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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



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

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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
- Social workers
- Volunteers



The partners involved in the project:

Institutul Postliceal Phoenix Asocitie (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.

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 Nonprofits 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 Medicinasi 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**.



General information about the use of the Internet and social media/networks for education and its specifics in partner countries

Increasing role of social media in the field of education

Social media are starting to play more significant role not just in our daily lives or in a business environment, but also in the field of education, including vocational training and adult education. There is a constant discussion among social media and education experts, some of emphasizing the benefits of education through social networks, while others consider them to be more of an obstacle, claiming they only work as social, not an effective learning tool. Let us look at the fact, considering both benefits and risks in using the online media as an education tool and also to find a way how to minimize its negative impacts.

Collaborative learning

The high effectivity of studying in groups had been proven before social media even started to exist. According to the *Social learning theory*, people are the ablest to learn through observation and sharing, which implies that study groups can be more effective than individual study (Miller and Dollard, 1941). Social media only emphasize this fact. Social networks can be used as a communication channel not only between the student and the teacher, but also among the learners. They can provide increase in communication during the study session– which leads to a high rise in student collaboration. It also allows students to share materials and videos and supports their teamwork skills.

Enabling remote access

Collaboration has advantage in terms of saving time and erasing distances. Due to their capability to overcome great distances, online media and Open Education Resources (OER) have been labelled the „distance learning providers“. The possibility to learn from anywhere in the entire world is considered to be one of their greatest benefits.

Increasing students' interest

Research conducted at universities shows, that learning through the social media ensures greater participation of students. Social networks enhance their learning experience and the students are less likely to leave the education programme.¹

Social networks are more interesting and attractive than traditional learning platforms, such as Moodle, so it is very efficient to connect these learning platforms with social media. They can be linked with popular SNS such as Facebook, Twitter or YouTube, to raise the attractiveness of this learning platform. It is important to mention that social media provide more mutual motivation than other learning sources, due to the possibilities of comparing one student to another.

¹<http://www.bbcactive.com/BBCActiveIdeasandResources/Howsocialmediaischangingeducation.aspx>



Potential risks of using the social media and their elimination

Security

Students are often concerned about online security and the safety of their data. In order to ensure this will not be a cause of a problem, the website has to be made very safe and students' personal information secure. We will show the students, that there is no risk using our learning materials and participating in discussions and their personal information will not be misused or revealed.

Generation gap

While social networks and media are a domain of young people, cancer is present in all age groups. We need to respect, that there will be various age-groups using the learning materials, adjust them and make them as simple to use as possible.

Solutions and notice

It is very important to realize, that every type of social media targets different social/age group. This needs to be taken into consideration while adjusting the e-learning materials. It is one of the types of information that will be found out by the questionnaire survey.

We also have to consider the fact, that different social media play a different role in society. While Moodle might be the perfect tool for creating e-learning material, Facebook and Twitter would be preferred for the learning discussion and dissemination of the materials.

Using social media during study course can help different individuals to engage in creating common content. This can be effectively used for various goals, such as leading the learning discussion and sharing students' knowledge and opinions. YouTube would be best used for the dissemination of video-based learning materials.

Use of the Internet and social networks is different among countries. We conducted a research in order to identify, how users approach the issue in all partner countries in order to adjust our learning materials about how to live and work with cancer to their situation.

Use of the Internet and social media in partner countries

Romania

There is a great number of people using the Internet and social networks (SNS). Over 65 % of all households have Internet connection. There is a significant difference among demographic group, while there is a smaller number of people who are retired connected to the Internet, in employed families with children, **around 90 % have access to the Internet**. If Romanian people choose not to use the Internet, it is mostly because they do not find it useful or because it is too expensive. They consider using the Internet to be quite safe (only one percent of people has any safety concerns).

Over 70% of people use the Internet every day, while the other access it weekly. Desktops, laptops and smartphones are frequently used to access the Internet in Romania. They prefer to use their laptops or desktops when they are at home, but smartphones are used more frequently altogether. Romanians use the internet for communication and to access social media, to check their e-mail,



search for goods and services, read the new and listen to music. **Also, almost 50 % of Romanians look for health related information on the Internet.**

Social media are widely used in Romania; the most popular is Facebook, which is being used by over 83 % of Internet users. Over 70 % also uses YouTube and smaller number of users is interested in Google+ (37%). People usually used them to read posts from other, search for news and information, to watch photos and videos, to play games or to look for jobs. Twitter is used for keeping up with professional news and information, while LinkedIn is used for searching for better jobs.

Around 30 % of Romanians admit to posting their personal data online for e-commerce/online banking. The information they submitted consist of contact info (such as phone number or email address), personal information (date of birth or ID number, photos location or health related information).

The Czech Republic

In the Czech Republic, both the Internet and social media are very widely used. Based on the newest official statistics (2015), the Internet is used by 70.2 % of the entire Czech population. If we only focus on people in their **working age**, the number is **almost 90 %!**² Moreover, more than half of the population³ uses the Internet every day - people of working age present 70.5 %.

Social media are used by approximately half of Internet users. There are again large differences depending on age, education and economic activity. While **61 % of people in their working age** use social media, the number comes to around 80 % among young people under 30. On the contrary, older people (65+) use social networks very rarely, although it is difficult to assess, it can be estimated, that it is less than 10 % of those who already use the Internet, less than 5 % altogether.

Unfortunately, there are no exact numbers saying how many people use Open Education Resources. What is very clear, however, is that roughly half of the entire population uses social networks. Even though we cannot be completely sure about the numbers, according to the latest research of media agency AMI digital – around 93 % of regular Internet users also have Facebook.

According to the official statistics, about 11.6 % (15.7 % working age) of people use the Internet for private (non-working) purposes for more than 20 hours per week. Approximately half of the Internet users (47,7 %) under the age of 45 - the largest number being persons under 25 - spend more than 1 hour browsing the net every day. As for the users older than 45, the numbers are declining significantly.

According to the statistics by AMI Digital, Czech Internet users spend (on average) more than 2 and half hours per day using the social media. There has been a shift towards visual content and communication (Instagram/Snapchat). During the year 2015, the most popular network was without a doubt Facebook. Rough estimate is, that there are about 4.2 millions of active accounts, which is around 40 % of the entire Czech population including children and seniors. Second most favourite is LinkedIn (450 000 users), Google Plus (400 000 users), Twitter (300 000 users) and Instagram (200 000 users) and other results show that it is even significantly more.

²88,2 %

³53,7 %



Even though there has been an elevation in using SNS that support visual communication, the main reasons for Czech people to use the SNS remain the same. They use them mainly to send personal messages to friend, look at other people's profile, to search for job offers, to play games and event to meet new people. One of the most current activities, whose popularity is still rising, is sharing photographs and videos with friends and others, be it through Facebook or other means of communication, such as YouTube, Instagram or Snapchat.

As for the devices that are used to access the Internet, various portable devices are very popular. Around 50 % of people use laptops (61.5 % people of working age). Little less popular is accessing the Internet via tablets, only around 10 % do that. There is also a large number of people, who use their cell phones to access the internet, around 37 % altogether and almost half of the population in their working age (47.2 %).

As for the safety of the Internet in the Czech Republic, there are specific laws on cybersecurity in the Czech legislation. They define security measures (acts needed for protecting IT systems or electronic communication), lead an evidence collecting records of their breach, issue warnings and describe reactions. The laws and regulations are fairly recent (1. 1. 2015) and they are being updated quite often.

Especially young users are vulnerable and are not always careful when sharing their personal information. For example, on Facebook, there are over 60 % of users who would add an unknown woman to their profile, 42 % in case of an unknown man (tested by the use of fake accounts by Technet.cz). There is also a **high rise in trust towards social media** compared to traditional media in terms of **searching for information**.

As for publishing their information through social media, Czech people are being quite careful. Over 95 % of Czech people think that others tell too much information about themselves on social media. Over 80 % thinks there should be some regulations on what is published and we should be more polite on social networks. Czechs are in general very sceptical towards sharing personal information, maybe because of the national history.

Italy

In 2015 it was estimated in Italy a number of "web surfers" of more than 41 million people, more than 86% of the population between 11 and 74 years, but confirming the last places in Europe for internet use. Very old and very young (under 10) people are excluded from access to the network, the first primarily for capacity reasons and interest, and the latter because of parental choice. In Italy there was a boom of social networks (SNS) in 2008, with the explosion of Facebook in particular, which still remains the most used SNS with over 23 million Italian members, followed by Twitter, YouTube and Google+ with almost 9 million accounts, LinkedIn and Instagram with almost 5 million. The other SNS (Pinterest, Tumblr, etc.) don't exceed 3 million subscribers each.

