

HEALTH DATA

A PATIENT PERSPECTIVE

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Secretary General

EMIF 2017

Session: "Harnessing Health Data for
Managing Patient Benefit Risk – What new
processes are needed?"

29 June 2017



@eupatientsforum

#Access2030

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



About EPF



- European Patients' Forum
 - Independent & non-governmental
 - Umbrella organisation
 - Active since 2003
 - EU patients' voice
- Our members
 - 74 patients' groups
 - EU disease specific organisations &
 - National patient coalitions
- Our vision
 - All patients in the EU have **equitable access** to high-quality, patient-centred health and social care



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EPF's Role – Patient Involvement and Health Data in Research

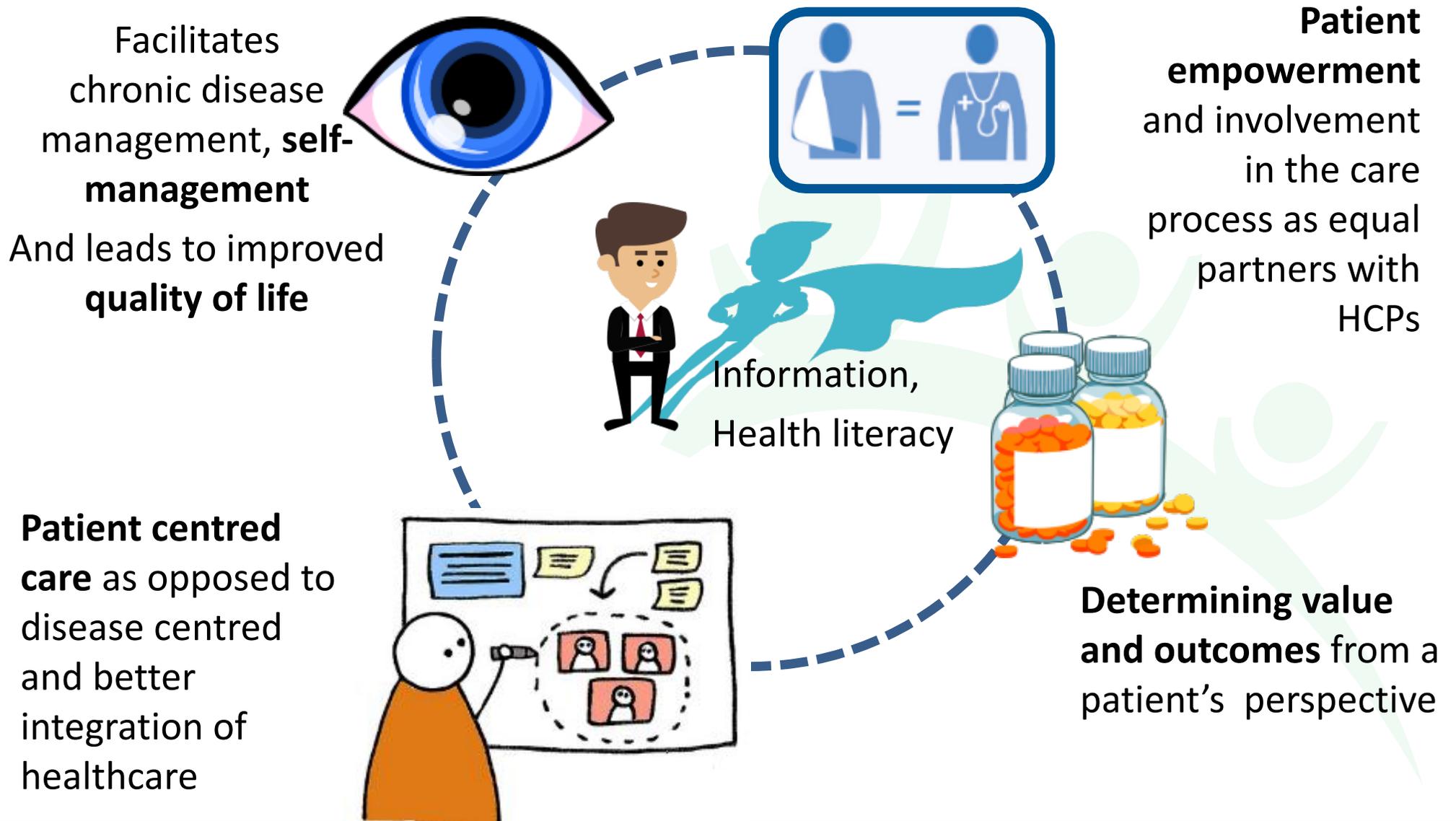
There is an **increasing drive** to improve collection and use of patients' data in order to achieve **better outcomes**, more **sustainable** healthcare and **advance health research**. The only way to do this in a meaningful and valuable way is **together with patients**.

