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ANNEX 1: Indicators from other HMP projects

1Pr.01 Consumption of fruit & vegetables

(From "Executive summary" of the EFCOSUM final report)

EFCOSUM (European Food Consumption Survey Method) underlined:

- Up to now DAFNE is the only database that provides comparable data (at household level)
- EPIC develops methods to collect comparable dietary data focused on cancer and adults
- Common guidelines are necessary in order to have comparable data among countries
- Data can be made comparable at the "raw edible" ingredient level
- At the beginning it is really important have comparable data on vegetables (potatoes excluded), fruits (fruit juices excluded), bread, fish (shellfish included), some nutrients (saturated fatty acids, total fat, ethanol) and some biomarkers (folate, vitamin D, iron, iodine, sodium)

EUROCHIP suggested the gathering of information on fruit and vegetable consumption and EFCOSUM appears to satisfy this criteria. EUROCHIP is aware of the difficulties in gaining comparable data on dietary habits but regards this information as of real importance because the consumption of fruit & vegetables is a major dietary protective factor for cancer. For this reason EUROCHIP recommends the continuation of projects like EFCOSUM, DAFNE and EPIC. EUROCHIP also recommends the collection of information on the national reports relating to the provision of fruit to children at school.

1Pr.03 Consumption of alcohol

(From "Conclusions and recommendations" of the ECAS final report)

ECAS (European Comparative Alcohol Study) underlined:

- The total alcohol consumption per capita by beverage categories is an important indicator for following developments in the public health area in the EU
- The EU should prepare an authoritative report on total alcohol consumption according to beverage categories and off- and on-premises sales in its member states
- The EU should also prepare a report on how basic figures for alcohol consumption are and have been collected in different studies and how units used for estimating individual alcohol consumption have been converted into alcohol litres
- The EU should carry out such surveys on a regular basis in order to monitor developments in drinking habits with implications for public health in Europe

EUROCHIP agrees with the ECAS recommendations to the EU and underlines the importance in having a common European guideline in order to have comparable data.

1Pr.04 Body Mass Index distribution in the population

The EHRM (European Health Risk Monitoring) project underlined the importance of having information on BMI in the EU. It proposed the same indicator that is recommended by EUROCHIP. We recommend the organisation of validation studies.

1Pr.05 Physical activity

EUPASS (European Physical Activity Surveillance System) advocated a European survey on physical activity including specific questions. The EUROCHIP indicator refers to question A2. We recommend the organisation of validation studies and the improvement of the examples in question A2 of the IPAQ survey.

Pr.08 PM10 emissions

In Europe there are several projects about air pollutant emissions and various organisations that collect information on air quality. National annual emissions of air pollutants (PM10 included) are already available on the internet. «Percentage of population living in urban areas with a PM10 daily average above 50 microgrammes per air cubic meter» is an indicator proposed in Europe by the group «Environmental health indicators for the WHO Europe». This group has already provided a methodological definition of the indicator and considers it to be a realistic goal in the future.The indicator of the WHO group was also proposed by EUROCHIP, therefore we recommend the EC include it in the European Database. We recommend the indicator to be classified by PM10 daily average (and not only above 50 microgrammes per air cubic meter).

ANNEX 2: European Health Survey

EUROCHIP proposes the introduction of a European health survey or an update of the various National health surveys in order to collect comparable data for the following indicators:

- **Consumption of fruit and vegetables *** (EFCOSUM project)
- **Consumption of alcohol *** (ECAS study)
- **Body Mass Index distribution in the population *** (EHRM project)
- **Physical activity *** (EUPASS project)
- **Prevalence of current tobacco smokers among adults *** (EHRM project)
- **Prevalence of tobacco smokers among 10-14 year olds *** (EHRM project)
- **Prevalence of ex-smokers *** (EHRM project)
- **Prevalence of exposure to Environmental Tobacco Smoke (ETS) *** (EHRM project)
- **Exposure to sun radiation**: the survey has to collect information on exposure to the sun for the skin cancer risks
- **Percentage of women that have undergone a mammography (breast cancer):** in order to collect information on last mammography examination among females aged 40-49, 50-69 and 70-74 years. The survey also has to collect information on the time of the last examination
- **Percentage of women that have undergone a cervical cytology examination (cervical cancer):** in order to collect information on last cervical cytology examination among females aged 20-29, 30-59 and 60+ years. The survey also has to collect information on the time of the last examination
- **Percentage of persons that have undergone a colo-rectal cancer screening test (age 50-74)**: in order to collect information on the last colo-rectal cancer screening test in the last 2 years

* Indicators proposed by other HMP projects

ANNEX 3: Summary from the WHO Report "Tobacco Country profiles"

Source: Corrao MA et al. Tobacco Control Country Profiles, American Cancer Society, Atlanta, GA, 2000.

