BUILDING THE NEXT GENERATION of PATIENT ADVOCATES

CLOSING THE CEE GAP IN FUNDING, ACCESS AND OUTCOMES

FROM UNDERSTANDING THE EVIDENCE TO INFLUENCING HEALTHCARE DECISIONS

Deyan Denev | Executive Director, ARPharM Bulgaria
AGORA Conference 2026 | Sofia



OPENING QUESTION

What needs to change for patients in CEE to achieve better and more equal health outcomes?

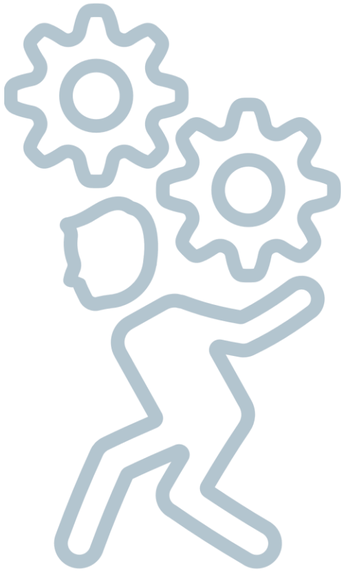


LOWER FUNDING → POORER ACCESS → POORER OUTCOMES



THE CORE CHALLENGE

The challenge is not only how much Europe spends, but what that spending enables for patients



LOWER PUBLIC FUNDING

Fewer resources and greater reliance on paybacks

POORER & LATER ACCESS

Fewer innovative medicines, longer waits

POORER HEALTH OUTCOMES

More disability and treatable deaths

Patient advocacy must make this chain visible, understandable and politically actionable.

CEE HEALTH SYSTEMS FACE A STRUCTURAL SQUEEZE

Healthcare demand is increasing while the workforce and fiscal base supporting care are shrinking.



Ageing population

Health spending accelerates after age 55; between 55 and 85 it roughly triples.

01

Shrinking workforce

CEE working-age population is projected to fall by 12.9 million, around 20%, by 2050.

02

Rising demand

More chronic disease, multimorbidity and disability require sustained treatment and care.

03

Narrower fiscal base

Projected annual income-tax revenue loss of €14.6 billion by 2050 versus 2023.

04

The policy question is not whether demand will rise. It is whether Europe will prepare fairly and sustainably

CEE INVESTS FAR LESS IN HEALTH THAN THE EU4

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Public healthcare investment remains around half the EU4 level per person

€ 1618

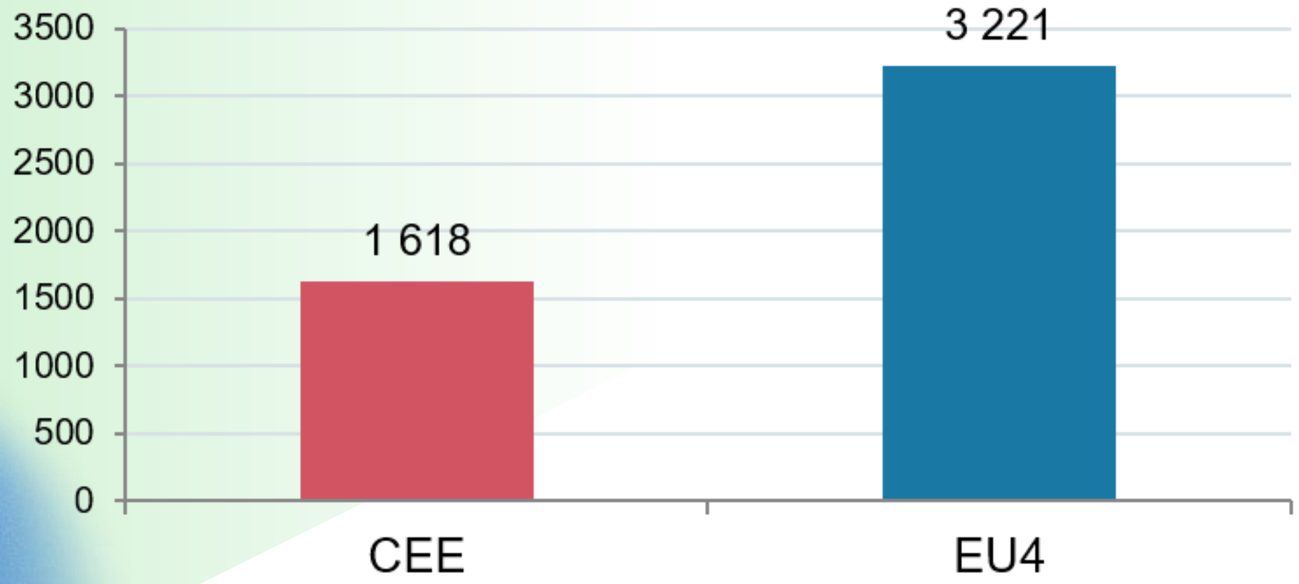
CEE public healthcare investment per capita, 2023

