

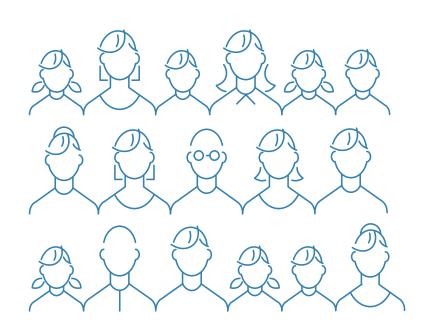
# Young patient engagement at EMA and EPF



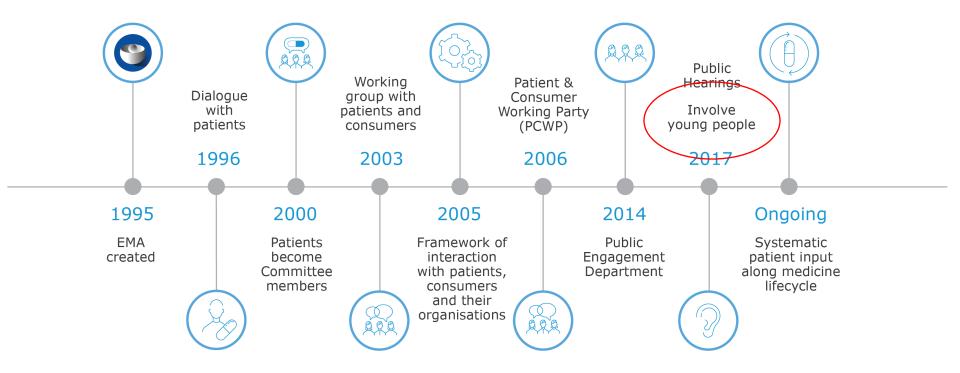
# Patient engagement:

## **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



CHAIR HET TYPES

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

The purpose of this document is to establish the principles for the involvement of young patients. consumers, and their carers, in the activities of the Agency's scientific committees and working parties in a consistent and efficient manner, whenever such involvement is appropriate in the interest of the ongoing adentific assessment within a particular (scientific) committee. This document aims at:

- Identifying in which altuations it may be helpful to seek input from young patients/consumers their carers and the organisations they may be members of:
- Defining what is expected from young pattering/sangureers/savery' involvement when they are consulted, and how best in capture their spinions;
- Establishing an appropriate process to silentify, support and consult with them.

#### 1. Introduction

Since its creation EMA has engaged in a constant dialogue and interaction with patients, consumers and their covers. The EHA Hanagement Search has endorsed a francusck of interaction which defines the structure and formulaution of the interaction and also tackles the challenges in ensuring the patients' year is heard throughout the Agency's different activities in a manner which is mutually beneficial. In this respect, although progress reports show that the work achieved as far has established a sustamatic interaction and involvement of patients and consumers within many different. Agency activities, there is still a need to further enhance interaction in some areas; one such area relates to the inclusion of the views and opinions of poung patients/isonsumers and their sarrers, wherever it may be appropriate

Historically, children have been underrepresented, and often excluded, from clinical research despite evidence that it can have many advantages; in addition to promoting children's rights, wellleting, and development of self-confidence, involving young people has been shown to improve health services. targeted to children.

Any reference to consulting with "young people" at EHA is topically linked to been gens/addisectors or even older children able to respond to the type of questions a scientific committee may ask, which send depend as their individual knowledge, experience and maturity. In addition, such consultation

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## 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.









#### Who are the EPF Youth Group?



Young patient representatives between 15 and 29 years old



Passionate about change, integration and patient empowerment



#### 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.



#### **EPF Youth Group goals**



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?

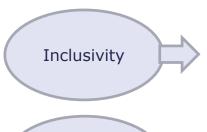




- Building a network of youth patients' organisations
- Mapping representation of young patients in patient organisations



- Representing young patient perspective at varius 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**



Capacity

building

- WAYS project report and promotion of results
- Start of the sexual health and well-being project
  - Summer Training for Young Patient Advocates 2021
- Guiding the EPF YG and supporting their progress, through tailored trainings

### **EPF Youth Group engagement with EMA**



EMA involvement in EPF EMPATHY capacitybuilding 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

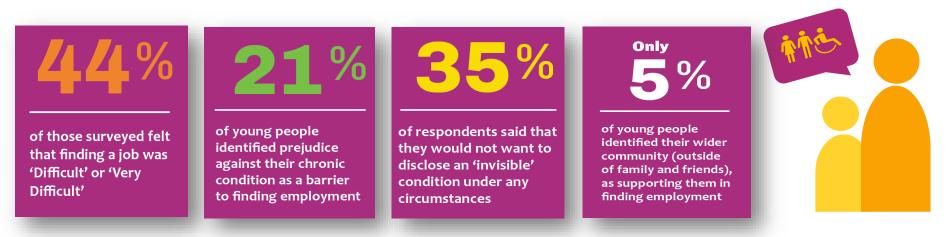




New Youth Group Members – 11 members in total, 4 new

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.







# 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



# THANK YOU FOR YOUR ATTENTION!

#### Follow us on Social Media!





@EPFYOUTH



More information youthgroup@eu-patient.eu