"Before comparing smoking prevalence across several countries or territories, the following questions should be considered:

- *What type of tobacco do respondents report smoking?*
- *What frequency of smoking defines a "smoker"?*
- *What is the age range defining "adult" and "youth" and how were the respondents selected?*
- *Where was survey conducted? Was the survey conducted throughout the country or territory?*
- *Is the survey conducted annually or less frequently?*

The first two questions relate to how the survey distinguished between smokers and non-smokers; smoking behaviour in two countries may not be comparable if the answers to these questions are different. Whenever possible, survey data that adhered to the WHO definitions of smoking were selected to increase comparability between studies. The WHO guidelines state that respondents who report smoking at the time of the survey, or "current smoker" should be further categorized as "daily" or "occasional" smokers. "Daily" smokers are individuals who smoke any tobacco product at least once a day, including those who smoke everyday except days of religious fasting. "Occasional" smokers are individuals who smoke any tobacco product, but not every day."

Smoking prevalence among adults: summary from Tobacco Country profiles

	Object	Age	Year	Notes
Austria	Regular smoking	15+	1997	
Belgium	Daily cigarette smoking	15+	1999	
Denmark	Daily cigarette smoking	14+	1998	(less than 15 cig per day)
Finland	Cigarette and pipe smoking	15-64	1999	
France	Current smoking of all products	18+	1997	
Germany	Daily cigarette smoking	18-59	1997	
Greece	Daily smoking	15+	1994	
Iceland	Daily smoking	18-69	1998	
Ireland	Regular and occasional cigarette smoking	18+	1998	
Italy	Regular daily cigarette smoking	14+	1998	
Luxembourg	Occasional and regular smoking	18+	1998	
Netherlands	Ever smoking	15+	1998	
Portugal	Regular daily smoking	15+	1995-1996	
Spain	Daily smoking	16+	1997	
Sweden	Daily smoking of any kind of tobacco	16-84	1998	
UK	Smoking	16+	1996	

Smoking prevalence among youth: summary from Tobacco Country profiles

	Object	Age	Year	Notes
Austria Belgium Denmark Finland France Germany Greece Ireland Portugal Sweden UK	Daily smoking	11-15	1998	Currie, C. et al. (2000). *Health behaviour in school-aged children: a WHO cross-national study.* Health Policy for Children and Adolescent Series No. 1. Copenhaghen: WHO Regional Office for Europe
Iceland	Daily cigarette smoking	10-16	1998	
Italy	Current smoking of at least 1 cigarette per week among eight graders		1994	
Luxembourg	Smoking	11-18	1998	
Netherlands	Smoking 1 or more cigarettes in the past 4 weeks	10-14	1998	
Spain	Daily smoking	11-15	1994	

1Pr.05a Tobacco survey: prevalence of current tobacco smokers among adults

Indicator context

The indicator regards the percentage of current smokers in the population aged 15+. All type of smoking are considered but we are not interested in the intensity of smoking.

Indications on data collection

Data should be collected by survey.

Standardisation

From the «Tobacco Country Profiles» (Corrao (2000). See annex 2) it is clear that the data currently available is not really comparable. For this reason, in order to have the same standardised questionnaire for all European countries, we recommend an international harmonisation of approaches, methods and tools in current national surveys.
Moreover, about smoking definition EUROCHIP should refer to "Guidelines for controlling and monitoring the tobacco epidemic" (WHO 1998)

Variability within countries

Smoking habits can differ between the various areas or regions in each country.
The survey and the reported summary data should be appropriately stratified.