The subjects that arouse more interest on SNS and on line in general are related to music and entertainment (52%), science and technology (51%), politics (45%), and health and medicine (42%), without special distinctions by age (except for "sports" that is more quoted among the under 34). Men prefer to look for and focus on discussion topics such as science and technology (61%), politics (59%) and business (24%), while among women topics that prevailing are health and medicine (54%),



literature (49%) and fashion/celebrities (40%). Women also declare a greater range of interests than men.

Users of SNS are also very active in the on-line research of commercial information and in on-line shopping, especially as regards to travel, electronic items and clothing; among young people, the interest is more focused on other categories such as gaming and beauty / fitness. Discriminating by gender, men look for and buy online especially products related to hobbies and leisure, electronics and telecommunications, while women are more oriented towards products of beauty and wellness in general.

Every Italian active on social networking sites (SNS) has on average 3 accounts on this type of platform. Facebook collects almost all (94%) of those enrolled in SNS, followed by Twitter and YouTube, with a spread of 48% and 47%. Most of those who are enrolled in YouTube do not know to be automatically signed up for Google+ (because of the aggregation of services by Google). Follow LinkedIn (32%), Instagram (25%, but rising), Myspace (9%, declining) and Pinterest (8%).

80% of Italian people on social networks own a smartphone (this rate touches 88% between 18 and 34 years, dropping to 62% only between 55-64 years). Despite decreasing, computers continue to maintain dominance over tablets; the percentage of those who prefer the computer to the tablet increases with age. The gradual replacement of the device, however, does not go in the direction of a shift to the latest generation of tablet; young people, in fact, tend to prefer laptops than tablets (80% versus 38%) and the greatest number of tablet owners belongs to the age group 35-54 (48%). Tablets are preferred for entertainment activities while the portable PC for daily operations of study or work; smartphone is the primary device for easy and fast online communications. This dualism between smartphones and laptops strongly characterizes the Italian consumer, showing good familiarity with both devices.

On average, the Italian web surfer is on-line for about four and a half hours a day, every day, with about 28% of the time spent on SNS (a percentage that rises to almost 35% among young people between 18 and 34 years). The SNS that more captures the time of the Italians is Facebook, followed by Instagram (growing) and YouTube. There are not evident gender differences in time spent online, but there is a north-south gradient (in the south people stay on-line daily more time). Italian people has been using Internet for 12 years on average and the age group that is exposed to the web from more time is 35-54 years, especially because of professional use.

The main activity of Italian people on the SNS is to keep themselves abreast of the news (70%), nationally, internationally and about their immediate community (city, district, etc.), especially through Twitter. The second most common activity (66%) is to comment on the contents, followed by the interaction with their contacts (59%). Women are generally more active than men on SNS, and are above them in the comments, in the publication of content, in games and in relationships with brands (preferring Facebook and, secondarily but significantly outdistanced, YouTube for this type of activity). Young people mostly use the SNS to manage events of interest and to produce a greater amount of multimedia content - videos, photos, music. Among all considered contents, articles, posts and photos are the main shares in the Italian population.



As for on-line security, particularly critical issues are the problem of the truthfulness of online information, the control of the sources and the difficulty in monitoring who holds the copyright of the news, in addition to the impossibility of promptly blocking the traffic on the web for news incorrect or even harmful. Equally important is the issue of protection of personal data in the network. With particular reference to the vast sea of medical information available online, it is also of primary importance the need to guide the user in the search on the web, so that the search does not is irrelevant or even harmful, creating anxiety, confusion and false beliefs.

The most recent law on the subject is the Prime Minister's Decree of 24 January 2013 called "National Plan for Cyber Security and Internet Safety", laying down guidelines for cyber security and national security, whose main operational guidelines concern: the strengthening of the intelligence and police activities, the extent of training and information in the field of information security, the strengthening of the network of people involved in the supervision, both nationally and internationally.

Recent surveys about cybersecurity in Italy, define Italians as "digital people characterized by easy clicks", distrustful in direct interpersonal relations, but ready to trust without hesitation to any link or email that displays on their electronic devices. As a result, Italy is the fourth European country most affected by malware after Luxembourg, Poland and Greece and the 40th in the world (last update 2016). If, on one hand, Italians say they are increasingly concerned to protect their privacy on the net, they are more disposed than the other Europeans to share personal information on the Internet: 48.5% of Italian people do it, against 35.2% of the continental average.

95.3% of Italian people states to take concrete actions and to assume behaviour in favour of a more careful use of the internet; to protect their privacy, more than half of Italians - 51.2% - says to differentiate the passwords on different websites, 38.1% avoids saving online passwords, while 36, 8% regularly scans their devices with an antivirus program.

Other more limited investigations, focused on the use of SNS among adolescents, show a high number of violations of privacy (theft of identity, password or photos) and other violations (sending viruses, stalking, offensive content) especially among more intensive users, to which, however, the young people respond with bland and extempore actions of self-defence, without changing substantially their methods of use and approach to the SNS.

Turkey

In Turkey, there is a very wide use of the Internet and of social media. Over 76,3 % of Turkish population has access to the Internet. According to Turkish Statistical Institute (TÜİK), Household Information Technologies Survey for 2016, over 60% of people (61,2 %) use the Internet on regular bases. This rate was around 5 % more when compared with the previous years. Most of the Internet users are between the ages of 16 and 74 – 54,9 % of the population to be precise. According to available information, around 74 % of people in Turkey have the possibility to access the Internet via broadband connection and around 65.5 % of people actually use this possibility.



The Internet users also often access social media/networks. When Internet usage is taken into account, 82.4 percent of individuals who had been using the Internet in the first three months of 2016, had been using social media to create profiles and send messages, almost 75 % had watched or shared videos. Around 70 % had been reading online news, newspapers or magazines, around 65 % had been searching for health related information or about goods and services. Also, around 64 % had listened to music over the Internet (web radio).

According to long term survey, there was only a little over 60% of people using the Internet for communicating with public institutions or benefiting from public services for personal purposes the previous year. And a year before that, this rate was 53.2 %, which indicates a high increase in the use of the Internet in Turkey. Among the purposes of using the internet, getting information from web sites belonging to the public institutions reaches up to 55 %. Turkish people used the Internet according to the following age division: 16 to 24 years of age - 70%, 25 to 34 - 62.7%, between the ages of 35 and 44 - 50%, between 45 and 54 - 32%, between 55 and 64 - 15.8% and finally, between the ages of 65 and 74, it was 5,3%. Internet users in Turkey spend an average of 4 hours and 37 minutes on the internet every day, 2 hours and 51 minutes on the mobile internet and 2 hours and 56 minutes on social media.

In 2015, 74.4 % of the individuals using mobile phones or smart phones used it to connect to the internet, 28.9% of them also used portable computers (notebook, tablet, etc.)

The most popular platform in Turkey is Facebook. Also, Turkish people like to use YouTube, WhatsApp, Facebook Messenger, Twitter and Instagram. There are 40 million active social media accounts in Turkey and 32 million are accessed by mobile phones. Facebook is the most popular for several reasons. It was one of the first social media known in Turkey. It is also very simple to use, and people like to share photos and videos through Facebook. People like to use YouTube to share their own production and because they can comment on the videos of others. Twitter is mostly used to get new information. WhatsApp is very famous and it is popular because it is easy to use and Instagram is used to be active in social life.

Turkish people are using social media to reach education and learn about science. Social networks are very popular and they affect today's society and change people's habits. There are many possibilities for education in many fields through social networks and other technology. Facebook allows users to connect with each other, to join groups and share resources, music, pictures and videos. With Twitter, they can discover information with 140-character messages.

As far as Turkey is concerned, 73% of internet users in are proven to use social media as a news source, according to the research conducted. This view of the users seems to be the highest in a report covering 18 countries. It turns out that Turkish people find the internet safe. Measures are being taken in adverse situations that may arise. However, awareness raising activities are being carried out through national press-broadcasting organizations in order to raise public awareness against national and international hazards that will be caused by sharing personal information.

For example, the law called the protection of personal data entered into force on 7th April 2016. Within the framework of this law, there is a balance of interest between the right to information and the privacy of personal information that the user has named as personal data.



