



Co-funded by  
the Health Programme  
of the European Union



*“This Deliverable is a part of the joint action “724161/JARC” which has received funding from the European Union’s Health Programme (2014-2020)”.*

*“The content of this Deliverable represents the views of the authors only and they are sole responsibility: it can not be considered to reflect the views of the European Commission and or the Country, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may of the information it contains”.*

**Deliverable: 8.3**

**Title: report on the development of Educational tools and learning programmes for the rare cancer patient community**

## **Table of contents**

### **1. Description**

#### **1.1 The Joint Action on Rare Cancers**

The Joint Action on Rare Cancers (JARC) is aimed to integrate and maximize efforts of the European Union (EU) Commission, EU Member States and all stakeholders to advance quality of care and research on rare cancers.

The public health challenges posed by rare cancers include the limited professional expertise in the community, the difficulties in clinical research, the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathologic and biological assessment of the disease of the individual patient is key to survival and cure, as well as an expert clinical decision provided by a multidisciplinary team. To this end, proper referral of patients and effective clinical networking are crucial in rare cancers. This is the main reason why JARC decided to shape its efforts around the new European Reference Networks (ERNs) with the following objectives:

1. Improving epidemiological surveillance of rare cancers in the EU
2. Identifying standards of care for all families of rare cancers to ensure sharing of best practices and equality of care for rare cancers across Europe, particularly through clinical networking
3. Improving the implementation at local level and within ERNs of clinical practice guidelines on rare cancers
4. Promoting integration of translational research innovations into rare cancer care
5. Improving education on rare cancers for medical and non-medical experts to ameliorate management of rare cancers and to improve rare cancer patients' empowerment in the EU
6. Identifying core strategies to incorporate in National cancer plans and Rare disease plans to address the specific needs of rare cancers across EU MSs

The JARC is structured in 10 work packages (WPs). Three cross cutting WPs (WP1 coordination, WP2 dissemination, WP3 evaluation) and 7 specific WPs based on the JARC objectives: WP4 epidemiology, WP5 quality of care, WP6 clinical practice guidelines, WP7 innovation and access to innovation, WP8 medical education, WP9 childhood cancers and, WP10 rare cancers policy. Patients work across all work packages, driving the JARC efforts along the needs of the only end users of all what we can do, in care and research as well.

The Joint Action on Rare Cancers and the European Reference Networks are crucial game changers for rare cancer patients in Europe bringing together scarce knowledge and fragmented resources to maximise synergies and results. The European Cancer Patient Coalition (ECPC) is one of the patient organisations representing the needs, rights and hopes of rare cancer patients in the EU Joint Action on Rare Cancers (JARC) along with EURORDIS Rare Disease Europe and the European Society for pediatric oncology (SIOPE) - Childhood Cancer Internation (CCI) Europe.

The within the JARC collaboration counts on rare cancer patient organisations' expertise from all over Europe to continuously represent the rare cancer patient community and provide feedback across all work packages of the JARC.

#### **1.2 Work Package 8**

WP8 aims to:

- 1) identify optimal ways and approaches to connect the educational resources available throughout Europe with networked health care, with special regard to ERNs;
- 2) to promote the improvement of European medical expert training instruments via the European Union of Medical Specialists (UEMS), as well as SIOPE – European Society for Paediatric Oncology, where paediatric oncology is concerned;
- 3) to provide recommendations on education of non-medical experts, patient advocates and patient communities involved in patient care, as a means to improve rare cancer patient empowerment in Europe.

### **1.3 Aim and purpose of deliverable**

This deliverable aims at:

- 1) identifying the needs for educational tools and learning programme of the rare cancer patient communities;
- 2) working out criteria for the production of educational tools, fact sheets, and/or learning programmes for patient advocates and patient communities.

### **1.4 The target group of the specific deliverable**

ERNs, patients' associations, patients, patients advocates, and patient representatives.

### **1.5 Summary of the main conclusions of the deliverable**

There is an evident need for further information on various types of Rare Cancers and the pooling of available patient material in an open-access repository. The gaps identified included a particular demand for general information in regards to advocacy tools, market access, health technology assessment, medicine authorization, the effects of treatment on social and family life, psychological support, in addition to information about disease, medical tests, treatment options and reference centers.

## **2. Introduction**

Rare cancer patients may face many significant challenges including difficulty in obtaining information about their rare conditions. ECPC's on-going contribution to WP8 was to identify the needs for educational tools and learning programmes of the rare cancer patient communities through a Mapping Exercise and Survey, as well as establishing criteria for the production of patient material/ fact sheets necessary to fill in gaps in patient needs.

## **3. Material and method**

In October 2016, ECPC established the Working Group on Rare Cancers (WGRC) operating in parallel with the JARC back in order to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, are able to contribute to the activities of the JARC. Currently the WGRC hosts 65 member organisations which work together continuously through an established online platform and have regular face-to-face working meetings. On 5 December 2016, ECPC kicked-off a test drive online platform for the WGRC, as initially discussed during the WGRC's first meeting on October, in order to create a safe online space where all the members can share their thoughts, news and exchange comments. WGRC Group Members can share To Do Lists, important Deadlines, and work together on creating various WGRC Documents and Files providing their invaluable input on the various activities under the JARC.

