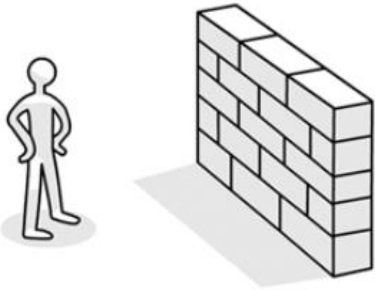
EPF Regional Advocacy Seminar

Presentation Outline

1. Background on EPF: our role, impact and interaction with national patient groups

2. A few examples of successful patient advocacy

3. Outstanding challenges or why we need strong patient organisations!



4. EPF's role in building capacity of patient organisations and empowering patients

Who is
the European Patients' Forum (EPF)?

EPF members

EPF members are pan-European disease-specific umbrellas or national platforms of patient organisations.

Mission and vision

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 2014-2020

Health Literacy

Healthcare Access and Quality

Patient involvement

Patient Empowerment

Sustainable Patients' Organisations

Non-discrimination

Evolution of EPF activities 2003-2016

EPF European Patients Forum

Strengthening Patients' voice in the EU

2003-2007

Influencing **policy developments** at EU-level

From 2008

EPF partnering in EU projects to gather evidence-based knowledge

2012 – present

Capacity Building and targeted activities for patient leaders, e.g. EUPATI

Evolution from 1 to 3 "pillars"

Strengthening policy impact

Patient advocacy in the EU legislative process?

A few examples…

EU Competences in Health

1

Article 168 TFEU
Limited Competence

- Responsibility for organisation of health systems and delivery of healthcare is with the Member States
- Principles of subsidiarity & proportionality
- Union action shall complement national policies

2

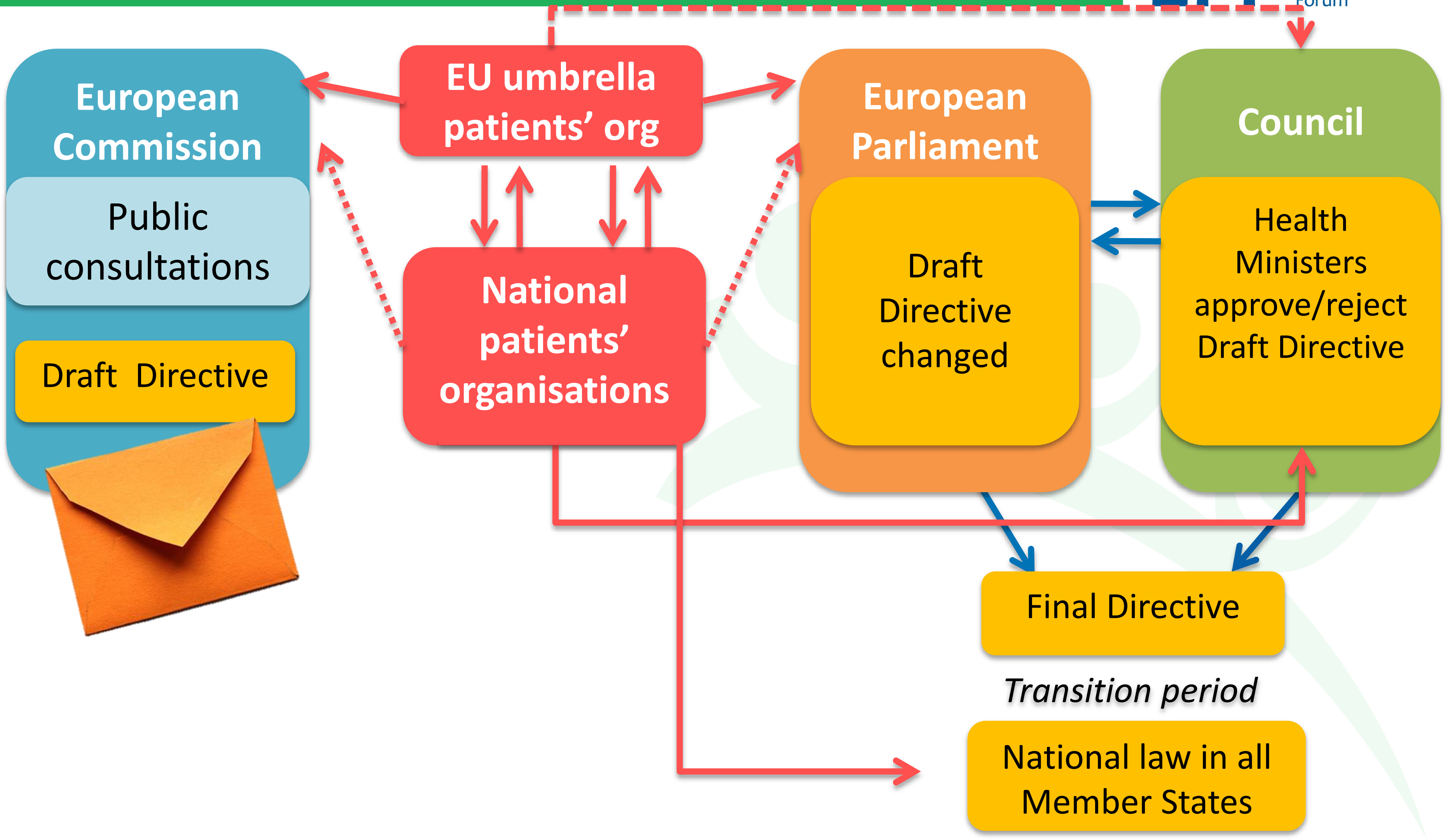
Binding legislation (regulations & directives) to harmonise MS laws in some areas of exception