Validity

Specific surveys (for example the Health survey for England), based on measurement of cotinine concentration in saliva, measured a relevant effect of the under-reporting on the prevalence of smokers. Moreover, the "Health Survey for England - The Health of Minority Ethnic Groups" shows the different level of under-reporting among the various inorities in England (Pakistani, Bangladeshi, Cinese…).
We do not know if the level of under-reporting is similar in all European countries.

Bibliography

- Corrao MA *et al*. *Tobacco Control Country Profiles*. American Cancer Society, Atlanta, GA, (2000)
- WHO (1998). Guidelines for controlling and monitoring the tobacco epidemic. Geneva
- Peto R *et al*. *smoking, smoking cessation, and lung cancer in the UK since 1950 combination of national statistics with two case-control studies*. BMJ: 321, 323-329 (2000)
- Tuyns *et al*. *Cancer of the larynx/hypopharynk, Tobacco and alcohol*. Int J Cancer (1988): 41, 483-491
- Berrino F *et al*. *A comparative study of smoking, drinking and dietary habits in population samples in France, Italy, Spain and Switzerland. II Tobacco smoking*. Rev. Epidém. Et Santé Publ.: 36, 166-176 (1988)
- Health Survey for England - The Health of Minority Ethnic Groups '99 http://www.archive.official-documents.co.uk/document/doh/survey99/hse99-04.htm

Suggestions to the European Commission

To recommend an international harmonization of approaches, methods and tools in current national surveys. To consider the possibility to organise specific surveys based on measurement of cotinine concentration in saliva.

1Pr.05b Tobacco survey: prevalence of tobacco smokers among 10-14 year olds

Indicator context

The indicator regards the percentage of the population aged from 10 to 14 reporting to be a daily or a weekly smoker.
All type of smoking are considered but we are not interested in the intensity of smoking.

Indications on data collection

Data should be collected by survey.

Standardisation

From the «Tobacco Country Profiles» (Corrao (2000). See annex 2) it is clear that data, currently available, is not really comparable. For this reason, in order to have the same standardised questionnaire for all European countries, we recommend an international harmonisation of approaches, methods and tools in current national surveys.
Moreover, about smoking definition EUROCHIP should refer to "Guidelines for controlling and monitoring the tobacco epidemic" (WHO 1998)

Variability within countries

Smoking habits can differ between the various areas or regions in each country.
The survey should be appropriately stratified.

Validity

Specific surveys (for example the Scottish Health Survey 1998), based on measurement of cotinine concentration in saliva, measured a relevant effect of the under-reporting on the prevalence of smokers among children.
We do not know if the level of under-reporting is similar in all European countries.

Bibliography

- Corrao MA *et al*. *Tobacco Control Country Profiles*. American Cancer Society, Atlanta, GA, (2000)
- WHO (1998). *Guidelines for controlling and monitoring the tobacco epidemic*. Geneva
- Currie, C. et al. (2000). *Health behaviour in school-aged children: a WHO cross-national study*. Health Policy for Children and Adolescent Series No. 1. Copenhaghen: WHO Regional Office for Europe
- Peto R *et al*. *smoking, smoking cessation, and lung cancer in the UK since 1950 combination of national statistics with two case-control studies*. BMJ: 321, 323-329 (2000)
- Tuyns *et al*. *Cancer of the larynx/hypopharynk, Tobacco and alcohol*. Int J Cancer: 41, 483-491 (1988)
- Berrino F *et al*. *A comp arative study of smoking, drinking and dietary habits in population samples in France, Italy, Spain and Switzerland. II Tobacco smoking*. Rev. Epidém. Et Santé Publ.: 36, 166-176 (1988)
- The Scottish Health Survey 1998: Volume 1: Chapter 8. http://www.show.scot.nhs.uk/scottishhealthsurvey/sh808-01.html

Suggestions to the European Commission

To recommend an international harmonization of approaches, methods and tools in current national surveys. To consider the possibility to organise specific surveys based on measurement of cotinine concentration in saliva.

1Pr.05c Tobacco survey: prevalence of ex-smokers

Indicator context

The indicator regards the percentage of the population aged 15+ reporting to have stopped smoking in the last 10 years subdivided by year span (1-4 and 5-9 years)

Indications on data collection

Data should be collected by survey.

Standardisation

In order to have the same standardised questionnaire for all European countries we recommend an international harmonization of approaches, methods and tools in current national surveys.

