



CREATEYOURFUTURE

CREATE YOUR FUTURE GOES EUROPE

Intellectual Output 9 - Expansion Survey



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

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01. Background



More than two-thirds of childhood cancer survivors experience late effects resulting from the treatment and the cancer itself (Childhood cancer survivorship: Improving Care and Quality of Life: 2003). These late effects might arise even years after treatment has ended.

Research shows that increased risks of unemployment were observed within all cancer diagnoses (Pediatric Blood Cancer 2008). Furthermore, long-term survivors of childhood cancer also have higher risk factors for poor educational attainment, less than optimal employment status, and interpersonal relationship issues. Cancers and treatments that result in impairment to the CNS (central nervous system), particularly brain tumors, or that impact sensory functioning, such as hearing loss, are associated with greater risk for undesirable social outcomes, as are emotional health problems and physical disability (CCSS 2009).

Within the EU project Create your Future an individual career counselling programme for a target group that has so far been left behind - childhood cancer survivors - has been developed. The programme is based on the experiences from the career counselling project 'Jugend und Zukunft', that is existing in Austria since 2012 and has been transferred to the three European countries Bulgaria, Spain and Greece in the period 2014 – 2017.

To assure the best possible exploitation and sustainable transfer of the Create your Future programme to other countries within Europe this expansion survey has been conducted. The Goal of this survey is to detect barriers as well as potential opportunities for implementing Career Counselling for Childhood Cancer Survivors in European Countries.

02. Methodology



Data were collected through a questionnaire comprising of both close ended and open ended questions. The Survey was sent out to Childhood Cancer Organisations and Survivors Organisations throughout Europe. In total 64 regional and national organisations have been contacted, 21 organisations have filled in and returned the survey.

03. Analysis

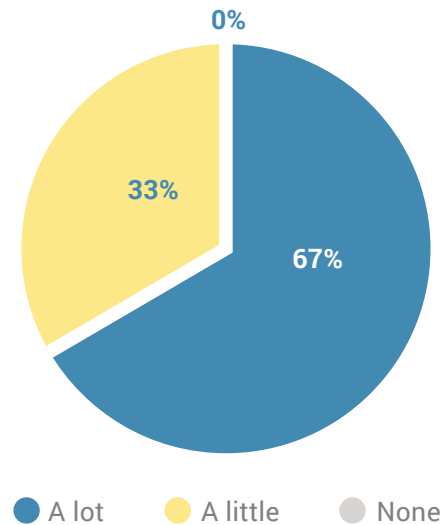


The survey has been filled in by 21 organisations, these organisations are located in 12 different European countries (see table below).

	Country	Number of responses
01	Romania	2
02	Slovakia	1
03	Serbia	4
04	Hungary	1
05	Luxembourg	1
06	Suisse	1
07	Spain	2
08	Italy	2
09	Croatia	4
10	Slovakia	1
11	Germany	1
12	Portugal	1

In order to establish whether or not the organisation is in contact not only with parents and childhood cancer patients but survivors as well, organisations were asked if they are in contact with childhood cancer survivors. 33,3 % of all respondents indicated that they have a little contact with childhood cancer survivors, 66,6 % mentioned having a lot of contact with childhood cancer survivors. None of the organisations mentioned that they are not in contact with childhood cancer survivors at all (see graph below).