The situation in partner countries regarding the occurrence of cancer

Romania

According to Globocan (2012), over 78 000 new cases of cancer (4000 more than in 2008) appear and 50000 people die from oncologic diseases each year in Romania. In 2012, the number of new cases of cancer was 43 100 (in a population of 10 370 000 men) and 35 600 in a population of 10 017 000 women.

The study estimates that there was a 14% increase during the year 2013 (from 195,5 to 223,5), there were 67 300 new cases, compared to 7% in Central Europe. In 2013, mortality caused by cancer in Romania increased by 0.8% (from 132.6 to 133.8) while the total number of deaths caused by cancer increased by 21.73% (from 41 400 in 2013 compared to 34 000 in 1990)

As for the year 2013, the leading types of new cancer cases in Romania in were lung (17,35%), colorectal(16,9%), breast (15,4%), prostate (11,49% - 5.890), other neoplasm (10,32%), cervix uteri (6,69%), oral cavity (6,48%), stomach (6,42% - 3.290), pancreatic (5% - 2.565) and bladder (3,9%) cancer. There was also a difference among men and women. For men, lung, prostate and colorectal cancer were the most common, while for women, it was breast and uterus cancer, followed by colorectal and others.

In Romania there are many associations and networks that focus specially on cancer. Some of them are concentrating on cancer in general (A.B.C Asociatia Bolnavilor de Cancer ([www.abc-brasov](http://www.abc-brasov.ro)) or on specific types of cancer (such as breast cancer- Asociatia "Clubul Amazoanelor Bistritene", leukemia- Asociatia Romana impotriva Leucemiei , liver cancer-Asociatia Bolnavilor de Cancer si Hepatita Oltenia). There are organizations that deal exclusively with children (Asociatia P.A.V.E.L; Asociatia Little People; Asociatia Impreuna pentru Copii cu cancer Targu-Mures).

Czech Republic

According to the newest data provided by the Czech register of oncology, there were 82 505 people newly diagnosed with cancer and 27 050 people died of cancer in the year 2014. There is a growing tendency in the new cases of cancer every year, but there was also a slight decline in mortality because of rising number of people who have had cancer repeatedly or keep living with it. Altogether, there are 595 253 people living with cancer in the Czech Republic, which is **5,64** % of the entire population. This number keeps rising because the population of the Czech Republic is getting older and also because a number of people has recurring tumours.

The most common cancers are the colon cancer and colorectal cancer (around 10 %), which is one of the four worst results in the entire world. This type of cancer is closely followed by bronchus or lung cancer. If we consider the difference between men and women, breast cancer is very common in women and prostate cancer is a great problem for men. If we added up the number of women suffering from breast cancer and man suffering from prostate cancer, the number would be even higher than in case of colon and colorectal cancer. From the long-term point of view, breast cancer is becoming more and more common. The frequent problem is that even though there has been



progress in early diagnosis, a large number of cancer cases are only caught in their later stage, when it is becoming more difficult to provide any effective treatment.

There are many associations, networks and websites that focus specifically on cancer and several of them try to cover the topic of psycho-oncology. They are mostly concentrating on cancer in general or on specific types of cancer (such as colon cancer, breast cancer or prostate cancer). There is much less of those focusing on living and working with cancer. The most notable is a project called **Amelie** (<http://www.amelie-zs.cz/>), which provides psychosocial assistance, various courses and provides advice on how to start working after cancer treatment. The organization also led a programme „Return to Work After an Oncological Disease“ that helps strengthening confidence and qualifications of cancer survivors.

There are charities focused on fighting cancer (The League Against Cancer), helping families with children where one of the members suffers from cancer („The Good Angel“) or focused specifically on breast cancer (<http://www.breastcancer.cz/cs/>).

Italy

In 2015, there were 3,037,127 people living in Italy after a cancer diagnosis (4.9% of the Italian population), 46% males (1,382,386) and 54% females (1,654,741). More than a third (35%) were people aged 75 and over; even more (39%) people between 60 and 74 years of age. Among Italian women the most frequently diagnosed cancer is breast cancer with 692,955 prevalent women in 2015, followed by colorectal cancer (201,617 prevalent), thyroid (124,850) and uterus (109,981). Among men, almost 400,000 (398,708) were prevalent after a diagnosis of prostate cancer; 225,459 after a diagnosis of colorectal cancer, and 204,158 after a diagnosis of bladder cancer.

The 5-year survival for all cancers (excluding skin cancers) has improved over the years and it is 57% for men and 63% for women. Survival is – usually - inversely correlated with age. An exception to this trend is represented by breast and prostate cancer, which have higher values in the age 45-54 years compared to 15-44 years. Although with less differences compared to previous years, there is still a North-South gradient, to the detriment of the southern areas, both for the total of tumours and for some of the main cancer sites.

Social media and smartphone-based applications are now changing how people interact with the healthcare and public health systems. Due to their possible implications in public health a growing number of scientists suggest to incorporate social media and mobile health in health promotion and healthcare programs. Sharing health data among members of an online community seems also to be correlated to better management of the disease they suffer from (2).

In this sense, in our country Scientific Societies (for example, Associazione Italiana di Oncologia Medica (AIOM), Società Italiana Cure Palliative (SICP)), the main Italian newspapers (for example, Repubblica, Corriere della Sera), the Ministry of Health, non-profit organizations and Research Institutes have a website where people can find out lots of information on living and working with cancer. In order to create network some of these websites have also a forum (see: *“Website and forum online”*).



Facebook, as social media, is strongly used by all the well-known and popular associations for the purpose of creating networks among people affected by cancer. For further cooperation l'Associazione Italiana Malati di Cancro, parenti e amici (AIMAC) is one of the most active Italian associations in giving information through the Internet. Recently AIMAC has developed the *Pro-Job project: working during and after cancer, a resource for the company and for the worker*, the general public can easily find this on the Internet.

In cooperation with several universities in Italy and abroad, the Association for International and Comparative Studies in the field of Labour Law and Industrial Relations (ADAPT) set up a School for higher education that is known as a centre of excellence in terms of research and education in the field of industrial and employment relations. The School carries out a number of editorial and research projects. One of the most recent funded researches was *"Promoting new measures for the protection of women workers with oncological conditions by means of social dialogue and company-level collective bargaining"*.

Since 2014 ADAPT has promoted, in collaboration with the **Coronel Institute of Occupational Health** of the Academic Medical Centre (the Netherlands), the **European Public Health Alliance** (Belgium), the **Work Foundation** of Lancaster University (UK) and the **Uniwersytet Warszawski Medyczny** (Poland), the Observatory CHRONIC DISEASES AND WORK, as a result of an innovative project on the employability and the re-employment of people with chronic diseases. In these pages people can find lots of publications and scientific information and there is also a special section called Tumors: European studies and research; European legislation; Academic literature; literature review. Most of the documents uploaded to the portal are in English, this could be very penalizing for the Italian general public; it is more intended for insiders.

The website of „Federazione Italiana delle associazioni di volontariato in oncologia” (FAVO), has lots of interesting material to go with the theme of working and living with cancer; this kind of reports and documents could be more easily consulted both for insiders and general public.

Turkey

Cancer is the second most common illness in Turkey right after cardiovascular diseases – heart diseases or high blood pressure are the most common. Turkish people also have problems with respiratory diseases or high cholesterol.

Altogether, there are around 174 000 new cancer cases every year, more in case of men (96,213 in 2014) than women. There is a similar number of people having cancer every year, without any significant increase or decrease in numbers. The most cases are connected to respiratory system - Trachea, Bronchus and Lungs. Very common are breast (little less common is uterus) and prostate cancer, also colorectal, bladder and stomach cancer.

As for men, the most common are the lungs and prostate cancer and tobacco-related cancer continue to be widely spread. The number of cases attributed to tobacco and tobacco products in males is estimated to 27,718. The most common cancer for women is breast cancer - it continues to be one of every 4 cases of cancer for women. A total of 16,646 women were diagnosed with breast



cancer within a year. The total number of cases attributed to obesity is estimated to around 5,896. Cancer caused by obesity is mostly affecting women. The third most common cancer for both men and women is colorectal cancer. Leukaemia is the most common among children. In case of young people (15 – 24 years old), testicular cancer is being diagnosed in males and thyroid cancer in females. As for lung cancer, more than half of the patients is diagnosed in its advanced stage. Only 11.1% of breast cancer is diagnosed at a later stage. Most of the cases of uterus and cervical cancer, are caught early. Seven out of ten people who are diagnosed with cancer are being cured.

