

## **WP-6 CANCER REHABILITATION INDICATOR LISTS ONLINE DISCUSSION**

*by Dr Piret Veerus, Camilla Amati, Paolo Baili*

### **EUROPEAN CANCER HEALTH INDICATOR PROJECT EUROCHIP-3 WP-6 CANCER PATIENT REHABILITATION INDICATORS**

#### **OUR MANDATE**

The EUROCHIP-3 “Common Actions” (2008-2011)<sup>1</sup> Work Package on cancer rehabilitation indicators<sup>2</sup> (WP-6) will list the health indicators for rehabilitation needs of cancer patients (including psychological, clinical, psychiatric, nutritional and social services) necessary for a structured collection of comparable data in the EU to guarantee equal care to all EU citizens. No data collection is envisaged.

#### **THE LIST**

1. Cancer prevalence
  - 1a. Prevalence by cancer site
  - 1b. Cancer prevalence by gender
  - 1c. Cancer prevalence in different age groups
2. Proportion of cancer patients with/without relapse
3. Amount of funding per cancer rehabilitation per patient per year
4. Existence of national strategy for cancer rehabilitation
5. Availability of guidelines for cancer rehabilitation
6. Availability of follow-up programmes for cancer patients
7. Number of NGOs and other organisations involved in cancer rehabilitation
8. Availability of social care workers at home
9. Training courses for persons involved in rehabilitation programmes
10. Availability of social counselling, psychological support, nutritional counselling for cancer patients and their family members
11. Proportion of persons with cancer diagnosis returned to work
12. Quality of life of cancer patients

#### **DISCUSSION**

In the following pages the indicators are briefly described and specific items of discussion are proposed (i.e. collection, methodology and/or availability in various countries). Please note:

- Included indicators must be at population level
- Included indicators do not necessarily have to be already available
- Included indicators can be a proxy
- Included indicators can be subdivided in high and low priority
- It is really important to discuss of common sources across Europe and on the efforts necessary for collection
- At the end of the project the list must be concise (5-6)

---

<sup>1</sup> The EUROCHIP Projects focus on cancer health information in the EU and are funded within the Program of Community Action in the Field of Public Health, Health Information strand.

EUROCHIP-1 (2001-2003) has produced the List of Cancer Health Indicators in the areas of cancer treatment, prevention, screening and epidemiology for the EC ECHIM list (European Community Health Indicators Monitoring).

EUROCHIP-2 “the Action” (2003-2007) has developed actions for the improvement of Cancer Health Information in 24 Member States. Actions included studies on Preventive Diet and Lifestyles, Treatment Best Practices, Cervical Cancer Screening Programmes and on Cancer registration inequalities in the EU.

The EUROCHIP-3 “Common Actions” (2008-2011) sets towards a common EU policy of cancer control for prevention, treatment and care for the improvement of survival and quality of life for cancer patients.

<sup>2</sup> WHO Definition of rehabilitation: “ process aimed at enabling patients to reach and maintain optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.”

**CANCER PREVALENCE (TOTAL PREVALENCE AND/OR 5-YEAR PREVALENCE)**

Acronym	PREV
Priority	high
Category	cancer burden
Rationale	to estimate the number of persons with a cancer diagnosis. Prevalence indicates how many people in an exact date (ex 31/12/xxxx) show potential medical, physical, psychological or social problems as a consequence of cancer. The indicator is useful for health planning, resources allocation.
Unit of measurement	proportion of persons with a cancer diagnosis per 100,000
Classified by	a. cancer site b. sex c. age
Main source of data	cancer registry (CR). In some countries CR covers the entire population, in others one or more CRs cover a fraction of population
Operational definition	Prevalent cases are people from a population, alive up to a given date, and who had previously been diagnosed cancer. New incidence cases and still alive incident cases of previous years are included in the prevalence. Prevalent proportion shows the proportion of prevalent cases on a total resident population in a given area. It is calculated as follows:  $p(s, sx, g, p, a) = \frac{P(s, sx, g, p, a)}{Pm(sx, g, p, a)}$ <p>P (s,sx,g,p,a) = estimated number of survivors who had been diagnosed cancer, specific per cancer site (s), sex (sx), geographic area (g), calendar year (p), age (a)  Pm (sx,g,p,a)= average population specific per sex (sx), geographic area (g), calendar year (p), age (a)</p>
Centralization of data	Five year cancer prevalence estimates are produced by GLOBOCAN; total prevalence estimates are produced by EUROPREVAL [Micheli A et al.. Ann Onc 2002;132(6):840-865 published data in Europe at 31/12/1992].
Cooperation	Methodology used by EUROPREVAL (Capocaccia R et al, Ann Onc 2002;132(6)) is used also by the SEER Program of the NCI in US. The SEER*Stat (the US CR database) implemented the EUROPREVAL methodology to estimate prevalence in US.