€ 3221

EU4 public healthcare investment per capita, 2023

5,47% VS 8.17%

Public health investment as a share of GDP: CEE vs EU4



Progress is real, but faster growth from a much lower base does not close the gap without sustained policy commitment.

HEALTH IS AN INVESTMENT

THE ACCESS GAP: FEWER MEDICINES, LONGER WAITS

Reimbursement determines whether innovation becomes a real treatment option.

31%

Share of 173 new EMA-authorised medicines reimbursed in CEE, 2020-2023

76%

Equivalent share reimbursed in the EU4

+260 DAYS

Additional average delay for CEE patients



EU4 average
445 days

CEE average
705 days

A medicine approved in Europe is not necessarily a medicine available to a patient.

PHARMACEUTICAL FUNDING IS ALSO DEEPLY UNEQUAL

CEE public net pharmaceutical expenditure per person is less than half the EU4 average

€ 218

CEE per capita

€ 487

EU4 per capita

2,2 X

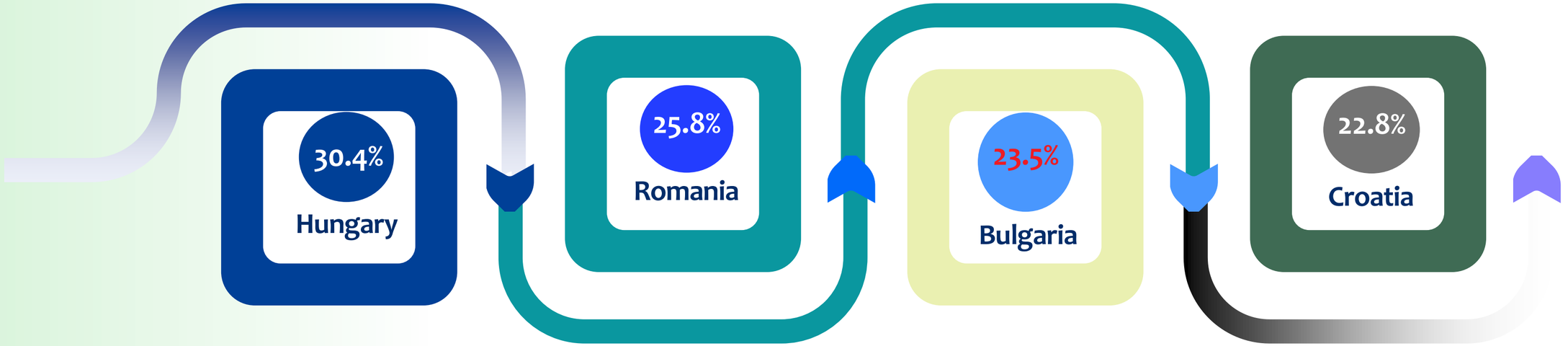
Lower national funding limits both the breadth and speed of access to treatment.



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THE INDUSTRY IS INCREASINGLY A “HIDDEN PAYER”

Paybacks can provide short-term budget relief, but cannot replace sustainable public funding.



High and rapidly growing contributions signal structural underbudgeting, not temporary overspending.

Public budget

Set below demand

Payback

Industry covers the gap

Market risk

Less predictability

Patient impact

Delayed launches or narrower availability

LOWER INVESTMENT IS ASSOCIATED WITH POORER OUTCOMES

The relationship is strong, but correlations should be explained responsibly, not presented as proof of single-cause effects.