In Turkey, the Ministry of Health has produced various policies together with the Cancer Department and developed a Cancer Control Plan in Turkey. A National Tobacco program was prepared on 28 April 2004. Within this program, many important projects such as smoke free air space and 171 smoking cessation lines have been prepared.

In addition, publications on cancer are being prepared by LÖSEV, Cancer associations and non-governmental organizations. Many experts also have personal publications. Associations and foundations founded on fighting and living with cancer in particular have their own periodicals. The cancer booklet prepared in Turkey is the first scientific publication about cancer cases and presents the historical development of cancer registration and personnel education in the world and in Turkey.

In addition to these, many new programs such as Turkey's Radon Mapping and Action Plan for Turkey, Strategic Action Plan for Turkey Asbestos Control or Monitoring of Health Effects of Electromagnetic Fields have been initiated. Screening services for breast, colorectal and cervical cancer are given free of charge by Cancer Screening Programs, Cancer Early Diagnosis, Screening and Training Centres (KETEM) and family physicians under the principle of "Early diagnosis saves lives!" There's also an effective "National Control Scheme". In Turkey, all citizens can easily reach the treatments applied according to international standards.



How do people affected by cancer/working with cancer patients use Internet and social media?

In the following chapter, we will show the current state of how people affected by cancer and other target groups view the social media. Based on the results, we will identify the best approach in creating the innovative study materials.

In order to uphold our high ethical standard, the questionnaire was anonymous. At the same time, the respondents were asked about their age and level of education, in order to better analyse the needs of the beneficiaries of the developing study materials.

In order to find out about how people affected by cancer and other target groups use the Internet and social media, a questionnaire was designed. It was composed of several levels, starting with the extent to which the target groups use the Internet and social media, including their expectations about learning through the Internet and social media, their experience with such learning, their abilities in information searching on the Internet and also about security on the Internet.

An example of the questionnaire can be found in the appendix section of *the Report on Learning through Social Media/Networks about Living and Working with Cancer in Partner Countries*.

Methodology and data collection

In order to get results, each partner organization obtained a minimum of 14 responses from different members of the project's target group. More specifically, the analysis is based on a sample of almost hundred people from all of our target groups and partner countries, including cancer patients/survivors, psychologists, caregivers, employers, medical staff, social workers or volunteers.

The questionnaire was completed in both online and a written form. The specific questions and topics were always compared in detail with identification data of the respondents. Some of them were previously mentioned, the required data included:

- Age;
- Gender;
- Target group (cancer patients/survivors, psychologists, caregivers, employers, medical staff, social workers , volunteers);
- Education;
- Nationality.

If there was any correlation found between a phenomenon and one of the identification data, it is mentioned together with the presentation of the results.

When it is relevant and there is a recognizable difference, there will be a graph showing a situation in particular countries.

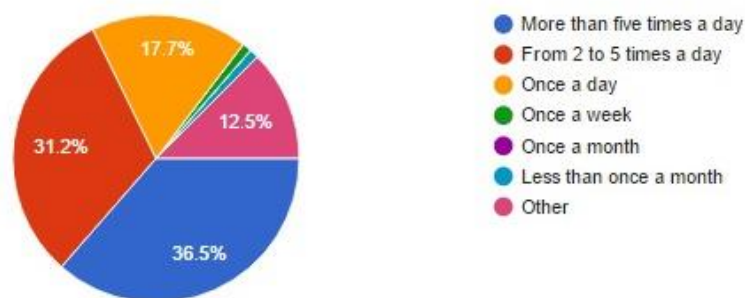


To what extent do people from the target groups use social media?

According to the research, Internet is being used very often and very widely among all the target groups. Most respondents indicated that they access the Internet more than five times a day. At the same time, over half of all respondents spend from one to three hours per day on the Internet. That is a positive message for the development of the online learning course, seeing that many people spend enough time to benefit from the learning materials.

How often do you access the Internet?

96 responses



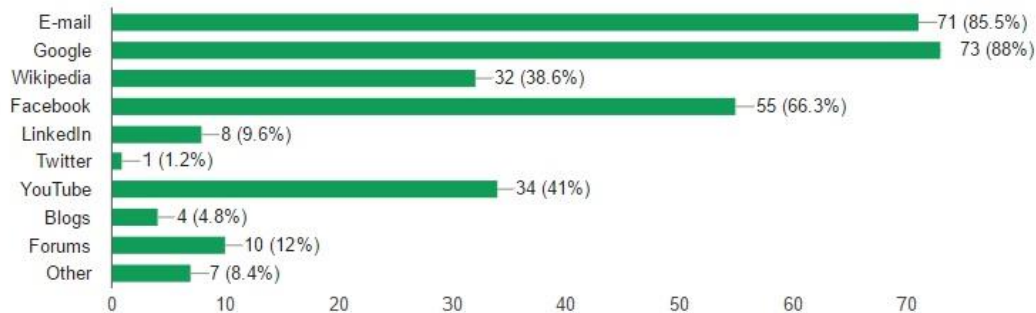
When members of the target groups access the Internet, they most often use Google (88 % of all respondents) and e-mail (85.5%). The third most used online instrument is Facebook (66.3 %). Large number of people also uses YouTube (41 %), which is very important to know, since YouTube videos can be a very effective instrument for online learning. On the other hand, one of the least used instruments among the target groups is Twitter, which is being used only by one percent of all the respondents.

In this regard, there is also a big difference according to the ages of respondents. Among younger respondents, between the ages 18 – 45, almost everyone uses Google and Email and almost 83 % uses Facebook. The numbers are much lower among the older generation. Only about half of the respondents between 46 and 60 uses Facebook and as for those over the age of 61, only about 37 % users have a Facebook account. That means that while creating the online learning materials, we have to make them accessible to all users, not only those who are engaged on Facebook.



What online instruments do you access the most while using the Internet? (Max. 5 options)

83 responses



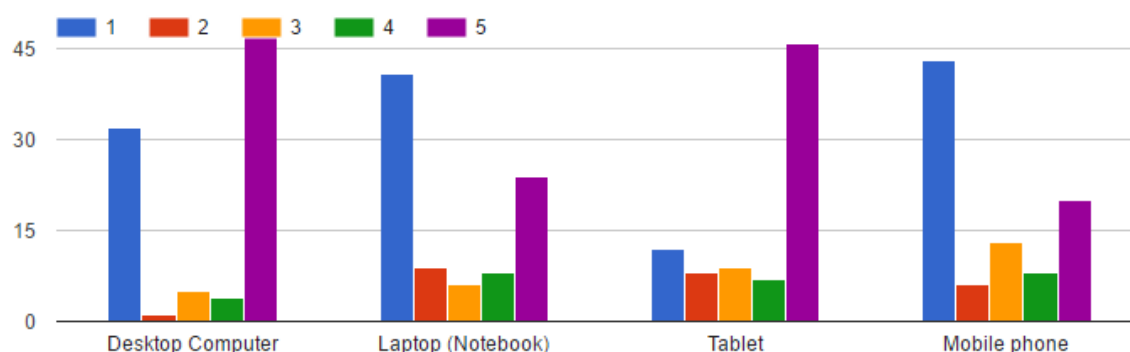
As for the activities that our target groups engage in while using the internet, among the most popular are sending instant messages and keeping in touch with friends, co-workers or family members. While around 19 % of respondents say, they do not like to find information or research different topics, around 63 % say, that they it's one of the most frequent thing they do on the Internet. Altogether, people search for information more often than they send instant messages or keep in touch with others.

As for using multimedia, watching videos or sending and receiving photos, they are very popular for about half of the respondent a less popular among the second half. Although age does not seem to be a very significant factor in our research, most people, who like to send and receive photos, also like to watch videos on the Internet. At the same time, the least performed activity by the members of the target groups is playing video games – without any dependence on age or education of the individuals. That means that it might be more useful to use videos than transforming the materials into “games”. Also, they only rarely start new friendships or post comments on social media websites. What can be seen as a risk to the project is the fact that about half of the respondents never take online professional or academic classes. About 33 % respondents take it very rarely and only around 18 % say they take the online classes. This needs to be kept in mind while designing the learning materials – and making them more attractive and accessible.

