Patient empowerment in Survivorship



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WP8 SURVIVORSHIP AND REHABILITATION

- Empowerment of patients in survivorship enables:
 - The patient to be actor of his care pathway
 - To actively participate to his rehabilitation program
 - To express both his own and his relatives' choices
- ☐ At an other level it also means that:
 - Enable patient representatives and associations to speak on behalf of users for a better consideration of their needs.
 - Advocate towards public powers on topics such as access to loan & insurance or on the difficulties of home surveillance.





Results from the literature review

- The leverages to better involve patients in the follow-up and management of late effects:
 - information
 - self-management
 - physical activities and dietary rules
- The leverages to improve the detection and evaluation of needs in supportive care:
 - online programs
 - e-health
- The leverages for a professional rehabilitation:
 - Patient-centered approach and involvement in back-to-work issues





DRAFT RECOMMENDATIONS

For a better involvement of patients and users' representatives in survivorship:

- ☐ Increased awareness and recognition of late effects is needed for prevention and management of cancer and treatment-related adverse events.
- □ Self-management programs should be developed, evaluated, and focussed on underserved populations. Evaluation of these programs should asses the impact on the personal level, the organizational level and the health care policy level, including cost-effectiveness and impact on health care quality.
- □ Planning and designing rehabilitation into the professional environment has to be done with a person-centred approach, giving to the person control on this process.





Areas for further research

- Research studies on the assessment of the self-management programs' impact.
- Study the impact of the role of patients and patients representative in the improvement of survivorship care.

Outstanding questions

- What role for « resource patients » in the support to survivors and care providers?
- What role for patients representatives in the implementation of survivorship care policies?