5 YEARS

Life expectancy gap in 2024: CEE 78.2 vs EU4 83.2

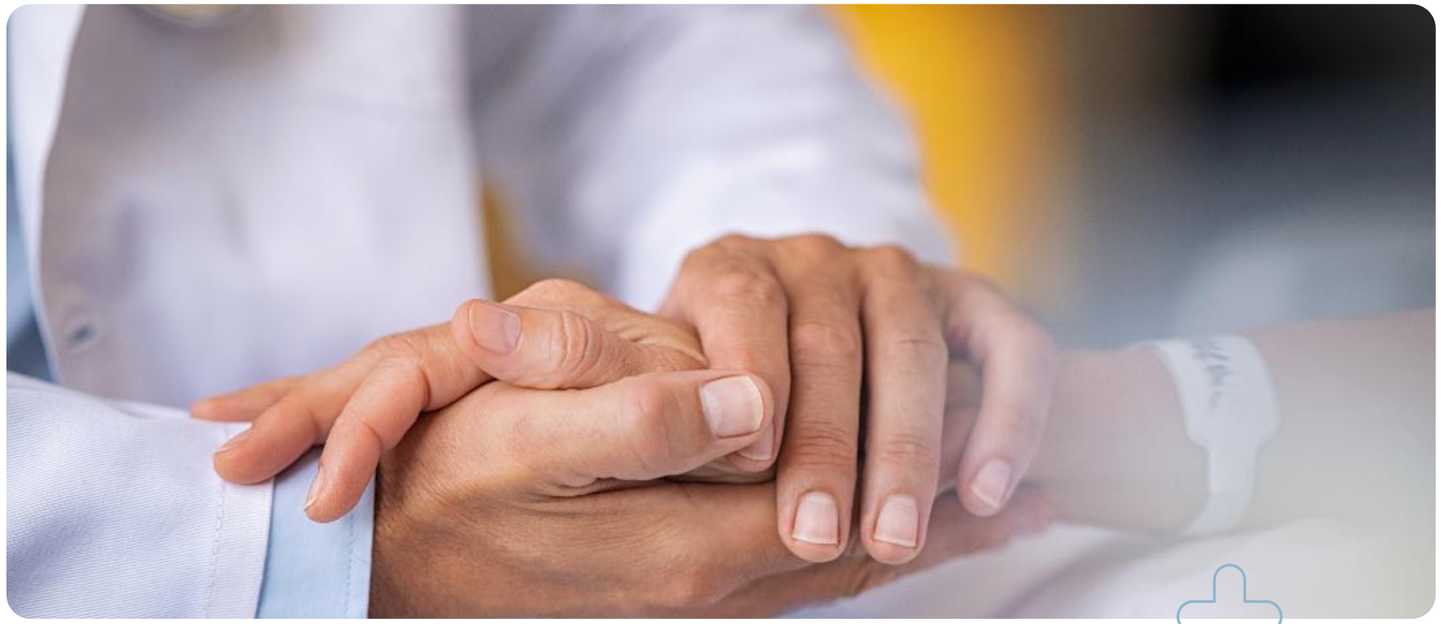
+41%

Higher DALY burden in CEE

+137%

Higher treatable mortality in CEE

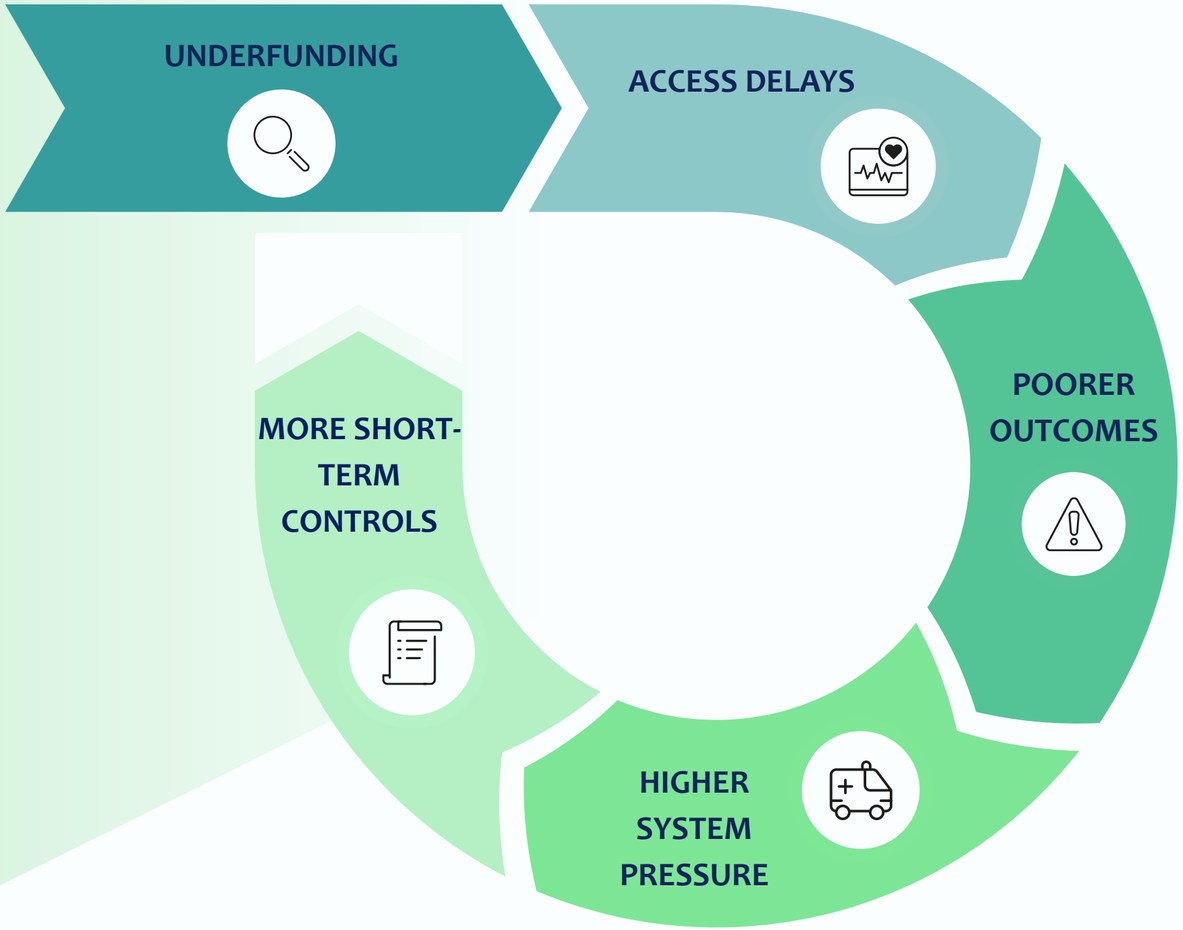
Across countries, higher public healthcare and pharmaceutical investment is associated with fewer disability-adjusted life years and fewer treatable deaths.



The honest message: funding is not the only determinant of health, but persistent underinvestment constrains prevention, diagnosis, care and timely treatment.

THE REINFORCING CYCLE WE MUST BREAK

Underfunding, delayed access and poorer outcomes create pressure for even more short-term cost containment



PATIENT ADVOCATES

Change the policy feedback loop

GLOBAL POLICY CHANGES CAN DEEPEN LOCAL ACCESS GAPS

MFN raises the stakes for Europe

If US prices are linked to lower international prices, launch and pricing decisions become more globally interdependent.



01

US MFN POLICY

US prices reference prices in other high-income markets

02

GLOBAL LAUNCH LOGIC

Low prices and visible benchmarks can influence launch sequence, price corridors and commercial viability

03

CEE PATIENT RISK

Later launches, narrower portfolios or less flexibility in already underfunded markets

MFN does not create the CEE gap. It can amplify an existing vulnerability.

BUILDING THE ADVOCACY RESPONSE

WHY IS A NEW GENERATION OF PATIENT ADVOCATES NEEDED?

The next challenge is not only to tell a personal story, but to connect lived experience with evidence and policy choices.