As for the different devices that the target groups use to access the Internet and social media, they prefer to use their laptops and mobile phones to connect to the Internet. Some people also often use desktop computers (30 %), but there are also 45 % who say the never use it. In case of mobile phones, there are only 20 % of survey participants, who do not use it to access the Internet and social media. Out of all the devices, Tablets are least popular for accessing the Internet. Not even 20 % of respondents use it often, while almost half of all respondents say, they never use it. For the project's success and utility, it would be most beneficial to make sure that the materials can be use on *both – laptops/desk computers and mobile phones*.



Which devices do you use the most to access the Internet/social media? (1 – Most often, 5 – Never)

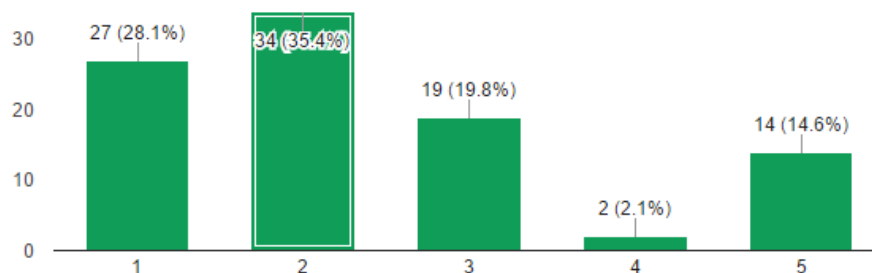


What are the targets' group expectations when learning online?

As using the Internet and engaging on social media became a regular part of everyday life, so did searching for information and improving skills through the use of both the Internet and social networks. Many people notice these changes and agree that their knowledge about the world increased after searching for information on the Internet. In the questionnaire, we asked about this phenomenon and 63.5 % of respondents think that their knowledge increased after using the Internet as an information source. Around 20 % is not very sure, but only 16.7 % thinks that they did not learn while searching for the information. It is surprising that there was no correlation or pattern found according to the respondents' age, gender, education or any other distinguishing factor.

Have you noticed an improvement of your knowledge as a result of searching for information on the Internet?

96 responses



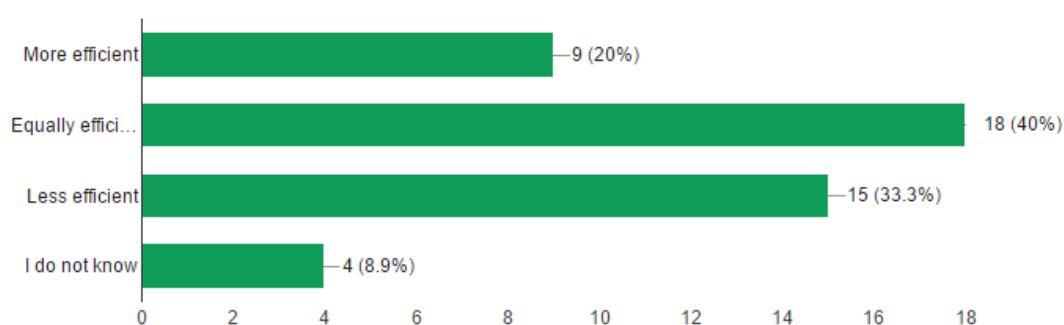
(1 – Significant improvement, 5 – No improvement at all)



As for learning online, almost half of the respondents say, they have some experience in using some of the platforms or environments (46.9 %), such as Moodle, intranet and wikis. Another risk for the project that the questionnaire identified is the fact that many people do not consider e-learning platforms more efficient than traditional learning. Only 20 % respondents consider it more efficient than traditional learning materials, while 33.3 % thinks it is less efficient. On the other hand, around 40 % of the respondents say that the efficiency was the same as in case of traditional materials, meaning they could still be open to using the online learning materials if the issue is approached well – ensuring high effectivity.

Was the e-learning platform more efficient than traditional learning?

45 responses



To get better view on with what online courses people have more experience with, they were asked about specific knowledge or certificates that they have received. The variety of courses the respondents underwent is very wide. To name just some of the fields and certificates obtained online:

- Certificates from the “University of Third Age” – courses ranging from history, art or ethic to working with computers and science;
- Certificate in workplace safety and health (Telecom Italia);
- Master degree in various fields (e.g. teaching philosophy);
- Attestations of training from universities;
- English language certificates;
- Online methods of promoting mental health;
- Certificate for being able to apply psychological tests.

Living and working with cancer

Very important part of the report was to find out about the way people search for information about cancer, so the materials can be adjusted according to the needs of the beneficiaries. As we mentioned before, Google was one of the most utilised websites of all. To specify what information regarding cancer target groups search for, more detailed questions had to be asked.

The respondents' answers indicate that they do search information related to the disease. They are most likely to search for information about classic treatments (72.3 %), healthy lifestyle (56.6 %), alternative medicine (57.8 %) or about news in the field of cancer (56.6 %). Even though some they



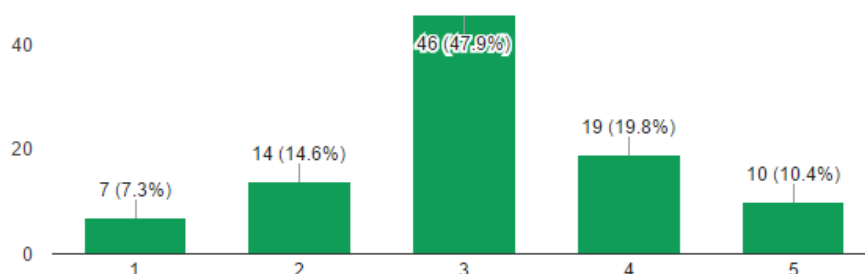
might search for information about topics such as psychosocial support and right of cancer patient, the numbers are lower (33.7 % and 26.5 %).

Also, after finding the information, some members of the research later said they would contact the institution regarding the researched issue. The number is not very large, only a little over 50 % contacted someone/organisation providing classic cancer treatment. Almost 47 % tried contacting more than one clinic and about 40 % a person/centre providing alternative medicine. Associations and specialist providing psychosocial supports contact about 30 % of respondents. In terms of general search engines, Google is number one, several respondents also used Facebook. Other options that members of targets groups used were publications of medical research, hospitals' websites and forums with answers given by experts, medical websites focused on different types of cancers and official websites of clinics and professional organizations.

In order to create the study materials, it is critical to know whether the potential beneficiaries believe the information they find on the internet and consider it reliable. Even though the opinions of the members of our target groups were varied, a large number of them claims, that they are unsure if they can trust it.

Do you think that information about living and working with cancer accessible on the Internet is reliable?

96 responses



(1 – Very reliable, 5 - Not reliable at all)

Those who consider the data found on the Internet completely reliable said that they are trustworthy or they believe that the expertise is on a good level. All those who believe these data completely are over 46 years old cancer patients, younger people or experts on cancer are more sceptical.

Among the 14.6 % of respondents, who say that they find information about cancer posted on the Internet fairly reliable, the opinions are also varied. They say it can depend on the scientific reliability of the source, that they have to be careful while using unofficial sources, and that those that are not affiliated with an institution or a specialist are not credible. Some are worried that the information can be copied or do not have only good experience. The largest percentage of respondents (47.9 %) is uncertain about the validity of information on cancer all around the Internet. They mention the same reasons as those, who think that the information is fairly reliable. They add several more



points, such as that anyone can publish information on the Internet, the information can be published only for commercial reasons, or they prefer to rely on a specialist whom they can consult directly. Many respondents say it is important to use critical thinking while searching for information about cancer or consult your findings with a specialist.

Around 30 % of people participating in the questionnaire either seriously doubts the information or does not believe it at all. There is no general pattern to be found in terms of age, specific target group or education. They say that false information can be found on the Internet, it is not specific and precise and it is of poor quality in general. An expert participating in the research even mentioned that she had to correct some of the information she had found online.

This information is extremely important for the project plans. Now we know that the expertise that partners will provide can make a difference for the target groups, who have doubts about information to be found online, but they do believe in expert opinions and information provided by experts on official website.

This is a great benefit for the project and the study materials that are about to be developed, since there are specialists who will be participating on creating the study materials, making it more valuable, reliable and trustworthy. Among the respondents, there were even those who said, that they believe specifically to information provided by ANT on their website. Since ANT is one of the organizations, under whose name the study materials will be developed, they can find the information provided by the project as very reliable. To summarize, we have to make sure that we point out our valid sources and do everything to secure the reliability and validity of the information that can be easily proven.