## **DISCUSSION**

Prevalence can be used as an indicator of the cancer rehabilitation burden. Prevalence is estimated with data collected by cancer registries.

Discussion referred to the use of 5-year prevalence (number of persons alive at a certain date with a cancer diagnosis in the previous 5 years) or total prevalence (number of persons alive at a certain date with a cancer diagnosis in their past).

5-year prevalence is routinely estimated by IARC and published in the GLOBOCAN database (last available year: 2002). Total prevalence in Europe was estimated for various countries by the EUROPREVAL project (last available year: 1992). In Italy a project recently published estimates of total prevalence using specific methodology (MIAMOD/PIAMOD models) starting from cancer mortality data (available at national level by national Statistic Offices) and cancer survival data (available from EUROCARE project in the majority of European countries). This methodology can be used also in other EU countries. In US total prevalence is estimated starting from SEER Stat data.

The group was favourable about including prevalence in the list of indicators. No agreement was yet reached on the inclusion of 5-year prevalence or total prevalence.

## **PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Type of indicator (5 year and/or total prevalence):

Methodology:

Availability in your country:

## PROPORTION OF CANCER PATIENTS WITH/WITHOUT RELAPSE

Acronym	RELAPSE
Priority	high
Category	cancer burden
Rationale	to estimate the number of persons who have had a relapse after primary cancer diagnosis and treatment
Unit of measurement	proportion of patients with/without relapse among total number of persons diagnosed with cancer
<u>Operational definition</u>	
Numerator	number of cancer patients with/without relapse x 100,000
Denominator	total number of cancer patients
Main source of data	Ad-hoc studies on cancer registry data. For methodology see: Gatta G et al, Annals of Oncology 15: 1136–42, 2004

### FIRST DISCUSSION

This indicator should be used as a proxy to estimate how many prevalent cases need “clinical help”.

Discussion referred to the way to collect this indicator.

- Data on relapses are not routinely collected by cancer registries in the majority of European countries. Ad hoc collection (with ad-hoc protocols and standard definition of relapses) should be implemented on cancer registry database samples for specific cancer sites. These studies are expensive.
- Information on relapse percentages could be obtained from clinical trials and clinical databases and combined to total prevalence estimates for specific cancer sites.

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Methodology:

For which cancer site/s:

## FUNDING FOR CANCER REHABILITATION

Acronym	FUNDING
Priority	high
Category	financial resources for rehabilitation
Rationale	to estimate the financial resources for cancer rehabilitation
Unit of measurement	amount of funding per cancer rehabilitation per patient per year
<u>Operational definition</u>	
Numerator	total amount of funding for cancer rehabilitation per year in EUR (both public and private resources)
Denominator	mean number of cancer person with a cancer diagnosis per year

### FIRST DISCUSSION

This indicator should be used as a proxy to political attention to cancer rehabilitation issue.

Discussion referred to the possibility of collection and comparison among countries. Similar indicators were also discussed during the EUROCHIP-1 project for other cancer fields (e.g.: cancer registry funds, cancer screening funds, etc) yet no solution was reached to find comparable indicators. It is really difficult and quite impossible to extrapolate funds for cancer rehabilitation from the total public/private funds devoted to cancer or to health in general.

An alternative way can be a cost analysis of cancer rehabilitation experience of a cancer registry patient sample. These studies are expensive.