From recipients of policy to shapers of policy

UNDERSTAND
Funding, access, HTA, payback and outcomes

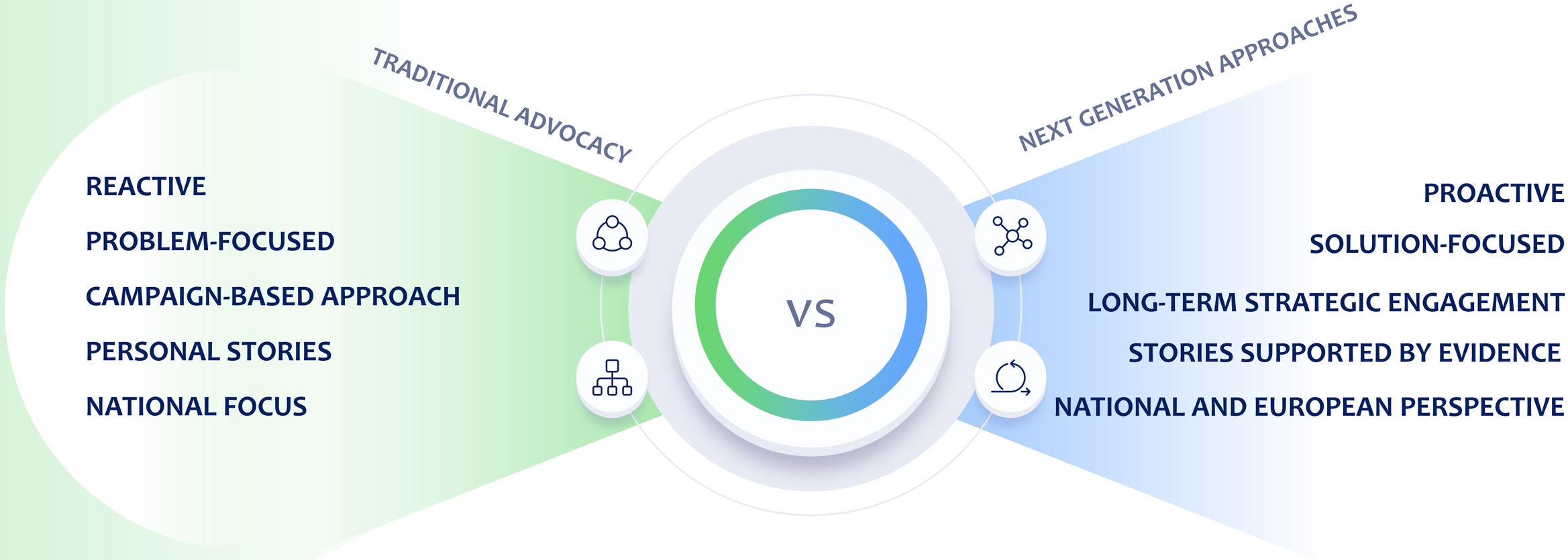
TRANSLATE
Turn complexity into clear human meaning

MOBILISE
Build coalitions and public attention

INFLUENCE
Engage policy decisions early and credibly



REDEFINING PATIENT ADVOCACY IN A CHANGING HEALTHCARE LANDSCAPE



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THE ADVOCATE'S TRANSLATION FRAMEWORK

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A simple discipline for turning evidence into influence

Example

CEE reimburses fewer new medicines and waits longer → patients lose treatment options and time → postcode should not determine access to innovation → fund predictable, timely, value-based access.

A strong message moves from a statistic to a decision without losing accuracy.



EVIDENCE

01

What do the data show?



PATIENT MEANING

02

What changes in a person's life?



PUBLIC MESSAGE

02

How do we explain it in one sentence?



POLICY ASK

03

What decision must change?

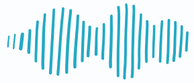
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ADVOCACY BECOMES INFLUENCE WHEN IT IS ORGANISED

Patient advocates need a repeatable operating model, not one-off visibility

01

LISTEN



Collect lived experience systematically

02

LEARN



Build policy and data literacy

03

FRAME



Agree the problem, narrative and ask

04

ALIGN



Form broad, credible coalitions

05

ENGAGE



Reach the public, media, and policymakers

06

MEASURE



Track commitments, decisions and access

Credibility comes from evidence. Legitimacy comes from patients. Influence comes from combining both.