Source: PatientPartner FP7
Project (2010)



Clinical
Research

Patients' expectations of digital health care



Patient-centred data?

Health quality indicators

- Health systems need to **change** because they are not designed to meet the needs of patients with chronic conditions.
- Data that is gathered, should put **patients at the centre** by taking into account the patient's perspective:
 - **PROMs** (patient reported outcome measurement)
 - **PREMs** (patient reported experience measures)
 - **PRIMs** (patient reported incident measures)



What can change?

- **Outcome measures should include measures defined by patients themselves, “what really matters”**
- **Many measures that are currently described as “PROMs” were not co-designed with patients. “Patient-designed” and “patient-prioritised” outcome measures could be used as terms**
- **Process also matters. Patient experience of care should be adopted as a key dimension of quality in healthcare**

Health Quality Indicators (OECD)

PROMs/PREMs/PRIMs

- **Patient perspective** taken into account when gathering data about the **quality of care**
- The [PaRIS Initiative](#) (“Patient Reported Indicators Surveys”)



EPF's role: helping define the right indicators, and developing where none exist e.g. multiple chronic conditions

Data reuse for health research (1)

Patients – generally **comfortable** and **willing** to share health data and recognise that this is of **vital importance to advance health research**

- **Trusted environment** – healthcare and research setting
- To help peers – general community and **peer support**
- To help future generations
- Looking for **solutions to unmet needs**
- Have already **experienced** the benefit of research, through therapy or management of their disease
- Patients learning from their own data - **self-management, empowerment**

Data security is vital



Principles and Questions

- Informed patient -> empowered patient
- Patient access to health data
- Safety and Quality of data
- Protect against harm
- Harness good use of data

➔ Patient-centred data ecosystem



Reuse of data by who and for what purpose?

- Quality management
- Disease registries
- Organisational learning
- Health research
- Pharma observational studies
- To support decision-making

Meaningful Patient Involvement

- Need to acquire thorough understanding of **patients' needs and perspectives**, with patients at the centre of digital health and care design
- Ensure that the digitalisation of health and social policies and systems is accompanied by strategies for **strengthening health literacy and patient empowerment**



Patient-centred digital technologies: privacy by default and accessibility (including affordability) and design for all

PREFER Project



Unmet need PREFER addresses

Currently a lack of understanding of how **patient perspectives on benefits and risks can best inform decision-making.**

PREFER aims to identify, characterise, and apply preference elicitation methods in all stages of drug life cycle.

prefer.
PATIENT PREFERENCES

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PREFER project goals

- Establish **recommendations to support development of guidelines** for
 - Industry
 - Regulatory Authorities
 - HTA bodies & payers
- **on how and when to include patient preferences** on benefits and risks of medical products.



