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Supporting People Affected by Cancer in their Social and Professional Life (SPAC)

Report on Learning through Social Media/Networks about Living and Working with Cancer in Partner Countries

Introduction and Evaluation



INSTITUT INPRO, a.s.
VZDĚLÁVACÍ, PORADENSKÁ, OBCHODNÍ SPOLEČNOST

FONDAZIONE
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1978 ONLUS
Assistenza Nazionale Tumori

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Introduction

There are only very few diseases in the world that have such a strong psychological impact as cancer. In terms of diseases, it is the second most frequent cause of death, just after cardiovascular diseases. Romania, Czech Republic and Turkey are among the countries with the largest share of deaths caused by cancer in the entire world and the percentage of the sick is still rising.

One of the key points in fighting cancer is one's state of mind, positive attitude and the will to fight on. At the same time, the disease has very serious impact on a person's psychological state. The insecurity, difficult decisions connected to the treatment and other difficulties present a serious problem and a challenge for cancer both patients and those close to them.

The project "Supporting people affected by cancer in their social and professional life" aims to raise awareness among adult learners on how the Internet and social media/networks can help to increase their chances on integrating back into the society. It will provide them with new skills and competencies that will contribute to their professional and personal development.

To say it simply, the aim of the SPAC project is to empower the people with cancer and people working with/for persons with cancer to be more confident, financially independent and appreciated by their family and community and to find a way to involve them in social life.

Goals of the Report on Learning through Social Media/Networks about living and working with cancer in partner countries

The *Report on Learning through Social Media/Networks about living and working with cancer in partner countries* will be the basis for the entire project. The report answers the following questions, that are necessary for the development of the project's output - study materials about living and working with cancer for these affected by cancer:

- To what extent do the target groups use social media and networks to find information about cancer? What are their expectations and how do they meet the real options?
- What is the level of trust towards social media and online learning environments?
- What types of security measures are needed for the SPAC platform?

Who are the target groups of the project?

The project is targeted not only at cancer patients, but also at people close to them, those who work with them or others, who can have an impact on cancer patient's mental health. That includes their families and loved ones, but we must not forget others, who come to contact with cancer patients – even their employer.

- Cancer patients
- Psychologists
- Caregivers
- Employers
- Medical staff



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- Social workers
- Volunteers

The partners involved in the project:

Institutul Postliceal Phoenix Asociatie (IPP), Romania

Institutul Postliceal Phoenix (IPP) is an NGO, situated in North-West Romania, working at national level.

Since 2006 the organization provides adult training courses, qualifications/specializations for the following occupations: Art director, DTP- designer, Web designer, Graphic design, Human resources inspector. It also offers modules in word processing, data bases, graphic design, multimedia and Internet skills. Most of their activities have targeted vulnerable groups: disabled people, Roma minority, young people from placement centres, people from rural areas, migrants and unemployed people. During the period 2008-2015 the organization has developed Phare, Leonardo da Vinci, Grundtvig, Erasmus for Young Entrepreneurs and European Social Funds projects with the purpose of increasing the social and professional integration of vulnerable groups from North-West, Central and South-East Regions of Romania and to promote the entrepreneurial spirit. An important result of the exchange of best practices accomplished during the EU partnerships was the development of the Moodle-based e-learning environment in the Adult Education department.

Since 2013 the organization has developed the Oncosuport department in order to help the reintegration of people with cancer in the social and professional life, providing: ICT courses, nutrition courses, psychosocial support activities, occupational therapy. The activity of the Oncosuport department is voluntary. Since April 2017, the Oncosuport department is accredited by the Ministry of Labour for Social Services.

The association is founder member of Cluj SMEs Business Women Patronat, Romanian Accredited Trainer Organizations Patronat and Integrative Medicine Patronat.

Asociatia Pentru Servicii Comunicare in Oncologie (APSCO), Romania

Romanian Association for Services and Communication in Oncology - APSCO is a non-profit association whose goal is informing and changing patients and societies' mentality regarding cancer diagnosis, physical and mental rehabilitation of cancer patients, promoting and implementing their rights, psychosocial cancer care for patients and their families, as well as giving support to medical staff in order to provide complex and complete services which contribute to quality of life improvement.