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ETHICS, TRANSPARENCY AND TRUST

Trust is the bridge between ethical leadership and collective influence

THE ETHICAL FOUNDATION

- Independence
- Conflict of interest management
- Transparency
- Integrity





WHEN SHOULD YOU SPEAK ALONE, AND WHEN SHOULD YOU BUILD A COALITION?

SPEAK ALONE — When lived experience, patient needs or independence must remain unmistakably authentic.

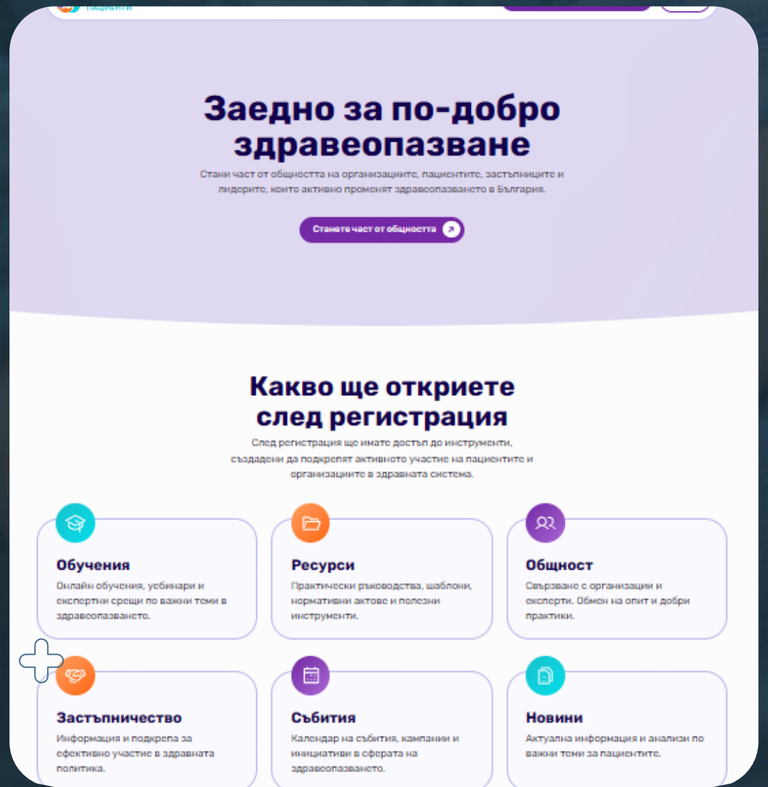
When systemic reform, access, funding or legislative change requires broader expertise and influence. — **BUILD A COALITION**

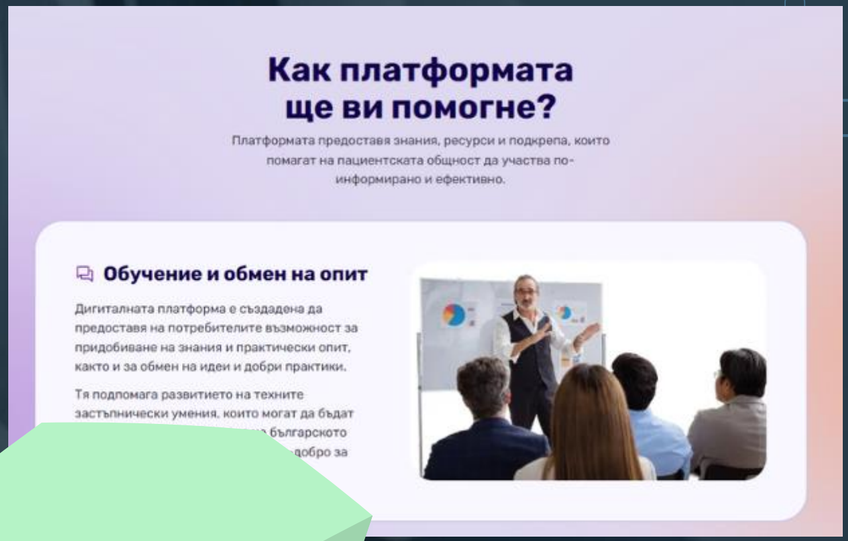
Ethical conduct earns trust. Trust enables partnerships. Partnerships create impact.