### WGRC Contribution:

WGRC representatives provide the patient perspective on the joint action on the rare JARC and discuss on any topic relevant to rare cancers, in specifically, they:

1. contribute to the JARC activities, providing feedback and advice on all relevant tasks
2. ensure that patient concerns are appropriately addressed within the JARC
3. contribute to the development of patient information, rare cancer policies, quality standards for rare cancers, best clinical practices and recommendations
4. contribute to the dissemination of patient information on rare cancers both at national and European levels
5. provide the patient perspective on the unmet needs of people living with rare cancers in their country
6. share with ECPC any other topic related to rare cancers
7. contribute to the increase of the WGRC membership in order establish networks of rare cancers organisations in all countries for a better connection with the Member States and for a better support to rare cancer patients

### WGRC Priorities include:

1. Raise awareness: disseminate information on rare cancers to the medical community to improve early, timely and correct diagnosis
2. Empower rare cancer patients: disseminate information on rare cancers to patients and provide Contact Points at the National Level
3. Contribute to European Reference Centre (ERNs): disseminate information to the medical and non-medical community ensuring patients are referred to centres of excellence
4. Integrate patient input in JARC: provide solutions and ensure collaboration among healthcare professionals through a multidisciplinary approach to guarantee expertise and sharing of best practices
5. Incorporate rare cancers in National cancer plans: push for affordable and sustainable access to treatment, innovation, and psychological support, increase funds for RC research to improve, and the facilitation of country-level decisions on pricing and reimbursement

Working Group Membership: WGRC Members are ECPC Members (Full and Associate) and non-member organisations with an interest in rare cancers. Through the WGRC patients, patient advocates and patient representatives have been working together on mapping patient educational tools and learning programme of the rare cancer patient communities.

### Mapping exercise:

<https://docs.google.com/spreadsheets/d/18fv54hwagHXbH8r5cXaAjCuELryZaGLHqKXsqWUg3IM/edit>

The table itself addresses ECPC specific mission within the JARC identifying the needs for educational tools and learning programmes of the rare cancer patient communities and criteria for educational tools and learning programmes.

### ECPC Survey:

<https://www.surveymonkey.com/r/ECPC-JARCSurvey>

The survey examined the information needs and sources of the rare cancer patient population. The survey was translated to 5 different languages and

disseminated online through newsletters, website links and social media accounts.

#### **4. Results**

The mapping exercise demonstrates that there are many unmet needs, particularly in the provision of disease-specific information, treatment, treatment options and listing of reference centres.

Survey demonstrated that patients are not receiving information from their preferred source, healthcare providers, and are turning to the Internet for information even though they do not report high levels of trust for this source. Accordingly, improvements can be made in the provision of information at the health care level and development of online information portals.

Survey results also highlighted that the information received by patients did not cover effects of treatment on social and family life (45% need vs. 11% received), possibility of psychological support (50% need vs. 20% received), rare cancer care/excellent center sites (41% need vs. 15% received). The survey identified top 3 essential topics based on priority that need to be addressed in patient educational tools include: Advocacy and leadership skills, Effective communication and negotiating tools and Market Access and Health Technology Assessment.

#### **5. Discussion**

There is an evident need for further information on various types of Rare Cancers and the pooling of available patient material in an open-access repository. A comparison of information needs of patients with rare cancers with those diagnosed with common cancers is important to ascertain the differences in information needs, sources, and information satisfaction between those diagnosed with general cancers and those diagnosed with rare cancers. By identifying these needs, we address an important gap in educational tools and learning material for rare cancer patients. Identification of these needs allows us to tailor information to more effectively meet them.

Based on the mapping exercise, ECPC has also created a patient survey to further understand the needs of the rare cancer patient community and create a final list as the WP 8.4 Milestone. The survey has been circulated within the WGRC members and was translated for distribution to various stakeholders.

The gaps identified within our mapping exercise/survey included a particular demand for general information in regards to advocacy tools, market access, health technology assessment, medicine authorization, the effects of treatment on social and family life, psychological support, in addition to information about disease, medical tests, treatment options and reference centers.

A patient/material fact sheet on HTA has been produced based on ECPC HTA e-module and in collaboration with EURORDIS, another in regards to Cancer multimodality approach to treatment, as well as other 19 fact sheets listing rare cancer excellence centres in each country for the 4 European Reference Networks on cancer which will be in turn translated. This includes Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Hungary, Italy, Latvia, Lithuania, Netherlands, Norway, Poland, Portugal, Slovenia, Spain, Sweden, and United Kingdom. \*Material to be sent separately.

The need for continuing education for healthcare professionals of all oncology specialties is necessary as an increasing number of new biomarker tests and

treatments become available. Similarly, information suitable for cancer patients and the public is needed, to keep pace with the latest scientific and technological developments. The role of this is important vital. ECPC, EURORDIS, and SIOPE CCIE are fully committed to increasing patient education and active contribution in cancer research programmes.