In summary, PREFER

- Will develop evidence-based recommendations to guide industry, Regulatory Authorities, HTA bodies, reimbursement agencies
- Carried out by a diverse consortium that involves stakeholders: both as partners and advisors



Conclusions

Patient involvement- why it matters

- Patient involvement is needed for determination of true value/added therapeutic value
- Different perspective– Benefit / Risk
- Outcomes that are meaningful for patients
- PROMS, PREMS – Quality of life
- Patient and public education and engagement



THANK YOU



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BACK UP

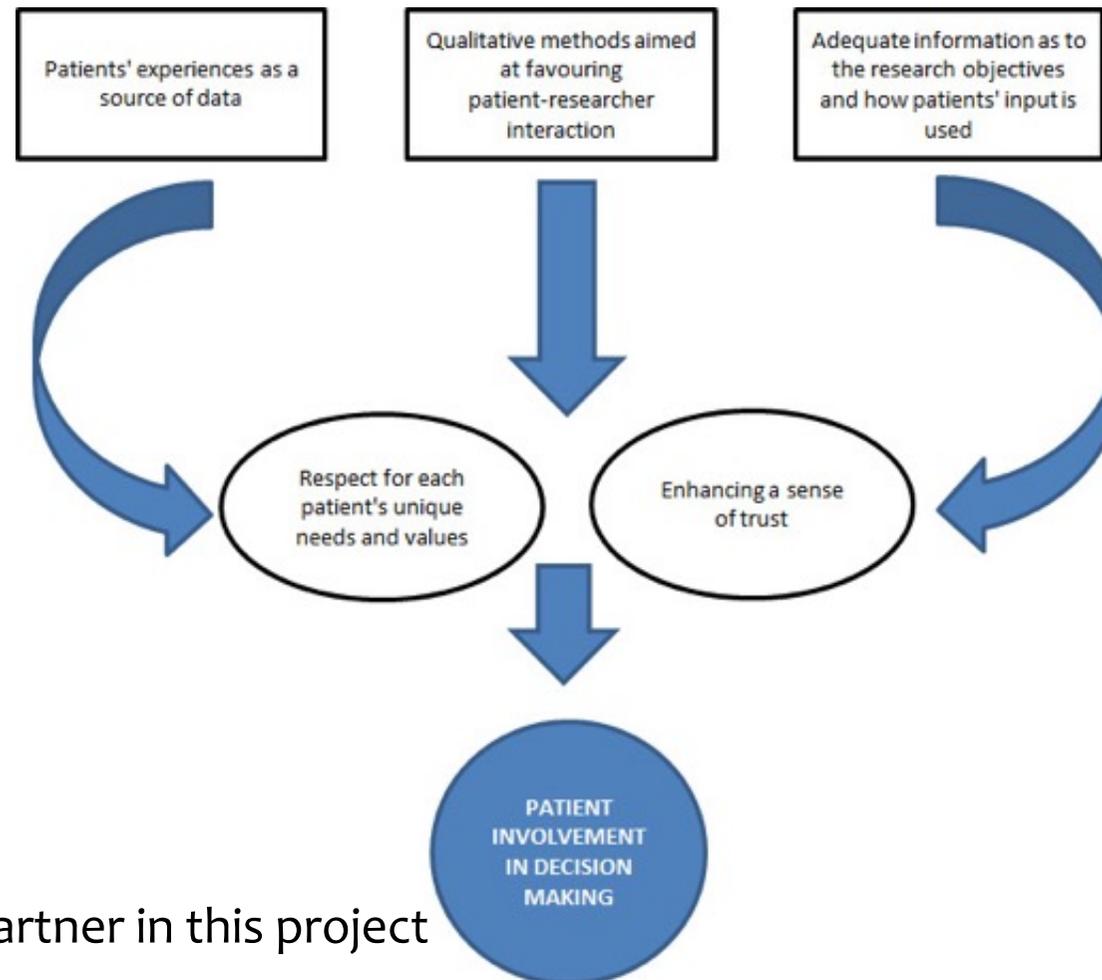


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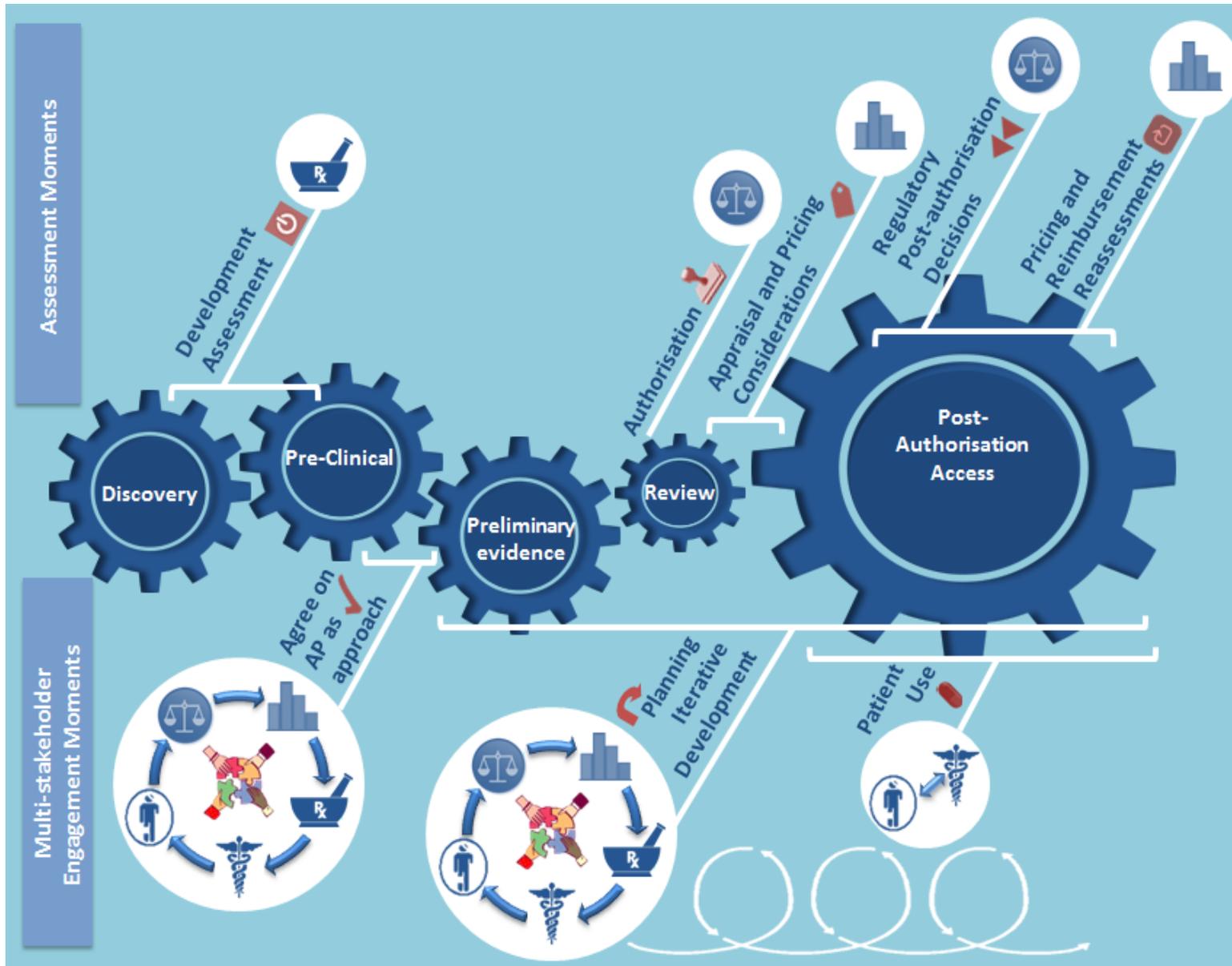
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Ways to involving patients in medicines development



*  Is not a partner in this project



Involved Stakeholders

-  **Patient Representatives**
-  **Health-Care Professionals**
-  **EU Regulatory Network**
-  **Pricing and Reimbursement Authorities**
-  **Medicine Developers**
-  **Project Manager**

Accelerated Development of Appropriate Patient Therapies a Sustainable, Multi-stakeholder Approach from Research to Treatment-outcomes

- Member of Navigator Group – strategic direction
- Identification of, and management of uncertainty
- Ethical and legal implications for patients
- Selection criteria
- Creation of tools to ensure appropriate use by patients
- *Benefit/Risk, Patient preferences, End -Points*