Variability within countries

Smoking habits can differ between the various areas or regions in each country.
The survey should be appropriately stratified.

Validity

No validity aspects recognised.

Bibliography

- Peto R *et al*. *smoking, smoking cessation, and lung cancer in the UK since 1950 combination of national statistics with two case-control studies*. BMJ: 321, 323-329 (2000)

Suggestions to the European Commission

To recommend an international harmonization of approaches, methods and tools in current national surveys

1Pr.05d Tobacco survey: prevalence of exposure to environmental tobacco smoke (ETS)

Indicator context

The indicator regards the percentage of the population reporting to be exposed to ETS (Environmental Tobacco Smoke) by place of exposure (work or school, public places or at home)

Indications on data collection

Data should be collected by survey.

Standardisation

In order to have the same standardised questionnaire for all European countries we recommend an international harmonization of approaches, methods and tools in current national surveys

Variability within countries

Smoking habits can differ between the various areas or regions in each country.
The survey should be appropriately stratified.

Validity

A lot of survey used the cotinine concentration in saliva to measure the level of ETS.

Bibliography

Suggestions to the European Commission

To recommend an international harmonization of approaches, methods and tools in current national surveys

1Pr.06 Exposure to sun radiation

Indicator context

The indicator refers to the proportion of persons reporting to be exposed to the suns radiation at work and during the leisure time.

Indications on data collection

Data should be collected by survey.
The questions could be similar to: “Are you habitually exposed to sun light in your occupational activity?” and “Are you frequently (weekly) exposed to UV (including sunbathing) in your leisure time?”

Standardisation

If current surveys do not provide requested information, an ad hoc survey should be carried out in order to have the same standardised statistics for all European countries whether or not periodicity is necessary to be defined at a later stage.

Variability within countries

No variability problems recognised.

Validity

A control study should be organise to validate the questions for the survey.

Bibliography

Suggestions to the European Commission

To organise a control study to validate the questions for the survey and, then, to recommend an international harmonization of approaches, methods and tools of current national surveys

1Pr.08 Indoor exposure to radon

Indicator context

It refers to the percentage of people living in houses with radon gas concentration above 200 Bq/m^3 and above 400 Bq/m^3

Indications on data collection

National survey.

In the 90s Each European country organised a survey to know the radon levels in dwellings in their territory. One of the results was the percentage of dwellings with a radon level over 200 Bq/m^3 and over 400 Bq/m^3

Standardisation

No standardisation aspects recognised.

Variability within countries

No variability problems recognised.

Validity

No validity aspects recognised.

Bibliography

- Bochicchio F *et al*. Radon in indoor air. Luxembourg, Office for Official Publications of the European Communities, 1995 (European Collaborative Action: Indoor air quality and its impact on man, No. 15)

Suggestions to the European Commission

To subsidise an ad hoc inquiry

1Pr.09 Prevalence of occupational exposure to carcinogens

Indicator context

The indicator refers to the prevalence of exposure to carcinogens (recognised by the "International Agency for Research on Cancer" in the classifications 1, 2A and 2B).

Indications on data collection

We recommend the updating and expansion of the present CAREX database.
This database, subsidised by the «Europe Against Cancer» Programme, estimated the occupational exposure in all European countries by agent and by industries for the period 1990-93.
By updating the already available database with the same methodology we could also study the changes to occupational exposure to carcinogens in the countries in the past 10 years.
We suggest improvement of the job-exposure matrix.

Standardisation

The standardisation problem will be a crucial point for the CAREX group in the updating of the database

Variability within countries

No variability problems recognised

Validity

No validity aspects recognised

Bibliography

- Kauppinen T, Toikkanen J, Pedersen D *et al*: *Occupational exposure to carcinogens in the European Union in 1990-93*. Finnish Institute of Occupational Health, Helsinki 1998

Suggestions to the European Commission

To subsidise the update and the expansion of the present CAREX database

1Pr.10a/10b Exposure to asbestos: mesothelioma incidence and mortality trends

Indicator context

The recent trends of mesothelioma or pleural and perithoneal cancers mortality and incidence (last 3-5 years) can be real proxies of the exposure to asbestos in the past.
They indicate either increasing, decreasing or even stable rates, thus indicating a different phase of the asbestos epidemic.

