

5th international congress of breast disease centers- Antwerp

Patient expectations and sharing decision making

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The patient



The Patient's Bill of Rights

- the right of every European citizen to receive accurate information and be involved in their own care;
- the right of every European citizen to access specialized cancer care underpinned by research and innovation;
- the right of every European citizen to cost-effective health systems that ensure optimum cancer outcomes.

Lancet Oncol 2014 Published Online February 4, 2014 [http://dx.doi.org/10.1016/S1470-2045\(13\)70552-7](http://dx.doi.org/10.1016/S1470-2045(13)70552-7) a bill of rights for patient with cancer in Europe

**PATIENT
PARTNER**
patient and his/her
cancer

**PATIENT
EXPERT/RESOURCE**
patient and the cancer

**Shared decision
making**
announcement of a
diagnosis
therapeutic education

Representation of patient :
micro level : HC establishment
meso level : national organisations
macro level : international organisations

PATIENT /CITIZEN

Patient Partner

Announcement of diagnosis:

- after the medical consultation, a nurse explains diagnosis and treatment modalities .
- These consultations are mandatory to obtain the cancer treatment authorizations.



Patient Partner

Therapeutic education:

- this model is well known in diabetology, and is now adapted to cancer care.

- WHO definition :

The main concern is to help the patients acquire or maintain skills to manage living with their cancer disease.

Patient/Expert-Ressource

- Patients' convention in 1998 on behalf of patients association against the cancer (LNCC)
- Three consecutive cancer plans 2003-2007, 2009-2013, 2014-2019 with about 700M€ every four years for new actions



Patient/Expert-Ressource

UNICANCER

- innovative compendium of patient views.
 - ◆ Aim : gathering the patient satisfaction but also their expectations about of their own care.
 - ◆ the comprehensive cancer centers in France could lead their policy of care according to those expectations.
- 2013 another survey on the role patients play in organizational decision making authorities within the comprehensive cancer centers.

Patient/Expert-Ressource

The French government is willing to involve patients in decision making authorities with regard to :

- the report of Claire Compagnon
- the Action 7.15 of the 3rd cancer plan : the experience of ex patient with cancer should be used to help patient with cancer. The French “Ligue contre le cancer” has been mandated by the government to lead this action

Training the patient !

Learning Outcomes

- Contribute to enhance the quality of caring patient with cancer
- to be the voice of patient with cancer in decision making organisation within health care establishment and/or at national level
- To be confident and efficient by seaching relevent information and publications in the domain of health

Training the patient !

Condition of participation :

- to be involved or willing to be involved in health care activities, to have taken distance in relation to the disease

Blended learning /action learning

- One and one day with 4-6 monthes break between both days

Content

- as E learning : legislation, principle of cancer care, search of littérature and publication
- Face to face meeting : Communication skill, follow up of the actions undertaken

CONCLUSION

- Great challenge
- Training user ex patient to get professional in the health care system

BUT

- Are HCP prepared ?
- Useful to train them also ?

What do you think?

Bibliographie

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**THANK YOU FOR
YOUR ATTENTION**

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