BEST PRACTICE IN BULGARIA

Platform of the Active Patients in Bulgaria

A platform that empowers the next generation of patient advocates through knowledge, resources, expertise, and continuous engagement with the community they represent.





Learning & Training Center

Access to External Experts

Advocacy Resources & Templates

Knowledge Center

Key Updates & Information

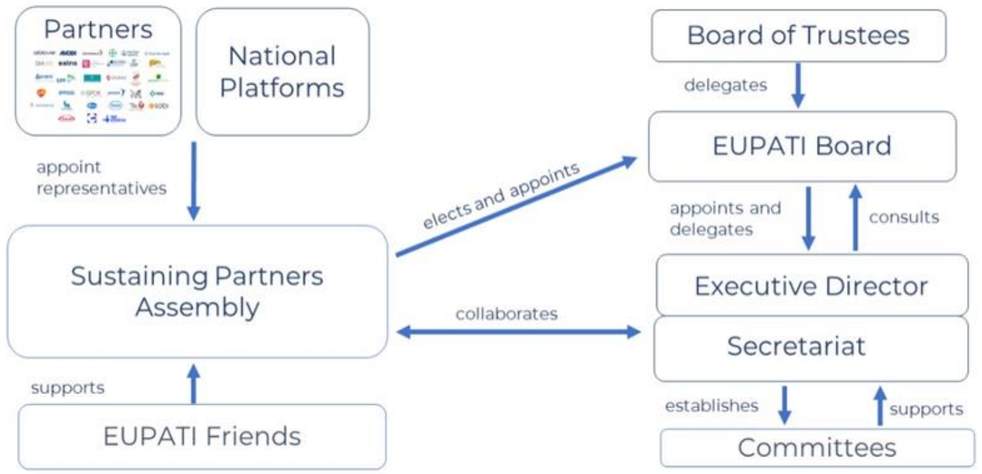
Petitions, Complaints & Policy Statements

Additional Resources

BEST PRACTICE IN EUROPE

MULTI-STAKEHOLDER PUBLIC-PRIVATE PARTNERSHIP

IMI-EUPATI 2012-2017 → EPF - Bridging Period 2012-2017 → EUPATI FOUNDATION 2020



EUPATI

History

The European Patients' Academy on Therapeutic Innovation (EUPATI) was launched as a flagship project of the Innovative Medicines Initiative (IMI) in February 2012. It **aimed to trigger a major rethink in the way patients and the public understand the medicines development process and their own involvement within**. Armed with a deeper understanding, patient experts and advocates are empowered to work effectively with the relevant authorities, healthcare professionals and industry to influence the medicines development process for the benefit of patients. The main objectives of the project were to:

- Develop and disseminate accessible, well-structured, comprehensive, scientifically reliable and user-friendly educational material for patients on the processes of medicines research and development.
- Increase the capacity of "patient experts" and well-informed patients in patient organisations to be effective advocates and advisors in medicines research and development.
- Empower patients to provide appropriate patient-relevant advice and insight to industry, academia, establishments and ethics committees.

Please find more information about the results & legacy of the initial project here below.
From February 2017 until August 2020, EUPATI was hosted by the European Patients' Forum as an educational programme.
A second IMI-funded project – Ensuring the Future of EUPATI (EFOEUPATI, 2018-2020) focused on the sustainability of EUPATI ensuring the continuation of patient education in mid- and long-term.
On 11 August 2020, EUPATI was established as independent non-profit Foundation in the Netherlands.



- LOWER FUNDING
- POORER ACCESS
- POORER OUTCOMES

EUROPE'S PATIENTS NEED ADVOCATES WHO CAN TURN EVIDENCE INTO DECISIONS.

Be informed. Be credible. Be influential.

"The next generation of patient advocates will not simply be part of the healthcare policy conversation. They will help shape it."

OUR TASK IS TO BREAK THE CHAIN.

THANK YOU