APSCO unreservedly endorses the IPOS International Quality Standard of Cancer Care: 1. Psychosocial cancer care should be recognised as a universal human right; 2. Quality cancer care must integrate the psychosocial domain into routine care; 3. Distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain. The IPOS Multilingual Core Psycho-Oncology Curriculum in Romanian was officially launched in 2015 with APSCO's full support and collaboration.



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APSCO received approval for partnership with the Faculty of Sociology and Social Work of „Babeş-Bolyai” University, and is active member of the Google for Non-profits program. In 2016 APSCO provided the first cancer distress screening app available on Android platform in Romanian and Hungarian.

INSTITUT INPRO, a.s. (INPRO), Czech Republic

INSTITUT INPRO, a.s. is an educational and counselling organization which is operating mainly in the fields of adult education, vocational training and in the conceptual frame of lifelong learning. The organization was established in 1971. Today, the organization employs approximately 8 specialists as permanent staff and, in addition, cooperates with approx. 100 well selected freelancers, external lecturers and advisors for development of particular projects on regular basis.

Main activities of the organization include long-term certified educational courses from various fields (Marketing, Sales, HRM etc.) open for broad public on regular basis. INSTITUT INPRO, a.s. organises educational courses for companies, develops modern forms of education such as different types of ICT tools incorporated into the different clients' e-learning systems, prepares and implements various national and international projects in the frame of European Social Fund, Erasmus+ and other Community Programmes.

INSTITUT INPRO, a.s. is very active in the area of entrepreneurial education, soft skills training and training of Human Resource Management. The organization implements certified course of HRM on regular basis. This course Human Resource Management is a comprehensive modular training program that enables participants to acquire the knowledge, skills and abilities of best current European practices in the field of HR. At the same time, it helps to create conditions for the introduction of professionalism in the field of human resources management, professionalism comparable with other developed EU countries.

Çay Vocational and Technical High School (CVTHS), Turkey

Çay Vocational and Technical Anatolian High School is a health school that educates nurses and emergency medical technicians in our province. It has enough skills in the field and is ready to start work after graduation. Seminars and meetings are held with the experts in the field of cancer in the courses related to the curriculum and in health informing studies conducted in other schools and non-governmental organizations.

In hospitals and internships, our students work with medical staff to provide services such as informing the society and patients about psychosocial cancer care together with their teachers, contributing to raising the quality of life.

Rize RTEÜ Robotic Oncology Centre has been approved by our ethics committee and we have gotten our cancer studies with our Rize Cancer Control and Life Centre and our non-governmental org.

Universtitatea de Medicina si Farmacie Cluj-Napoca (UMF), Romania

“Iuliu Hațieganu” University of Medicine and Pharmacy Cluj-Napoca (UMF Cluj) is the oldest medical Higher Education institution of Transylvania, its history goes back five centuries ago, being



considered one of the most reputable university of the country. As early as its foundation in 1919, its mission had been to provide high-quality education, training and research aimed at excellence in healthcare. Part of the University, the Faculty of Medicine from Cluj-Napoca is among the first two universities in the country in results wise. It stands out through its educational offer: 4 undergraduate programs, 11 master's programs, the doctoral school and numerous residency specializations. Up to present, 52 projects for which UMF acted as coordinator have been financed within European and international financing programmes (e.g. RDI –national programmes: Human Resources, Ideas, Partnership, Innovation, Capacities, Erasmus) or Horizon 2020, FP-7. Through the "Quality and professional competence in European medical education and management of educational activities" E-MediQual, being an partner in implementation, UMF has contributed to the development and implementation of innovative instruments based on ICT, a support, monitoring and evaluation of teaching and learning and achieving a harmonized transnational and multiregional curricula. This project has improved the quality of medical education activities through the implementation of a new curricula structure, integrative student oriented and supported by innovative software tools for monitoring and evaluation of quality. The clinical education, offered to students and residents is provided in University hospitals, integrating lectures and bedside teaching. The clinical education is enhanced by the Centre for Simulation and Practical Skills (<http://www.umfcluj.ro/en/educatie-uk/resurse-uk/centrudesimulare-uk>), a valuable recent investment.

