



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Young patient engagement at EMA and EPF

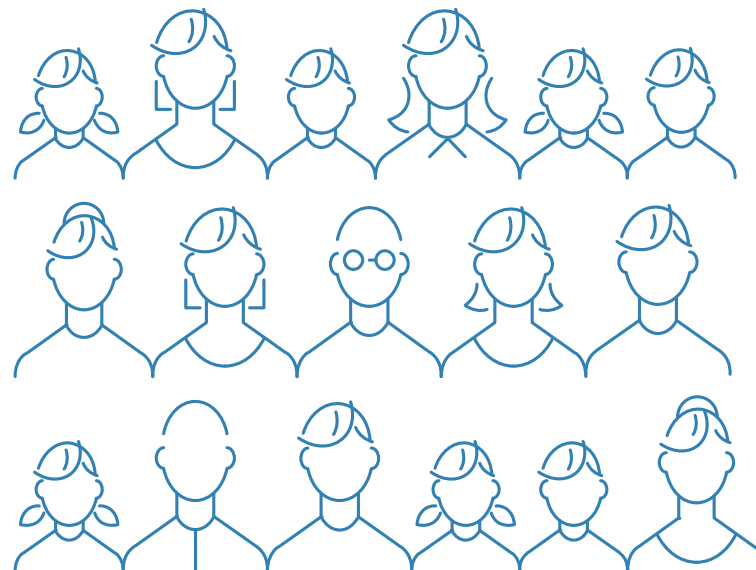
Presented by Kaisa Immonen

An agency of the European Union



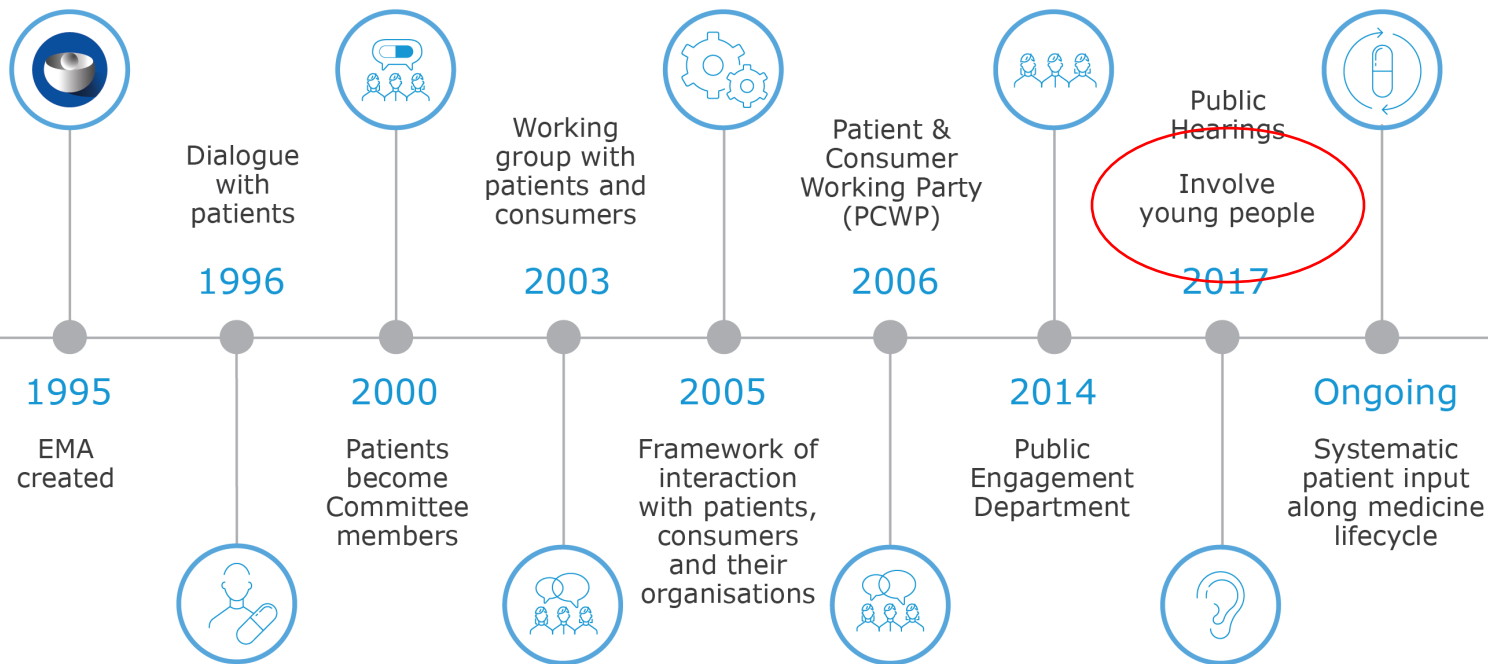


Patient engagement: Integral element of EMA activities





Engaging with patients at EMA: a progressive journey...