3

Health Programme since 2003

For a strong European Patient Movement…

POs in the EU legislative process



European Commission

Public consultations

Draft Directive

EU umbrella patients' org

National patients' organisations

European Parliament

Draft Directive changed

Council

Health Ministers approve/reject Draft Directive

Final Directive

Transition period

National law in all Member States

Example 1 – CBHC Directive

EPF European Patients Forum

How do we engage our members?

Consultation during the legislative process

Guidance for Pos + Template **Recommendations** to send to ministries

Regional conferences to raise awareness + define the role of POs in ensuring the directive is well implemented

An informal network of **patient leaders on CBHC** across Europe: for peer support and to report on how it is working locally

Example 1 – CBHC Directive

The Directive has provisions for:

Equity: Right to reimbur ment of that patients received in

More quality an care and transpa quality of care

Better informa the setting up of na (NCPs)

Patient involvement in impleme of the directive

Key role for Patient Organisations to unlock potential of this Directive!

But!

- → Upfront payment, prior authorisation may be requested, cost of treatment only
- Difficult to put in place in practice atients should have access to ore information on quality
- uld take into account what information do patient need
- → Requirements for NCPs to "consult" patients is not enough

Example 2: Pharmacovigilance

Directive and regulation adopted in 2010 – What benefits for patients?

1 - Direct Patient Reporting: Possibility for patients to report directly suspected adverse drug reactions to competent authorities

2 - Better information on pharmacovigilance to the public through the creation of national websites

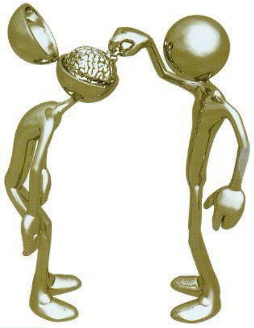
3 - More effective collecting of medicines safety and adverse reactions information thanks to the development of a European database

Our Achievements as EPF

Why do strong European patient groups matter?

- **EU legislation is demonstrably more patient-centred**, thanks in part to our advocacy work

- **Soft law and policy:** a clearer, more nuanced patient perspective



- **Real evidence for change** (thanks to our investment in solid project work)

Complementary levels of action!