ANTFondazione ANT italia (ANT), Italy

“Founded in Bologna in 1978 by Professor Franco Pannuti, the non-profit organization, ANTFoundation Italy, is one of the leading private organizations working in Italy in the field of palliative care and pain management. ANT provides free social-health assistance at home to cancer sufferers and it runs free of charge cancer prevention initiatives. ANT’s philosophy can be summed up by the term “Eubiosia” (from the Greek “good life”), meaning overall quality to guarantee a dignified life right up until one's last breath.

The foundation, with its Head Office in Bologna, operates nationwide, through over 120 local groups, known as ANT Delegations, which are responsible for coordinating fundraising at local level.

ANT is the most experienced provider of free **home care** to tumour sufferers in Italy and Europe. Since 1985, ANT has assisted more than 110,000 sufferers, completely free of charge, in 20 home oncology clinics (ODO-ANT) in 10 Italian regions. There are currently 4,000 patients receiving care throughout Italy every day. ANT offers specialized care provided by 433 healthcare professionals, including doctors, nurses, psychologists, nutritionists, physiotherapists, social-health workers, pharmacists and other employees, who are able to provide patients with round the clock care, 365 days of the year. Since 1988 ANT has teamed this care with a psychology service to provide help, support and comfort to cancer sufferers and their families.

ANT is committed also committed to cancer **prevention** (with free services available to diagnose early signs of skin cancer, thyroid tumours, breast and gynaecological neoplasia). Finally, **training and research activities**.



Evaluation

The aim of the SPAC project is to empower people with cancer and people working with/for persons with cancer to be more confident and involved in family, social and working life. In order to identify the best approach in creating innovative study materials through the web, we have explored, using qualitative and quantitative methodologies, the use of internet and social media by cancer patients, caregivers, volunteers and healthcare professionals.

In this regard, we learned from SPAC's results that in our partner countries, according to self-selected respondents, there is a growing trust towards social media platforms compared to traditional media outlets. In this perspective on-line, E-Learning platforms look more like places for reliable information searching, trust network finding and help seeking.

The conducted survey verified the widespread and frequent use of the Internet and social media among respondents in all countries. It helped to recognize some of the elements to be considered in building the future platform:

- people look for reliable, professional and practical information on line and prefer portals administered by professionals - This is a great opportunity for the SPAC platform as our respondents tend to believe in information provided and delivered by experts on-line;
- people look for information about disease and treatment options, but also about psychological aspects and social services;
- great number of respondents searches for information about classic cancer treatments (72.3 %), healthy lifestyle (56.6 %), alternative medicine (57.8 %) or about news in the field of cancer (56.6 %) and only 14.6 % of respondents actually find it reliable;
- web technology can be very useful in keeping in touch with other people who live the same problems, in raising awareness about the disease and in sharing experiences;
- sharing experiences is very helpful in order to deal the situation with more confidence and optimism;
- it will be a challenge to design efficient e-learning modules since only 20 % respondents consider it to be more efficient than traditional learning materials, while 33.3 % thinks it is less efficient and around 40 % says the efficiency was the same as in case of traditional materials. Those are the ones that can still be convinced to use the online learning materials if high effectively is ensured;
- respondents think that their knowledge can increase using Internet as an informational and educational source.

These elements suggest that to be both successful and efficient, the SPAC education materials and tools need to:

- be SEO friendly and easily accessible through Google;
- be simple to use and to understand for all age-groups, attractive and adapted to different uses of Internet among countries;



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- exploit the different features of social media (for example Facebook for discussion and dissemination, and YouTube for videos), It could be beneficial to use video for learning modules, since 41 % of our respondents said they use YouTube;
- be usable on both laptops and mobile phones;
- provide scientific and reliable information about cancer on the platform and be made responsibly due to people's insecurity about unverified information on the Internet.

In conclusion, it can be noted, that the SPAC e-learning materials have a great potential and a wide range of possibilities. If their production is approached correctly, according to information and needs found out in the survey, they can have broad positive impact on people affected by cancer and those close to them.

Link to the whole report: <http://www.spac-help.com/local/pagini/reports/report-o2.pdf>