Graph 1: Contact with Survivors



03.1. Barriers and support mechanisms in the Implementation of Career Counselling

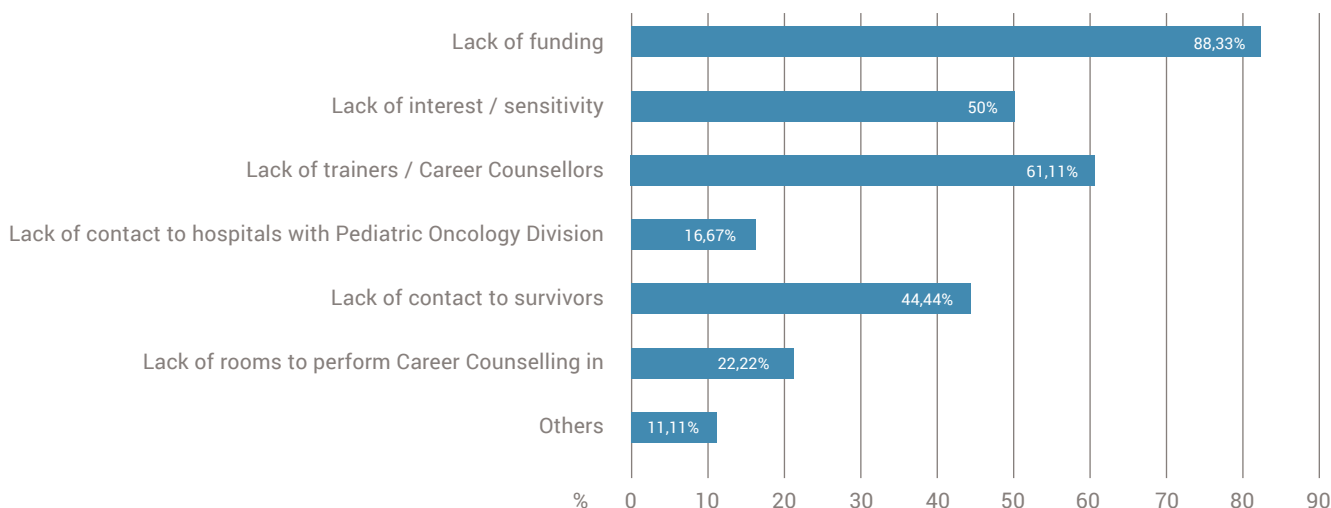
From the desk research performed within the project Create your Future the project consortium has learned that Career Counselling for Childhood Cancer Survivors within Europe is only offered in Austria, Germany and the Netherlands. The survey therefore aimed at exploring if the organisations have ever considered supporting survivors with their integration into the labour market and 12 out of 21 answered 'yes' (57 %). 43 % of the respondents answered 'no' and explained their answer by mentioning the following reasons:

- Organisation has been founded just recently but is aware of importance of Career Counselling
- Organisation is focusing on children with cancer and not on survivors
- Organisation is just starting to establish survivors groups

Nevertheless 20 out of 21 respondents (95,24 %) stated that Career Counselling would be a necessary support system for Childhood Cancer Survivors in their country. What has to be mentioned further is that 17 out of 21 respondents consider the implementation of Career Counselling in their countries as **feasible**.

Even though the majority of respondents support the implementation of **Career Counselling** for Childhood Cancer Survivors in their country, in fact the reality check shows that **it does not yet exist in any of the respondent countries**. Therefore, the survey aimed at detecting potential barriers of implementation: some of the barriers mentioned by 83,3 % was a lack of funding, followed by the lack of trainers / Career Counsellors (61,1 %) and lack of interest / sensitivity (50 %). The lack of funding was not checked by organisations from Germany (1 out of 1), Luxembourg (1 out of 1), Italy (1 out of 2), Croatia (1 out of 4) and Serbia (2 out of 4). Interestingly enough 44,4% also mentioned that a lack of contact to survivors might be a barrier in the implementation of a Career Counselling support system (see graph below). As an open answer 2 respondents mentioned that the geographical dispersion of survivors could be a barrier too, therefore leading to costs connected with travelling and housing.