European POs

- Closer to European decision-makers (better access to the European Commission, European Parliament’s Committees)
- In a better place to monitor the legislation at EU level
- Have a better “overview”, able to compare situations and transfer best practices whenever possible

Influence

Knowledge

National Alliances

- Closer to national decision-makers (including Council of the EU)
- Have a greater influence on MEPs from their country (they are voters!)
- Know about national-specific situations, realities
- Know about national legislation
- Closer to patients

Outstanding challenges: The case for strong Patient organisations!

The intrinsic role of patients organisations

WHY do we need empowered patient organisations?

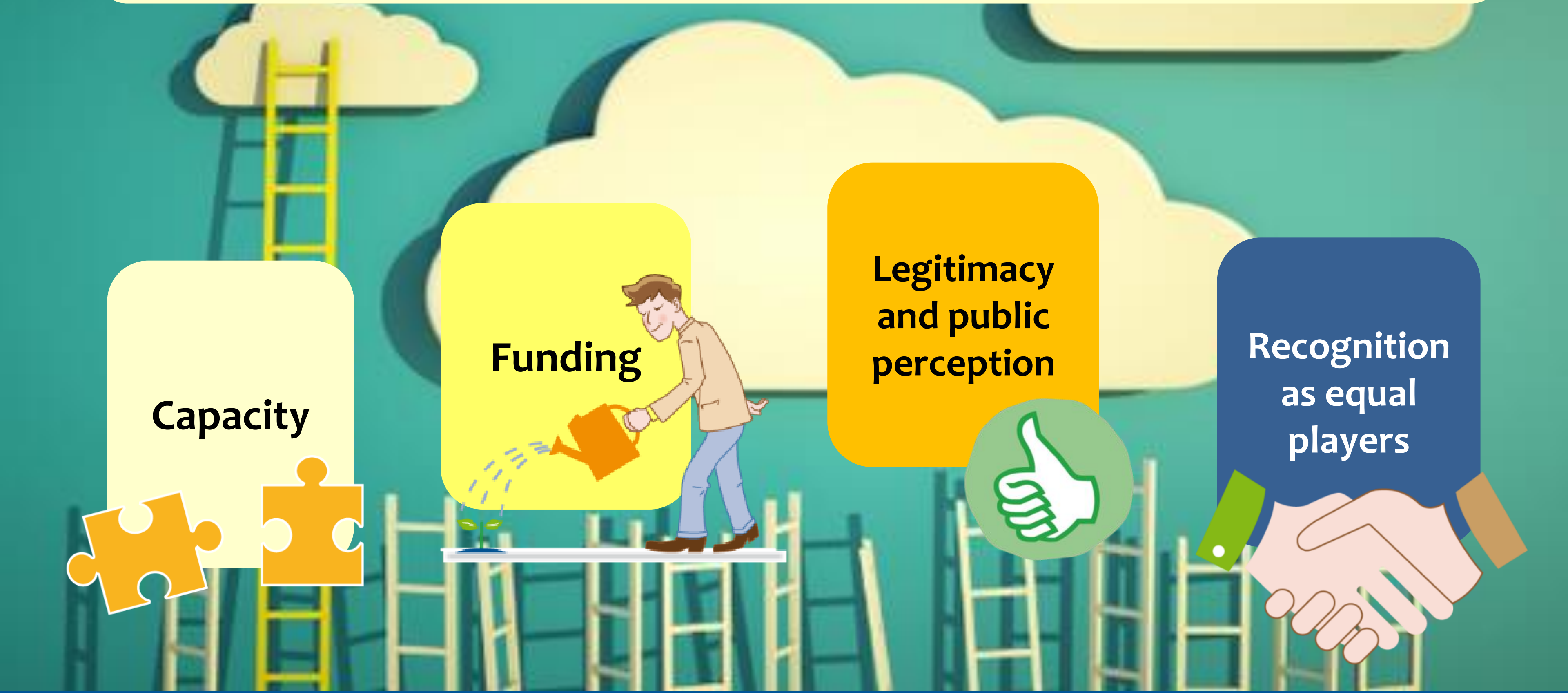
To achieve **balanced policies**, we need balanced views from **across the spectrum of health stakeholders.**

Therefore a strong civil society voice is needed!