Indications on data collection

Mortality data is easily available for all the European countries from the WHO mortality database .
Incidence data is easily available from the EUROCIM database.
Collecting complementary information on country legislative actions is important.

Standardisation

By using age-standardised mortality rates (world standard) the indicator is comparable among European countries.

Variability within countries

The variability within countries might be relevant.

Validity

A special quality study on mesothelioma diagnosis is suggested.

Bibliography

Suggestions to the European Commission

Even very few cases in a limited area should be followed by a public action to find the asbestos source.
It is strongly recommended to integrate this exercise with the collection of reports from European Countries related to disposal of asbestos and asbestos products after the implementation of the 1999 European ban

2Ep.1 Population covered by high quality Cancer Registries

Indicator context

The indicator strictly refers to the population-based Cancer Registry areas. Due to specialized Cancer Registries, the indicator should be cancer site specific. To contain information on the evaluation of cancer registration in each country, it should present coverage by duration of registration, e.g. at least for 5, 10, 20 years.

Indications on data collection

The source is the "Cancer Incidence in 5 Continents".

Standardisation

No standardisation aspects recognised.

Variability within countries

No variability problems recognised.

Validity

We include the Cancer Registries present in "Cancer Incidence in 5 Continents" because this publication comprises only Cancer Registries considered to have a high quality of registration

Bibliography

- Parkin DM *et al* (1997). Cancer Incidence in Five Continents Vol VII. IARC Scientific Publications n° 143

Suggestions to the European Commission

No direct suggestions to the European Commission.

2Ep.5b Person-years of life lost due to cancer

Indicator context

Potential Years of Life Lost (PYLL) is a summary measure of premature mortality which provides an explicit way of weighting deaths occurring at younger ages, which are, a priori, preventable. The calculation for PYLL involve adding up deaths occurring at each age and multiplying this with the number of remaining years to live until up to a selected age limit.

We suggest to use the limit of the life expectancy at birth while the limit of 70 years has been chosen for the calculations in OECD Health Data.

In order to assure cross- country and time-wise comparison, the PYLL are standardised, for each country *i* and each year *t* as follows:

$$\sum_{a=0}^{l-1} (l-a)\frac{d_{at}}{p_{at}}\frac{P_a}{P_n} * 100000$$

where *a*=age, *l*=age limit, d_{at}=number of deaths at age *a*, p_{at}=number of persons aged *a* in country *i* at time *t*, P_a=number of persons aged *a* in the reference population, P_n=total number of persons aged *0* to *l-1* in the reference population.

Indications on data collection

The source should be the age-specific death statistics provided by the World Health Organisation.

Standardisation

The reference population should be the world standard population while in the OECD Health data the total OECD population in 1980 is taken as the reference population for age standardisation

Variability within countries

No variability problems recognised

Validity

No validity aspects recognised.

Bibliography

Suggestions to the European Commission

No direct suggestions to the European Commission.

2Ep.6a Stage at diagnosis: percentage of cases with early diagnosis

Indicator context

The indicator is the percentage of cancer cases classified as "localised" with the condensed-TNM by site, sex and age.

The expected value of this percentage is site dependent. For some sites (like lung) the expected value of the indicator is lower than 100%, but comparisons among countries are still informative.

Indications on data collection

The sources are the Cancer Registries routine registration statistics.
At the moment, the TNM data collection is not usual in the cancer registration. Sometimes, we have information on TNM classification for areas covered by organised screening programmes and only for the screening sites.

Standardisation

We recommend to use the condensed-TNM classification proposed by the ENCR (European Network of Cancer Registries).

Variability within countries

The variability within countries is relevant.

Validity

Cancer Registry data can be validated using specific studies such as the "EUROCARE High Resolution Studies".