Opinions of the target groups about Internet and social media security

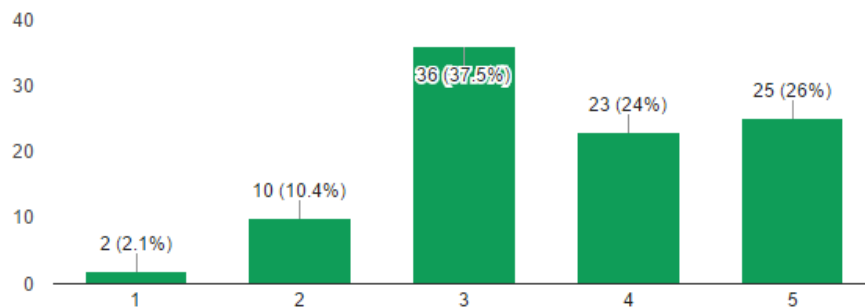
A big part of the “Internet life” is also the topic of online security, which is crucial for this project. Since the study materials target people, whose situation is often very sensitive, it is important to have online security in high regard. To find out, how much do members of the target groups know about Internet security, questions regarding the topic were also a part of the questionnaire. An inquiry into how much do members of the target groups believe that their information on the Internet is safe, how they work with it or if they check more sources while looking for answers, was also made.

The answers regarding security on the Internet and social media were quite unexpected. Only 2 % of all respondent consider their information to be fully secure on the internet and about 10 % are convinced it is fairly secure. Almost 38 % of answers signified, that respondents are not sure about the security of their information. The other respondents do not really believe their information is safe.



Do you believe your information is secure on the Internet/social media/networks?

96 responses



(1 – Very secure; 5 – Not secure at all)

From all the answers, only 23.2 % of respondents said, that there are laws or regulations focusing on the Internet or social networks. Over 66 % of the answers were 'do not know' and about 10 % of respondents think that there are no laws regarding the Internet and social networks. This was one of the few questions, where age played an important role, although there was no pattern to be found in regard to education, gender or country of origin. All, except for one, respondents over the age 60 said that there are no laws and regulation or that they do not know about them. The younger respondents' ideas, on the contrary, varied much more. They said that they either 'do not know' or that there certainly are laws regarding the issue, even though they often were not sure which ones. Among the most frequent answers were privacy law, copyright, regulation regarding personal data and youth and children.

What a large number of respondents agrees upon is the reluctance to post or share personal information about themselves on the Internet. Although around 15 % of respondents are willing to sometimes post personal information (with varying frequency), the largest number of respondents refuse to share it at all. About 60 % of respondents claim that they would never publish information about their dating history, information about their purchases and about their religious and political beliefs. At the same time, only about 6 % of respondents publish information about their dating history often, 4 % do so in case of shopping and only 2 % in case of political beliefs. Even though there are not many more people who would share information about lifestyle or gossip about friends, it is still more, and around 7 % admits to often sharing information about professional life or about information related to cancer.

The respondents were asked to specify their answer. Never publishing "private information" was by far the most frequent answer. It was also mentioned by the participants, that they would not publish information about other people or about their health.



Conclusions for further work

The respondents were asked to provide their own thoughts regarding learning via the Internet and gave us some interesting ideas:

- They suggest that the Internet could be very useful to create an online community for sharing experience and suggestions with other in the same situation/same job (this idea is very close to the idea of “circles of trust”);
- They would appreciate a website dedicated to oncologic topics that would be verified by professionals; it would be possible to verify sources; the information could be a part of hospital websites;
- They would appreciate a course/being taught about reliable information; usage of the Internet should be “completed” by knowledge about how to verify information;
- They like webinars as a study format for this project; they feel that many websites have a lot of additional text without substantive information – which should be avoided when designing the learning materials;
- They think that there are many websites with information about the disease but not enough about social services.

The information gained in the questionnaire survey gave the project an insight that provides an important help for further development of the study materials. Except for the general information discovered by the research mentioned in the previous chapter of the report, it offers a closer look specifically on our target groups, how they use the Internet, social media, and what is the correct approach in designing the innovative e-learning materials focusing on living and working with cancer.

According to the results, most people falling into the category of our research frequently use the Internet, usually between one to three hours per day and some of even more. That gives them a lot of opportunities to benefit from the online study materials that will be quite compact and will not require long hours of tiring studying. Except for the frequency of using the Internet and social media, only very few results were affected by different identification data, such as gender, age or education. But since the people affected by cancer participating in the questionnaire were of all ages and education, we have to make sure that the materials will be accessible for a very wide variety of people with different level of computer skills.

To be even more specific, according to our results, it would be for example much more effective to use Facebook than Twitter, due to the interest in this type of social media among the target groups. Also, even though the number is a little lower than in case of Facebook, YouTube is the fourth most used platform by the target groups. That indicates that YouTube videos can play a major role in the learning materials, which are being designed for the project. Since Google is the most frequently used online tool, we have to make sure, that the project materials will be easily found through the search engine, which can be done for example by engaging the principles of SEO (search engine optimization). It is important to keep in mind all the benefits and risks that were identified by the questionnaire survey.



Learning discussion

Introduction

The aim of the learning discussion was to find out, what do people affected by cancer and other target groups, think about various topics connected to cancer. The ideas gained from the learning discussion were meant to bring some ideas about the thoughts and needs of our target groups. The topics for discussion included questions about how cancer influences the patients and caregivers, what are the necessary skills to deal with cancer patients in distress, questions about online learning, recognizing formal and non-formal skills learned online, promoting use of social networks among people with cancer and employers' behaviour.

The idea of the learning discussion underwent a number of changes before it was settled, that the partners will conduct interviews on several given topics. As in the case of the questionnaire survey, this discussion was conducted anonymously to get the most valid and reliable answers from our respondents.

In the following lines, it will be shown, what are the target groups' views on the previously indicated topics. Each topic has been discussed with at least two members of our target groups.

Topic 1: HOW CANCER INFLUENCES THE PATIENTS AND THEIR CAREGIVERS: THEIR RELATIONSHIPS, THEIR WORK AND THEIR STYLE OF LIFE

How to deal with physical changes connected to the disease? According to cancer patients they cause a shock. One respondent said there are major changes, which are hard to deal with, but she found a way by consulting a specialist. She found a psychologist to guide her and tell her what to do to get over the physical changes that occurred. Another respondent agreed that physical changes are difficult. "During the first treatment you experience hair loss, an impact that is not that big for elderly people, but for others it may represent 50% of the suffering. When you lose your hair, you can't go out anymore. Everyone asks you about what happened to you."

Third respondent said that she dealt with the hair loss problem by using a wig because she didn't want to feel under observation, especially from unknown people. Even now when she sees herself with short hair, she doesn't feel herself the same as before. She said that it was harder when she lost her eyebrows, because it is an obvious sign of the disease and it's difficult to mask.

A caregiver said that one her friends decided to invest in coloured scarves instead, that she changed depending on how she was dressed. In her opinion, the point is to be always careful about personal care because it definitely helps to deal with more grit the course of the disease and the effects of chemotherapy. It is necessary to overcome the initial impact of the illness and then, after a period of adaptation, is possible to learn to live with the changes.

The second respondent said that people become stressed. They also feel very weak due to the disease. Her family tried to help, everyone said what they read somewhere, they tried their best, but advice was not helpful. I kept myself busy in my yard. I would call people, who would not stress me,



have helped me before, colleagues who had gone through other diseases. People who had gone through disease were much more helpful.

In an opinion of a caregiver discussant, disease really affects relationship, because not everyone is ready to face such a situation. Not just patients, but also family members. In some cases, it binds people, in other alienates them. In families where members communicate, it's easier to deal with the disease. In her opinion, the biggest difficulty is when families tend to hide or over-suppress problems. She thinks it's a test. The same goes for the other relationship: there are friends who are first interested, but then reduce their visits because people prefer to stay with people who feel good. "There is the fear of the disease", she said, "the rejection of all that is suffering even though this is part of life"

First respondent said she got much closer with her family. Her friends offered help when needed. "I didn't feel pity or inconsideration from their side. They were by my side and tried to help me feel comfortable and to finish my treatment as easy as possible. They were willing to help me even financially. I found true friends and good neighbours who helped me. I didn't feel any repulsion from their side towards the disease I suffered from." Second respondent said it put pressure on the family and it is harder for families without money. He also admits that some people do not know anything about cancer and will not even shake a hand with a cancer patient. There are people in Romania who think that cancer is contagious.

Another patient said that she is working on the interpersonal dynamic with her psychologist, because she faced the disease looking the other way, with her partner and her family: "I tried to limit the moments of despondency to a minimum. In fact, I have the *white wail syndrome*: I cry only with doctors or with the healthcare professional. My family and my friends have never seen me crying."

One discussant tried using the Internet to find information about cancer but found out that each case is special with different symptoms and problems. Discussions among patients matter, but the most important was the discussion with a specialist. The other found online information to be contradictory, without control. He thinks website for sharing experiences would be helpful. "The patient chats, forgets a bit, gathers strength, can talk with another sick person about their experience."

In the caregiver's opinion, sharing experiences with other persons by using internet is positive: "Sometimes you have a problem and you don't know how to solve it, but if someone had the same problem maybe they can tell you how they did it. Furthermore, knowing it can be solved helps to deal the situation with more confidence and optimism. It is fundamental not to feel alone and abandoned; loneliness would worsen a situation that is already quite dramatic".

As for cancer and work the respondent thought that after finding out and having treatment, you need to focus, get informed and follow the treatment. Only after you feel enough energy and trust that you can resume working, you do so. "You have to relax, to do other things than work like before, because it is important to focus on the treatment." Other respondent said that stress, work and irregular lifestyle can even cause cancer, but time spent at work gets your mind off the disease. The patient should return to work after treatment.



As for the way how cancer affects sexuality both said it influences it and also depends on the patient's age. They think it is more important for younger person for an older one. Younger people have bigger problems with it and admit that their sexual life has been altered. First respondent also thought it was better to protect her children and not to cling to them during the disease. She addressed a specialist and found the answers needed. "I tried to let the children be by my side, but more loosely and not to stress them." Second respondent thinks the children should not know how serious the disease is, so they do not suffer during the whole disease. Families with young children should be helped financially and children's attention should be distracted if they are very young. Another respondent said she doesn't know if it's harder for the one who has the disease or for the partner. She said it was necessary to find a new balance in the relationship, especially if the physical appearance has changed.

Topic 2: CORE SKILLS ON DEALING WITH PEOPLE WITH CANCER IN DISTRESS

According to a medical expert, professional life is affected in the way that we become more withdrawn, less communicative and cannot perform as well as before. In social life we become less extrovert, prefer to stay at home in a familiar environment, safe, more concerned with our own problem. We prefer to only keep family and perhaps a few friends close, becoming more selective about people around us. As for communication, distress can show as weaker focus. It involves unanswered questions that make us more distracted. We start talking about negative things, not seeing the positive side. Everything is viewed in an unfavourable light. A cancer patient mentioned she was always tired and only wanted to sleep and did not care about others. She was either crying or screaming, very nervous and not talking to anyone. She would go out to calm down, but could not stay at home. It was easier for her to communicate with complete strangers, but difficult to be at home and talk with her husband.

For achieving empathy and understanding, medical experts said he acts as if a patient was a family member. Does everything like they were someone he loved. His own feelings of course affect interactions, beside professional life, we also have, not always successful, personal life. We have to disconnect from those at work. He considers the core skills in dealing with people to be: patience, discipline, empathy and a kind word when needed. No matter the situation, we should not take it too personally. For those communicating with cancer patient, it is necessary to use common language that is easily understood. Another very required skill is empathy, if we develop it, the other abilities will come. The cancer patient mentioned she is compassionate, understands diseases of others and prays for them to heal, trying to speak and be optimistic. As for necessary skills for dealing with patients, she said that if the medical personnel are nice to patients, it helps with the healing process. Communication with patients needs to get better. Patients should always be given hope, even if the treatment is not helping. Nurses need to pay more attention to the patients. At the same time, the doctors should be telling patients the truth.



Topic 3: HOW PEOPLE LEARN ABOUT CANCER USING SOCIAL NETWORKS AND ACTIVE LEARNING EXPERIENCES THROUGH SOCIAL NETWORKS

Respondents mentioned searching for information on several website, specifically through www.google.com, www.cancer.net, www.cancer.gov or Wikipedia for general information.

Considering how the information helped them, participants of the discussion mentioned that it provided them with a general idea about the disease, helped to understand it better, showed the treatment options, what the side effects of the treatment could be and how to live with the diagnosis. When someone is not an expert in the medical field, general statistics and prognostic information are helpful, as well as a map of symptoms and possible solutions.

The answers differed even when regarding the questions like if the respondents could find useful the availability of website incorporating information and details about cancer offered by professionals. They said they would appreciate it and like to find information that everybody can understand, not only specialists. Other suggested they can pose questions that doctors in hospital may not have time to answer. They would expect to find written information in a way that everyone can understand. General information about the disease, available treatments, side effects, treatment for reoccurrence. The last respondent never really controlled if the website was written by a professional.

As for what partners or families of persons suffering from cancer could find useful, one of the respondents said it is important to find something on how to support the ill person. Other respondent mentioned that it would be appreciated to find general information about cancer and about providing psychological support and where to find the sources for the information. There was also an answer that people need to know how to handle each specific problem that cancer can cause, also psychological tips how to handle the disease for the patient and the family are useful.

The respondents did not consider online forums to be useful, they either never visit it or think the information is very dissipated. And neither one asked their doctor for an opinion about what they found on the Internet.

Topic 4: HOW TO RECOGNIZE NON-FORMAL AND INFORMAL SKILLS THROUGH SOCIAL NETWORKS TO A DIGITAL AND SOCIAL INCLUSION

Neither of the respondents discussing the topic knew the difference between non formal and informal learning. For that reason, it will be beneficial if we introduce the concepts to potential beneficiaries.

*Definition 1: **Informal education** refers to everyday experiences that are not planned or organized and run by an informal learning. This type of education does not aim in particular, the achievement of educational goals, but by continually exerted its influence may have special educational effects both positive and negative.*

*Definition 2: **Non formal education** is any educational activity deliberate and systematic held usually in the traditional school, whose content is adapted to the individual and special situations for the*



purpose of maximizing learning and knowledge and minimize the problems faced by it in the formal system (stress notaries in the catalogue, discipline imposed, homework.)

After learning the definitions, one of the respondents said they participated in informal learning, while the second did not. On the other hand, they all participated in non-formal learning, one respondent mentioned taking webinars. Both think that it is possible to apply the gained information to daily and professional life. One of the respondents claimed that everyone in the medical field uses the website of “The National Centre for Biotechnology Information” (link: <https://www.ncbi.nlm.nih.gov/>).

There are differences among how the respondents perceive the recognition of knowledge through the Internet. One does not really consider them to be very important and the other considers them important for both, personal and professional life.

In terms of ensuring the recognition or knowledge, the first respondent does not really know how to approach it. The other says they would quantify the hours spent on these e-learning platforms, but also the number of pages, accessed topics or the frequency of access. Then, they would attach a short questionnaire at the end of each topic to evaluate the knowledge gained and to avoid fraud.

Topic 5: HOW TO PROMOTE THE USE OF SOCIAL NETWORKS AMONG PEOPLE CONCERNED ABOUT CANCER

One of the discussed topics was the possibility of promoting the Internet among people concerned about cancer. The discussants said that all new information is important for personal development or one mentioned that it depends on the source. It was mentioned that a person needs to be selective about the information found on the web, but that it is a great tool for finding tips and solutions to personal development and growth.

If we consider what sources the respondents use, they said they found information about cancer at the doctor's, then in magazine articles, books or studies, others use foreign sites (American and British) or they search through Google or Wikipedia.

Somebody expects that the sources will offer them the details needed to help themselves. “It should provide complete information to a question and not just raise more questions.” Another respondent expects the information to be accurate, concise and oriented towards helping in a practical way – both the patients and their relatives.

There are differences in sharing information with a physician. There is a cancer patient who consults everything they find online with the doctor and also those who refuse to share anything at all. But none of them has a session just to talk about the information they found about cancer.

When discussing what they would do to attract more people suffering from cancer to social media, they say they would share useful information of social media. Then they would distribute articles they consider useful, create a page that would provide links to other pages with information provided by specialists. The last discussant doubts if it is a good idea to attract cancer patients to the internet, because they do not think patients should be obsessed about the disease, because it may bring negative belief and depression. But they would like a portal administered by medical



authorities (hospitals, clinics, doctors) that allows the family members to find the information and a virtual support group among people experiencing the same issue.

Topic 6: HOW TO IDENTIFY THE APPROPRIATE WAYS TO RESPOND TO AN EMPLOYEE WHO HAS RECEIVED A CANCER DIAGNOSIS OR IS CARING FOR SOMEONE WITH CANCER

It is very interesting to consider, what should be the employers' response, if they find out their employee suffers from cancer. One of the respondents said that the priority of a person diagnosed with cancer is to take care of themselves and to find the best way to recover. The employer should be responsible for finding a substitute; he/she should not be counting on the sick person's performance. It is important not to pressure the person diagnosed with cancer. The other mentions that employer should do everything so that the person does not feel discriminated or marginalized, integrate and socialize with the employee.

Very sensitive question is what the employer would do, if the person came back after cancer treatment and their previous position was already filled. One says that they would try to find easier work according to the skills of the person. Other respondent suggested creating a job with flexible hours, maybe part-time, according to an agreement with the sick person and his/her colleagues.

According to the respondents' opinions, the employer should offer the employee a flexible program or reduce the number of hours. At the same time, one of the respondents says that the employer who already pays taxes should not be given any extra burden. Both respondents can agree that the employer should not be forced to provide assistance to the employee, it is his/her choice and is should be a job of the state, but some can help their employees just because they are good people. On the contrary, there also appeared an answer that employers are only focused on profit and will not bother with a person who cannot give full performance.

When asked if they would consider hiring a person who is being treated with cancer, for one respondent, it depends on the kind of job that is in question. Other respondent admitted that it would depend on the kind of cancer the person suffers from.

If the respondents would be faced with the choice if to employ a person suffering from cancer, they would have number of concerns. For the first respondent the worst would be that there can be an accident or the person can have sudden problem, which would be the employer's responsibility. The second thinks that the person needs to be given individual attention and their work program needs to be personalised taking in account his health and creating pleasant work environment.

Conclusion

According to the results of the learning discussion, we can see that contact with people who try to use unprofessional information can be even more stressful for cancer patients. Also it became very clear that it is important to raise awareness about the disease. There are many people who do not have even general knowledge about cancer, such as the fact, that it is not contagious.

People with cancer in general become less sociable and feel afraid if they have to go into society. We learned that implementing circles of trust is a very valid idea, since many people say they feel the



best among others with the same experience. The most important skill in this regard is considered to be empathy. We also learned that respondents were not aware of the difference between non formal and informal education and we have to take it into account during our further work.

The respondents agreed that it would be meaningful to have a website with professional information about cancer and especially about how to approach cancer patients. It is important to note, that the discussants do not consider important discussion forums without the input of professional medical staff. They want portals administered by professionals.

We also learned that respondents are very careful about using the Internet, do not always trust it and think that cancer patients should not spend too much time on it worrying about the disease. When they use the Internet though, they expect complete information, that is accurate and reliable and be of practical help for patients and those close to them. To promote information about cancer, they would use social media and distribute useful articles. Learning discussion also, same as the questionnaire suggests that we should make sure the material is SEO friendly and can be found through Google.

As for integrating people suffering from cancer into society and work environment, respondents also agree that cancer patients should not be pressured to work, but if they return to work after treatment, it can take their mind off the disease and help to feel positive. As seen in the learning discussion, question of employers and employees is a very difficult one with many contrasting opinions and raising a number of concerns.



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 effectivity 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;
- 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.



List of resources

- <http://21stoleti.cz/2012/10/08/cesi-na-socialnich-sitich/>
- <https://www.aimac.it/>
- Articoli da quotidiani nazionali > Repubblica.it; Iltempo.it; Siti governativi > www.gazzettaufficiale.it
- Bianco A, Zucco R, Nobile CGA et al. Parents Seeking Health-Related Information on the Internet: Cross-Sectional Study. J Med Internet Res 2013;15(9):e204.
- <http://www.bollettinoadapt.it/osservatori/>
- C. Cipolla, A. Maturo (2014), Sociologia della salute e web society, FrancoAngeli, Milano
- <https://www.campuscluj.ro/>
- <http://www.internetlivestats.com/internet-users/romania/>
- http://ec.europa.eu/eurostat/statistics-explained/index.php/Digital_economy_and_society_statistics_-_households_and_individuals
- E. Valdani, M. D'Amore (2015), Italiani 2.0, Egea, Milano
- <https://www.favo.it/osservatorio.html>; <https://www.favo.it/news/1212-lavorare-durante-e-dopo-il-cancro.html>
- <https://www.foreveryone.cz/blog/nejvice-uzivatelu-mezi-socialnimi-sitimi-v-cesku-ma-youtube-a-facebook>
- I numeri del cancro in Italia 2016, rapporto AIOM-AIRTUM
- Istituto Nazionale di Statistica: Istat.it; Blog: vincos.it
- <http://www.mediafax.ro/economic/jumatate-din-gospodarii-au-acces-la-internet-iar-61-6-dintre-cei-cu-varste-de-16-74-ani-l-au-folosit-13663169>
- <https://www.markomu.cz/socialni-site-2015/>
- <http://mediahub.cz/media/900742-cesi-travi-na-socialnich-sitich-v-prumeru-pres-dve-a-pul-hodiny-denne>
- Ministry of Health Cancer Research Department <http://kanser.gov.tr/>
- MG. Ruberto (2011), La medicina ai tempi del web, FrancoAngeli, Milano;
- Santoro E, Castelnuovo G, Zoppis I et al. Social media and mobile applications in chronic disease prevention and management. Frontiers in Psychology 2015;6,article 567.



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- Turkey Statistical institution 2014 <http://www.tuik.gov.tr/>;
<http://www.tuik.gov.tr/PreHaberBultenleri.do?id=21779>
- Turkey Cancer Foundation <http://www.kanservakfi.com/>
- <http://tyinternety.cz/socialni-site/snasphot-k-cemu-vyuzivaji-cesti-uzivatele-socialni-site/>



Appendix

The questionnaire used for inquiring about how the members of the target groups view the role of the Internet and social media in education.

Full questionnaire with all answers in English

<https://goo.gl/forms/SjwE3B7Vt21bNu1G3>

The Romanian questionnaire

<https://goo.gl/forms/NcndiAUVmzPRH1c2>

The Czech questionnaire

<https://goo.gl/forms/4QbdVjQITrgqNOeE2>

The Italian questionnaire

<https://goo.gl/forms/6MkEvftnCbJnqPOM2>

The Turkish questionnaire

<https://goo.gl/forms/eDNRgH13RqiUbhv63>



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Contact information



Institutul Postliceal "Phoenix"

Address: str. Aviator Badescu nr. 27, Cluj-Napoca, Romania

Phone: 0040264437313

<http://www.institutphoenix.ro/>

Contact person:

Mihaela Vonica

E-mail: mvonica2004@yahoo.com



Adress: Via Jacopo di Paolo, 36 – 40128 Bologna, Italy

Phone: +39 051 7190111

E-mail: info@ant.it

www.ant.it

Contact persons:

Sara Mezzetti

Phone: +39 051 7190151

sara.mezzetti@ant.it

Alessandra Pistani

Phone: +39 051 7190153

alessandra.pistani@ant.it



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Asociația Pentru Servicii și Comunicare în Oncologie

Address: 644, Sânzieni, Covasna, Romania

Phone: +40758511356

www.psychooncology.ro

Contact person:

Dr. Dégi L. Csaba, president

Email: csabadegi@gmail.com



Çay Mesleki ve Teknik Anadolu Lisesi

Address: Erzurum Cad.Hayrat Mah.Yazıcı Sok. No:11, RİZE/TÜRKİYE

Phone: 04642233528

<http://rizeanadulusaglikmesleklisesi.meb.k12.tr>

İlgili kişi :

Mine HACİÖMEROĞLU

E-mail: minemete_72@hotmail.com



INSTITUT INPRO, a.s.

Adress: Samcova 1, 110 00 Prague 1, Czech Republic



Co-funded by the
Erasmus+ Programme
of the European Union



Phone: +420 222 316 068

E-mail: vzdel@i2000.cz

<http://www.i2000.cz/>

Contact person:

Jakub Škába

Phone: +420 603 433 114

jakub.skaba@i2000.cz