The majority of colleagues in the group seem to be aware on the impossibility to include this indicator in the list. A possible proxy indicator of political attention to the cancer rehabilitation issue can be a YES/NO indicator on presence of cancer rehabilitation in national cancer control plans *[see next page]*

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at national level):

Methodology:

Possible other indicators:

## NATIONAL STRATEGY FOR CANCER REHABILITATION

Acronym	STRATEGY
Priority	high
Category	rehabilitation strategy
Rationale	to guarantee existence of national strategy for cancer rehabilitation
a. Unit of measurement	existence of national cancer plan [Y/N]
b. Unit of measurement	cancer patient rehabilitation included in the national cancer plan [Y/N]
Main source of data	Health ministry survey; expert survey; internet ad hoc collection

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

## NATIONAL GUIDELINES FOR CANCER REHABILITATION

Acronym	GUIDELINES
Priority	high
Category	rehabilitation strategy
Rationale	to guarantee existence of national guidelines for cancer rehabilitation
Unit of measurement	existence of national guidelines for cancer rehabilitation [Y/N]
Classified by	cancer site
Main source of data	Health ministry survey; expert survey; internet ad hoc collection

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

Do you have some example of guidelines?

## FOLLOW-UP PROGRAMMES FOR CANCER PATIENTS

Acronym	FOLLOW-UP
Priority	medium
Category	rehabilitation strategy
Rationale	to guarantee follow-up programmes for cancer patients
Unit of measurement	existence of follow-up programmes for cancer patients [Y/N]
Main source of data	Health ministry survey; expert survey; internet ad hoc collection

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

## ORGANISATIONS INVOLVED IN CANCER REHABILITATION

Acronym	NGO
Priority	high
Category	human resources
Rationale	to estimate the human resources for cancer rehabilitation
Operational definition	number of organisations and number of members in these organisations

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

**AVAILABILITY OF SOCIAL CARE WORKERS AT HOME**

Acronym	HOME_CARE
Priority	medium
Category	human resources
Rationale	to evaluate the availability of social care workers at home
Unit of measurement	existence of system offering social aid for cancer patients at home [Y/N]

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at national level):

Source of data:

## TRAINING COURSES FOR PERSONS INVOLVED IN REHABILITATION PROGRAMMES

Acronym	TRAINING
Priority	high
Category	human resources
Rationale	to check the availability of training courses for persons involved in rehabilitation programmes
Unit of measurement	existence of training courses for persons involved in rehabilitation programmes [Y/N - if possible description of courses; who organises them; whether accreditation exists)

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at national level):

Type of training courses:

Source of data:

## COUNSELLING FOR CANCER PATIENTS AND THEIR FAMILY MEMBERS

Acronym	COUNSELLING
Priority	high
Category	counselling for cancer patients and their family members
Rationale	to check the availability of systems for social counselling, psychological support, nutritional counselling for cancer patients and their family members.
Unit of measurement	existence of systems offering social counselling, psychological support, nutritional counselling for cancer patients and their family members [Y/N]

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at national level):

Type of counselling:

Source of data:

**PROPORTION OF PERSONS WITH A CANCER DIAGNOSIS RETURNED TO WORK**

Acronym	RETURN_WORK
Priority	high
Category	success of cancer treatment and rehabilitation
Rationale	to estimate the number of persons with a cancer diagnosis returned to work
Unit of measurement	proportion of persons with a cancer diagnosis returned to work
<u>Operational definition</u>	
Numerator	number of persons with a cancer diagnosis working (part-time, full-time)
Denominator	total number of cancer patients

**PLEASE GIVE YOUR OPINION ON**

Inclusion of indicator:

Possibility of collection (at population level):

Methodology:

Source of data:

## QUALITY OF LIFE OF CANCER PATIENTS

Acronym	QL
Priority	high
Category	success of cancer treatment and rehabilitation
Rationale	to evaluate the quality of life of cancer patients
Unit of measurement	quality of life scores (by cancer site and stage)
Operational <u>definition</u>	quality of life scores measured by general or specific scales

### PLEASE GIVE YOUR OPINION ON

Inclusion of indicator:

Possibility of collection (at population level):

Methodology:

Source of data: