I Indicators on burden of cancer

1. Desired indicator: cancer prevalence	
Acronym:	PREV
Priority:	High
Generic definition:	Proportion of persons with a cancer diagnosis per 100,000 inhabitants
Classified by:	A Cancer site B Gender C Age (5-year age groups) D By duration: 1-year, 5-year, total
Relevance:	Indicator for health care funding, resource planning
Rationale:	Proxy indicator able to quantify the generic burden of cancer rehabilitation at population level
Caveat:	• This indicator does not distinguish between cured and non cured patients • This indicator includes also those patients without rehabilitation needs This indicator can be the reference denominator for other specific indicators on rehabilitation
Methodological definition:	Prevalence indicates how many alive people at an exact date (ex 31/12/xxxx) in a certain population have been diagnosed with cancer: new incidence cases and still alive incident cases of previous years are included
Cost:	Medium
Data sources:	Data from national and/or regional population-based cancer registries. European projects (combining cancer registry data) allow to have common methodologies to estimate comparable indicators across Europe
Availability:	• EUROPREVAL [1], RARECARE [2] produced estimates of period and total prevalence • GLOBOCAN (IARC) [3] produced estimates of 5-year prevalence
Note:	In a few countries (e.g. UK), possibility to estimate by social class
References:	1. Micheli A, Mugno E, Krogh V, et al. Cancer prevalence in European registry areas. Ann Oncol 2002;13(6):840-65 2. Gatta G, van der Zwan JM, Casali PG, et al. Rare cancers are not so rare: The rare cancer burden in Europe. Eur J Cancer 2011;47(17):2493-511 3. Ferlay J, Shin HR, Bray F, Forman D, Mathers C and Parkin DM. GLOBOCAN 2008 v1.2, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10. Lyon: International Agency for Research on Cancer; 2010. Available at http://globocan.iarc.fr

2. Desired indicator: qualified prevalence	
Acronym:	QUAL.PREV
Priority:	High
Generic definition:	It indicates how many prevalent patients at an exact date (ex 31/12/xxxx) have had recurrence, metastasis, other tumours OR totally recovered
Classified by:	A Cancer site B Gender C Age (5-year age groups)
Relevance:	More precise indicator for funding, resource planning
Rationale:	Proxy indicator able to quantify some specific burden of cancer rehabilitation at population level
Caveat:	Requires long-term (at least 10 years) data on a cohort of cancer patients
Methodological definition:	Qualified prevalence is prevalence proportions subdivision among: • Those expected to die in a year • Those expected to die for cancer in more than a year • Those expected to survive with relapses • Those expected to survive without relapses
Cost:	High
Data sources:	Data from national and/or regional population-based cancer registries linked with clinical databases and clinical records. European projects (combining cancer registry data) allow to have common methodologies to estimate comparable indicators across Europe
Availability:	• High-resolution studies, based on data from cancer registries (ad hoc collection of clinical data on cancer patient samples) [1] • Data in cancer registry databases linked with clinical data in hospital discharge registers or similar clinical databases [2]
Note:	
References:	1. Gatta G, Capocaccia R, Berrino F, Ruzza MR, Contiero P; EUROPREVAL Working Group. Colon cancer prevalence and estimation of differing care needs of colon cancer patients. Ann Oncol 2004;15(7):1136-42. 2. Maddams J, Utley M, Møller H. Levels of acute health service use among cancer survivors in the United Kingdom. Eur J Cancer 2011;47(14):2211-20.

3. Desired indicator: quality of life of cancer patients	
Acronym:	QOL
Priority:	High
Generic definition:	Perceived quality of life of cancer patients before and after rehabilitation courses, measured at regular intervals
Classified by:	By cancer site and stage
Relevance:	Success of rehabilitation
Rationale:	To evaluate the quality of rehabilitation of cancer patients
Caveat:	The indicator requires interviews to patients: • non participation in the survey could false the population level coverage of the indicator • not necessarily patient is aware that he/she is a cancer patient. So it is necessary to contact before his/her GP
Methodological definition:	Quality of life scores. Questionnaire suggested to be used is EORTC QLQ-C30 [1]
Cost:	High
Data sources:	Studies should be at population level interviewing cancer patient samples extracted from cancer registry databases or from general population cross sectional survey linked to cancer registry databases
Availability:	This type of studies is performed in few areas of Europe: mainly in the Netherlands, Germany, Sweden and France [2]
Note:	Cancer registries might have problems in contacting cancer patients directly, due to confidentiality laws
References:	1. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993;85:365-76 2. See Table 6 of the WP-6 final report

4. Rate of return to work among cancer patients	
Acronym:	WORK
Priority:	High
Generic definition:	Indicator able to describe the return to work of cancer patients in working age (as it was demonstrated that cancer survivor are more likely to be unemployed than healthy control people)
Classified by:	By cancer site and by stage at diagnosis, by age group and gender
Relevance:	Success of rehabilitation
Rationale:	To evaluate the quality of rehabilitation of cancer patients
Caveat:	The indicator requires interviews to patients: • non participation in the survey could false the population level coverage of the indicator • not necessarily patient is aware that he/she is a cancer patient. So it is necessary to contact before his/her GP
Methodological definition:	Number of workers with a cancer diagnosis working full-time or part-time on the total number of cancer workers
Cost:	High
Data sources:	• Studies should be at population level interviewing cancer patient samples extracted from cancer registry databases. • There are some experiences in Europe in which the indicator were estimated linking cancer registry data with census data (Finland), Directorate of Taxes (Norway) or Labor Market Research Database (Denmark) but these types of studies cannot be extended to other countries
Availability:	Some studies were performed in North West England [1], Ireland [2] and South Netherlands [3]
Note:	In several countries, data protection problems may restrict data collection and analysis.
References:	1. Amir Z, Moran T, Walsh L, Iddenden R, Luker K. Return to paid work after cancer: a British experience. J Cancer Surviv 2007;1(2):129-36. 2. Sharp L, Timmons A. Social welfare and legal constraints associated with work among breast and prostate cancer survivors: experiences from Ireland. J Cancer Surviv 2011;5(4):382-94. 3. Mols F, Thong MS, Vreugdenhil G, van de Poll-Franse LV. Long-term cancer survivors experience work changes after diagnosis: results of a population-based study. Psychooncology 2009;18(12):1252-60.

5. Rehabilitation needs and their availability for specific cancer sites: • **speech & language therapy for head and neck cancer patients** • **physiotherapy for breast cancer patients** • **dietician therapy for colorectal cancer patients** • **psychological support for all cancer patients**	
Acronym:	MEET.NEEDS
Priority:	High
Generic definition:	The proportion of patients by cancer site who need these services and the actual proportion counseled
Classified by:	By cancer site
Relevance:	Success of rehabilitation
Rationale:	To evaluate the quality of rehabilitation services for cancer patients
Caveat:	The indicator requires interviews to patients: • non participation in the survey could false the population level coverage of the indicator • not necessarily patient is aware that he/she is a cancer patient. So it is necessary to contact before his/her GP
Methodological definition:	Questionnaires to patient groups to identify their needs; number of patients counseled among those who would have needed it
Cost:	High
Data sources:	Studies should be at population level interviewing cancer patient samples extracted from cancer registry databases.
Availability:	
Note:	In several countries, data protection problems may restrict data collection and analysis.
References:	