Graph 2: Barriers in the Implementation of Career Counselling



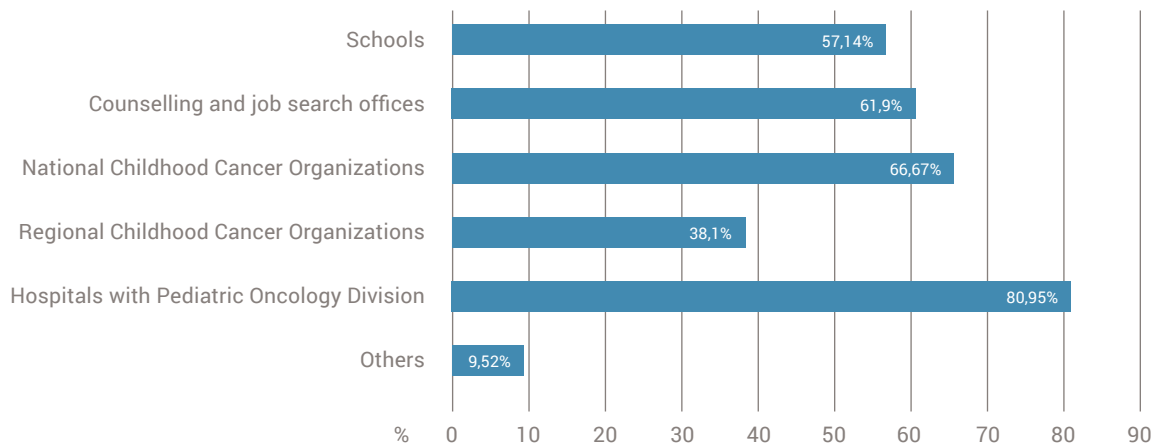
In order to possibly overcome those barriers the study also aimed at detecting support mechanisms which the Create your Future project consortium could offer to those organisations interested in implementing Career Counselling for Childhood Cancer Survivors. Three of the respondents mentioned that training for their staff and for Counsellors would be useful. Other organisations mentioned the need for support in:

- the field of accreditation and licensing for these counselling services
- funding
- motivating survivors to even have interest in career counselling, and motivation to participate on labour market
- the methodology and plan how to implement it in a country

03.2. Dissemination channels for awareness raising

Since the topic of Career Counselling for Childhood Cancer Survivors does not seem to be a focus within many European Countries, the survey aimed at detecting the most appropriate dissemination channels in order to potentially sensitise for the need of Career Counselling for Childhood Cancer Survivors. The hospitals with paediatric oncology departments were mentioned most often with 80,95 %, followed by National Childhood Cancer Organisations (66,67%) and Counselling and job search offices (61,90%). 57,14 % also stated that schools would be an important dissemination channel as well as Regional Childhood Cancer Organisations (38.10 %). 2 respondents also used the possibility of mentioning 'other answers' by stating Education and psychology counselling and prevention offices as well as the media.

Graph 3: Most appropriate dissemination channels



04. Conclusion and next steps



An interesting result of this survey is that **a little less than half of all respondents stated they have never considered offering Career Counselling to survivors**. This might be due to the fact that many organisations are focusing on offering support during treatment.

Furthermore, **a third of all respondents mentioned that there is only little contact with survivors**. The establishment of a Career Counselling offer however is closely linked to knowing and understanding the needs of childhood cancer survivors and not only childhood cancer patients. This results also in the perception of 44,4 % of all respondents as the lack of contact to survivors acting as a barrier in the implementation (44,4%). **Therefore, organisations might firstly need to focus on establishing the contact with survivors** and after this has been built up, projects for survivors such as Career Counselling can be established in a next step.

From the analysis of the barriers however we have learned that **funding is a big challenge** faced by most of organisations. Since the topic of late effects and Career Counselling has also only reached in middle european

countries, there is a possibility that these topics are not yet on the agenda of Eastern European countries, since from our working experience childhood cancer is still considered a taboo topic.

Since respondents mentioned that **training for their staff and for Counsellors would be useful**, the Training Programme developed within the European project Create your Future can be provided, also for a possible translation into other languages (The training Programme is currently available in English, German, Bulgarian, Spanish and Greek).

In order to support Childhood Cancer Organisations with the implementation of a Career Counselling Programme for Childhood Cancer Survivors, **this survey analysis will be sent out to all 64 organisations, who received the survey**. As a next step these organisations might create a profile on the Create your Future Online Community in order to get in contact with each other and offer support whenever needed.

Since the Childhood Cancer Organisations Community is very well connected via the legal brand **Childhood Cancer International (CCI) as well as its European branch CCI-Europe** and their two annual conferences (one Europeanwide conference each spring, one international conference each autumn), this topic can and will be further discussed and endorsed in order to overcome possible barriers.



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