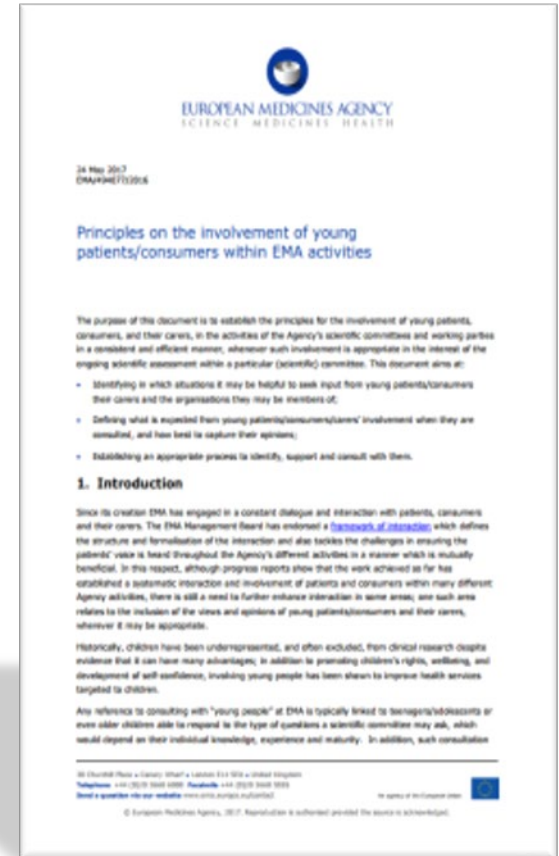


The “Principles on the involvement of young patients /consumers within EMA activities”

Provides guidance on the involvement of young patients, consumers and their carers in the work of EMA and its Committees;

Prepared with PCWP

- Establishes appropriate process to identify, support and consult young people;
- Defines what is expected from young patients involvement and how best to capture their perspectives;
- Identifies which situations may be helpful to seek input from young patients/consumers





Opportunities for young patients to contribute in EMA's work

- Scientific advice procedures (development plans) meeting or in writing
- Expert meetings on specific medicines under evaluation
- Committee written consultations
- Stakeholder meetings (medicine-related)
- Public hearings
- Review of package leaflet and other documents (appropriate language)



Involvement in EMA activities - examples

- 1. Alopecia;** PDCO reached out to young people with experience of hair loss to understand their views and perspectives about a potential treatment with some risks
- 2. Hormonal contraceptive;** PDCO asked young girls what they felt about different dosing options (how often to take the pill)
- 3. AADC deficiency** (very rare); PDCO wanted to better understand the needs and desired improvements versus the acceptable risks of a new gene therapy treatment
- 4. Haemophilia;** a young boy joined a Scientific Advice meeting with his father and shared his views on dosing and change over of medicines.



@weareEPF
@epfyouth

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



Who are the EPF Youth Group?

Young patient
representatives
between **15** and
29 years old



Passionate
about **change**,
integration
and patient
empowerment



They all have
special needs
and **expectations**



How does the Group function?

EPF Youth Group Board – made out of a President, Vice-President and EPF Youth Board Representative.

The YG Board is voted on by the group members, every two years or whenever a Board member “ages out” and has to leave the group.

The EPF Youth Board Representative, represents the YG in the EPF Board and is the key link between the EPF Board and the young patient advocates.



Connective
role

Strengthening **involvement and representation** of young patients **in patient organisations**

Represent
ative role

Promoting **young patients' rights and recognition of their needs and expectations** within and beyond health policy

Inclusivity
role

Encouraging **better integration** of young patients within society

Capacity
building
role

Empowering young patients to develop **leadership and advocacy skills, self-efficacy and confidence**

How are the YG getting to these goals?

Connective

- **Building a network of youth patients' organisations**
- **Mapping representation of young patients in patient organisations**

Representative

- **Representing young patient perspective at various events (Patient Engagement Open Forum, EUHFG), EU-funded projects, EPF Congress 2021**
- **Communications, e.g. monthly articles in The Patient Perspective & social media**
- **EPF Board**

Inclusivity

- **WAYS project report and promotion of results**
- **Start of the sexual health and well-being project**

Capacity building

- **Summer Training for Young Patient Advocates 2021**
- **Guiding the EPF YG and supporting their progress, through tailored trainings**

EMA involvement in EPF EMPATHY capacity-building workshop for young patients (2013)

Youth Group representatives participated in EMA annual training days

Youth Group presented to PDCO members at EMA (2019)

Ongoing – EMA speaker invited to annual Summer Training Course for Young Patient Advocates – 5 editions so far



New Youth Group Members – 11 members in total, 4 new

YG represented at numerous events and EU-funded projects

WAYS project results launched – webinar in November of 2020 – survey findings about the employment of young patients.

44%

of those surveyed felt that finding a job was 'Difficult' or 'Very Difficult'

21%

of young people identified prejudice against their chronic condition as a barrier to finding employment

35%

of respondents said that they would not want to disclose an 'invisible' condition under any circumstances

Only 5%

of young people identified their wider community (outside of family and friends), as supporting them in finding employment



What is happening in 2021?

Spring & Fall Youth Group Meetings – online

WAYS project publication in BMJ

Sexual Health and Wellbeing Project – gain insight on young patients' views of sexual health and areas of concern – 300+ responses to survey → next phase of the project



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More information

youthgroup@eu-patient.eu

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