We need to build that capacity, from the local level, to the national level, to the European level.

Outstanding challenges …

EPF has a responsibility to build empowered, transparent and ethic patient organisations



Capacity

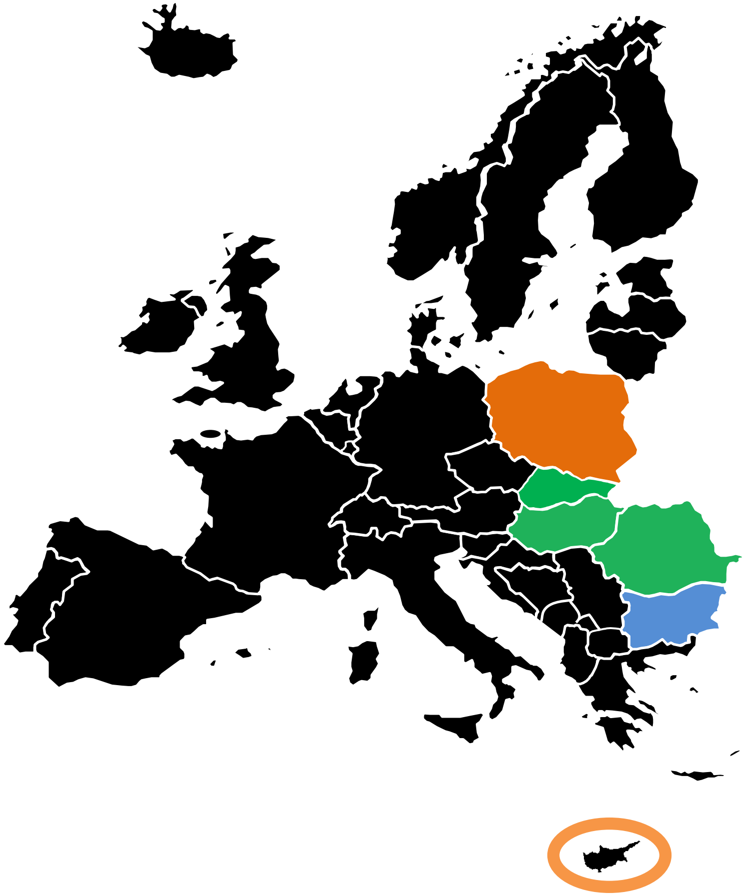
Funding

Legitimacy and public perception

Recognition as equal players

How can EPF best support our members and patient organisations?

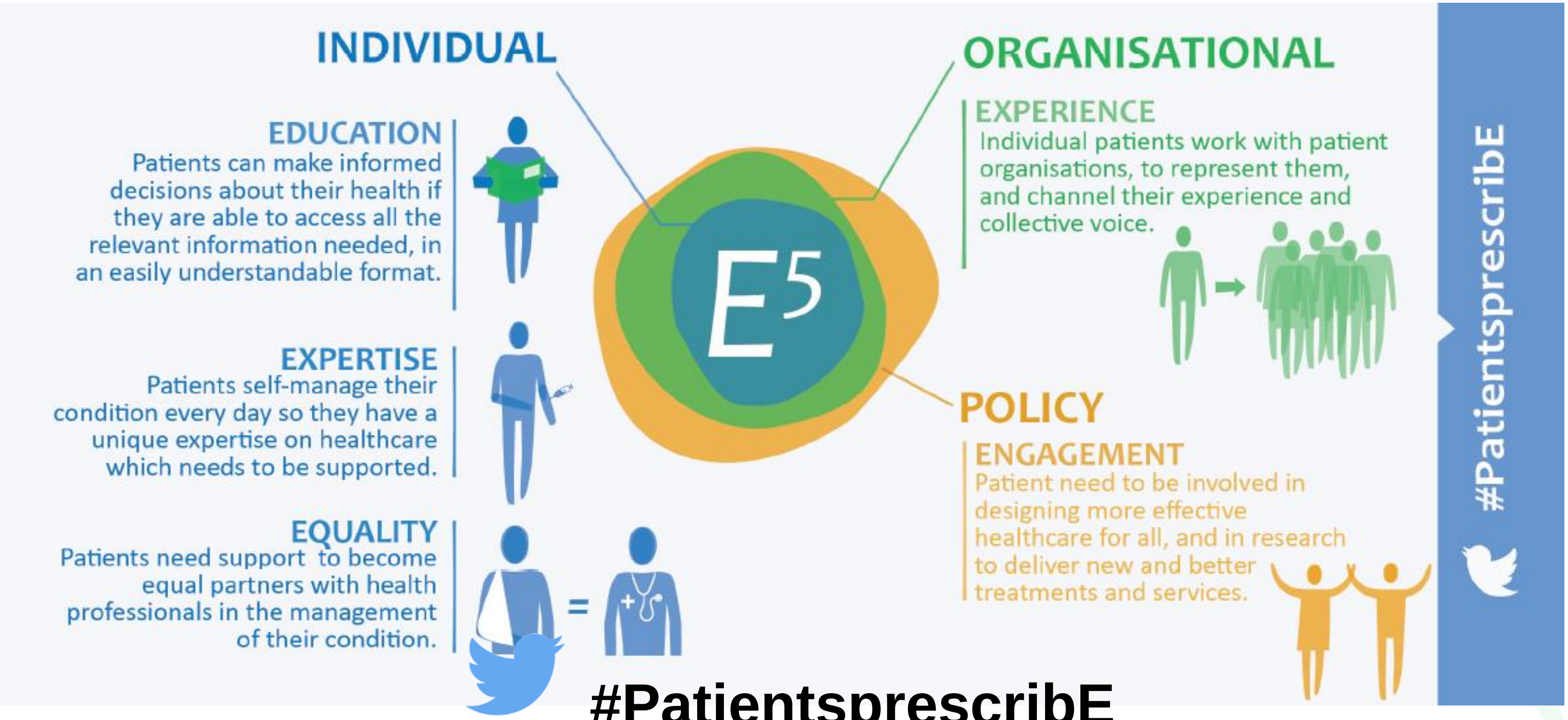
The EPF Capacity Building Programme



Objective: to strengthen organisational capacities and advocacy skills of national and European level patient organisations

EPF Empowerment Campaign

EPF Campaign on Patient Empowerment



INDIVIDUAL

EDUCATION
Patients can make informed decisions about their health if they are able to access all the relevant information needed, in an easily understandable format.

EXPERTISE
Patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.

EQUALITY
Patients need support to become equal partners with health professionals in the management of their condition.

ORGANISATIONAL

EXPERIENCE
Individual patients work with patient organisations, to represent them, and channel their experience and collective voice.

POLICY

ENGAGEMENT
Patient need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services.

#PatientsprescribE

EUPATI: an innovative training model

EPF European Patients Forum

An unprecedented collaboration: Patient organisations, health professionals, health tech experts, health NGOs, pharma industry

EUPATI
European Patients' Academy on Therapeutic Innovation

- Funded by IMI (PPP between EC and EFPIA)
- Launched Feb 2012
- Runs for 5 years
- Consortium of 29 members – led by EPF

Will develop and disseminate **objective, credible, correct and up-to-date information** on medicines R&D in 7 European languages

Will **build competencies & capacity** among patients & public to get involved

Will **facilitate patient involvement** in R&D to support academia, industry, authorities and ethics committees

Conclusions

1 EU competences in health are limited but they are being “stretched”

2 EU legislation has an impact on policies in Member States

3 Patient organisations can play a role in the EU decision-making process

4 This role is different according to the nature of the PO (EU vs. national)

5 Dialogue and exchange of information are the KEY to complementarity actions

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

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