

# The changing role of patients

- from people in hospital to advocates &  
partners

Quality of Life 4 OI-conference

Amsterdam, November 22nd 2019

Ingunn Westerheim – OIFE president





Children and adults with OI living active and independent lives - with access to competent healthcare and necessary social support





**OIFE's mission is to connect and empower organizations, professionals and individuals to improve lives of people with OI**



# OIFE's goals



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

- **Representing** our members and **be the voice** of people with OI and their families in Europe and on an international level;
- growing an **international network** between professionals, organizations, individuals and other stakeholders;
- **advocating for** access to competent **healthcare and social support**;
- encouraging scientific **research** on OI;
- **empowering our** member organizations by sharing information, knowledge and best practices;
- supporting **development** of OI organizations and support in more countries;
- **guiding individuals** towards information, healthcare and support.







**SAVE THE DATE!**



14TH INTERNATIONAL CONFERENCE  
ON OSTEOGENESIS IMPERFECTA

**OI2020**

**5-8 SEPTEMBER 2020**



**SHEFFIELD, UK**



For further information contact  
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# Who are the patients? People with OI in hospital





# Who are the patients? The patient organizations





# Who are the patients? People with OI & their families



*“Patients are experts by lived experience, whose perspective on disease and care is unique.”*



Person in hospital

Parent of person with OI

Person with OI

Person seen by doctor



Patient representative

Patient expert

OI-organizations

Volunteer of OI-org.

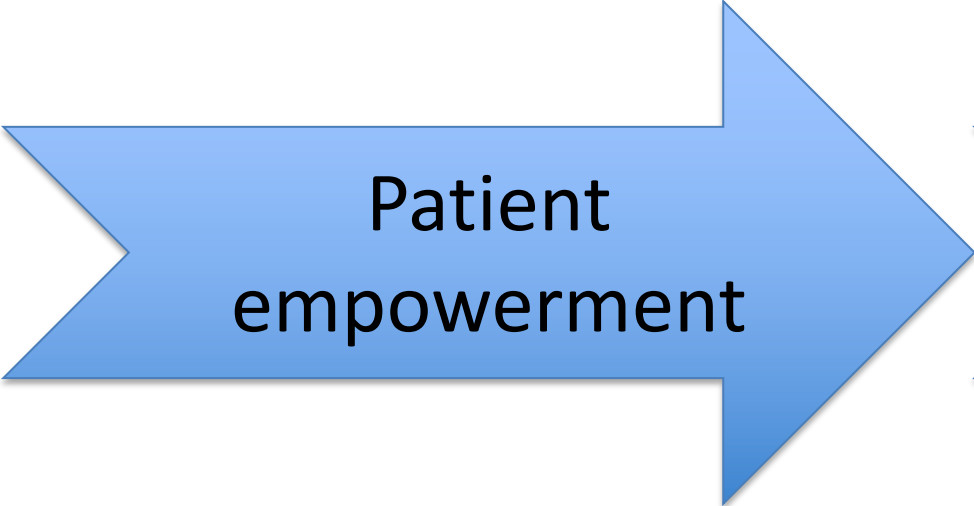
Staff member?

# Empowerment

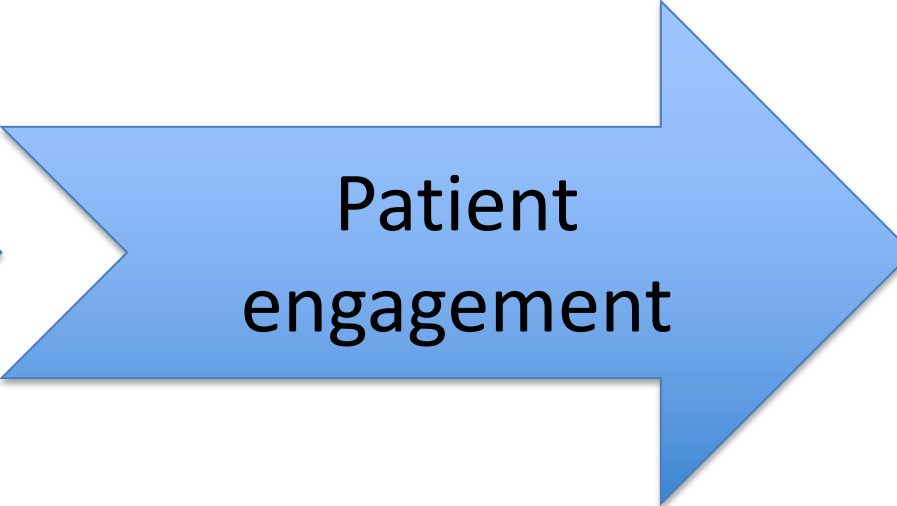
- The European Patient's Forum has the following definition of empowerment:
  - Empowerment is “a multi-dimensional process that helps people **gain control over their own lives** and increases their capacity to act on issues that they themselves define as important.”
  - Collective empowerment is “a process through which individuals and communities are able to **express their needs, present their concerns, devise strategies** for involvement in decision-making, **and take political, social, and cultural action** to meet those needs.”



Only once a person is empowered,  
can a person be engaged...



Patient  
empowerment



Patient  
engagement

**QUALITY OF  
LIFE4OI**

# How can we be empowered?

- 1. Support to self-care and self-management**  
The ability deal with all that OI entails, including symptoms, treatment, physical and social consequences, and lifestyle changes
- 2. Shared decision-making**  
Process by which a clinician and a patient jointly make a health decision after discussing options, potential benefits and harms, and considering the patients value and preferences.
- 3. Health literacy, education and capacity-building**  
Patient organisations often fulfil the task of ensuring education for patients and healthcare professionals through helplines, information and ad hoc trainings.



RESOURCE REMINDER  
New Materials for Adults with OI  
and Their Doctors

# TAKE CHARGE OF YOUR HEALTH

A toolkit designed to help  
adults partner with their  
doctors to lead healthy lives

[WWW.OIF.ORG/OIF\\_ADULTS](http://WWW.OIF.ORG/OIF_ADULTS)



OSTEOGENESIS IMPERFECTA FOUNDATION



# Topical Meetings



Orthopaedic aspects

Physiotherapy and rehabilitation (2009)

Psychosocial aspects in OI (2012)

Soft Issues & Soft Tissue - on adults with OI (2015)

See, Hear, Smile! (2019)



# Patients role in research

BOOSTB4)



MOI-study (LOSARTAN)

Asteroid   
Clinical study in Osteogenesis Imperfecta



the TOPaZ trial







And guess  
what?

We have OI!

# Join us...



We have almost 3000 followers on Facebook, but we would love to have more...

[www.oife.org](http://www.oife.org)



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[office@oife.org](mailto:office@oife.org)



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