



Patient Advocate project

Global Skin 2022 – Milan (Italy)



Project

- Why (business case)

1. Local country support

日本 საქართველო

2. Local conference option

- Saving eg travel costs
- Less hassle

3. Spread load

4. Increase awareness for people living with a rare disease

5. Get local healthcare professionals involved

6. Gather new ideas/contacts

7. Chronic disease → sustainable solution

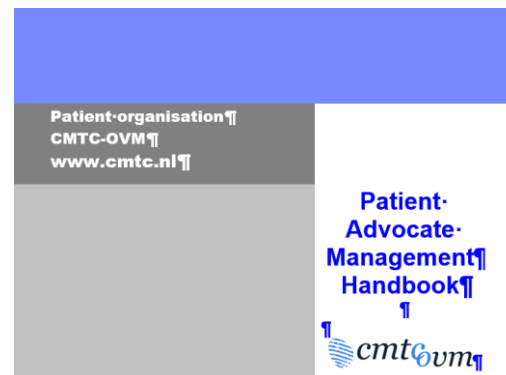
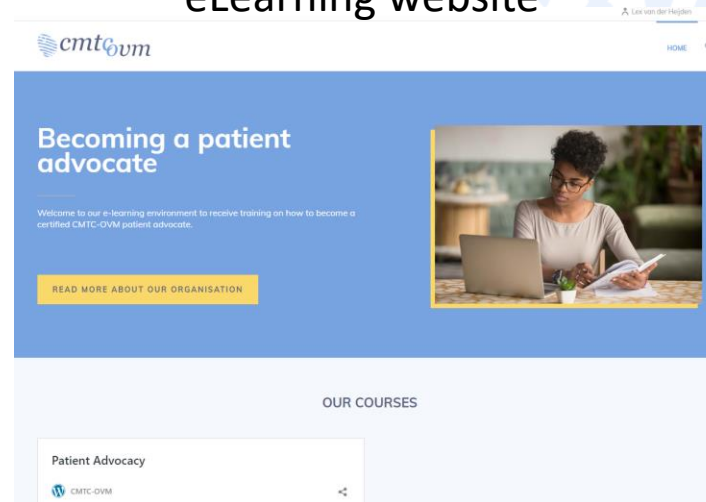


Project deliverables

Training Netherlands



eLearning website




Process Patient Advocate

1. Selection process
2. Training (Netherlands 2022, online \geq 2023)
 - Personal action plan
3. Encouragement/incentive program
4. Management of Patient Advocate
 - Progress/results measurement
 - Personal support



Challenges

1. Patient Advocate is 'just' a volunteer
2. Who is the expert?
3. Patient Advocates are rather often patients (or parents)
 - Due to illness no paid job (patient)
 - Due to carer role no paid job (parent)
 - Limited energy and financial resources
 - Social security financial support
4. Each country has different policies, tax, etc. regulations

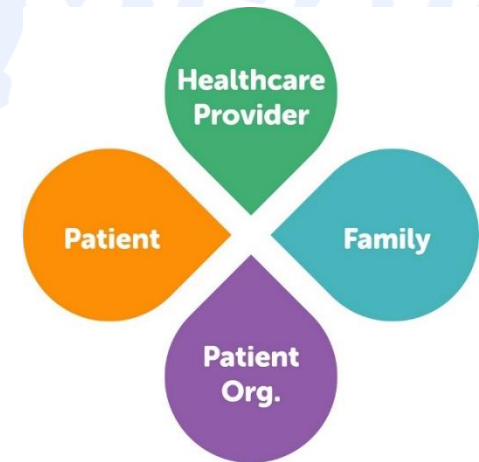


Take home message

1. Patient Advocacy should be recognised officially
2. Patient Advocates should be rewarded (financially) and not punished
3. Patient organisations are major stakeholders and must be involved also in policy making (and many other aspects as well)



European
Patient
Advocacy
Group



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