Bibliography

- ENCR RECOMMENDATIONS. Condensed TNM for Coding the Extent of Disease
- Sant M, Capocaccia R, Coleman MP, Berrino F, Gatta G, Micheli A, Verdecchia A, Faivre J, Hakulinen T, Coebergh JWW, Martinez-Garcia C, Forman D, Zappone A and the EUROCARE Working Group: *Cancer survival increases in Europe, but international differences remain wide*. European Journal of Cancer 37: 1659-1667 (2001)
- Gatta G, Capocaccia R, Sant M, Bell CMJ, Coebergh JWW, Damhuis RAM, Faivre J, Martinez-Garcia C, Pawlega J, Ponz de Leon M, Pottier D, Raverdy N, Williams EMI, Berrino F: *Understanding variations in survival for colorectal cancer in Europe: a EUROCARE high resolution study*. GUT 47-4: 533-538 (2000)
- UICC. *TNM Classification of Malignant Tumours*. 4th Edition. 2nd revision 1992

Suggestions to the European Commission

To subsidise Cancer Registries in order to systematically collect data on TNM

2Ep.6b Stage at diagnosis: percentage of cases with a metastatic test

Indicator context

The indicator is the percentage of cancer cases with presence or absence of a detection test for metastasis. The treatment group defines these tests for specific cancer sites:

- **Cervix**: chest x-ray and pelvic imagine
- **Colon and rectum**: liver ultrasound or CT and chest x-ray
- **Prostate**: bone-scan
- **Lung**: CT thorax

Indications on data collection

The sources are the Cancer Registries specific studies on major cancer sites.

Standardisation

We recommend use of the condensed-TNM classification proposed by the ENCR (European Network of Cancer Registries).

Variability within countries

The variability within countries is relevant.

Validity

Cancer Registry data can be validated using specific studies such as the "EUROCARE High Resolution Studies".

Bibliography

- ENCR RECOMMENDATIONS. Condensed TNM for Coding the Extent of Disease
- Sant M, Capocaccia R, Coleman MP, Berrino F, Gatta G, Micheli A, Verdecchia A, Faivre J, Hakulinen T, Coebergh JWW, Martinez-Garcia C, Forman D, Zappone A and the EUROCARE Working Group: *Cancer survival increases in Europe, but international differences remain wide*. European Journal of Cancer 37: 1659-1667 (2001)
- Gatta G, Capocaccia R, Sant M, Bell CMJ, Coebergh JWW, Damhuis RAM, Faivre J, Martinez-Garcia C, Pawlega J, Ponz de Leon M, Pottier D, Raverdy N, Williams EMI, Berrino F: *Understanding variations in survival for colorectal cancer in Europe: a EUROCARE high resolution study*. GUT 47-4: 533-538 (2000)
- UICC. *TNM Classification of Malignant Tumours*. 4th Edition. 2nd revision 1992

Suggestions to the European Commission

Recommend that the clinician register information on detection tests for metastasis.
Subsidise Cancer Registries for High Resolution Studies

3Sc.1 Percentage of women that have undergone a mammography

Indicator context

This indicator shows the diffusion of the mammography examination among females age 40-49, 50-69 and 70-74 years. It considers the effects of both organised and opportunistic screenings

Indications on data collection

Data should be collected by survey and we need also information from regional programmes.
The question should refer to the last mammography and also to the year of this last mammography.
The question could be similar to: "When did you have the last mammography?"

Standardisation

No unresolved standardisation aspects recognised.

Variability within countries

No variability problems recognised.

Validity

No validity aspects recognised.

Bibliography

- IARC, ENCR (2000): Evaluation and Monitoring of screening Programmes.
- European Guidelines for Quality Assurance in Breast Cancer Screening. Luxembourg 2000, 3rd edition. ISBN 92-894-1145-7.
- IARC Handbook 7 (2000): Breast Cancer Screening

Suggestions to the European Commission

To recommend that the question on the mammography examinations should be included in the National Health Surveys.

3Sc.2 Percentage of women that have undergone a cervical cytology examination

Indicator context

This indicator regards the diffusion of the cervical cytology (or pap smear) examination among females aged 20-29, 30-59 and 60+ . It considers the effects of both, organised and opportunistic screenings during the last 3 to 5 years

Indications on data collection

Data should be collected by survey and we need also information from regional programmes.
The question should refer to the last citology and also to the year of this last citology (or pap smear). The question could be similar to: "When did you have the last cervical cytology or the last pap smear test?"

Standardisation

No unresolved standardisation aspects recognised.

Variability within countries

No variability problems recognised.

Validity

No validity aspects recognised.

Bibliography

- IARC, ENCR (2000): Evaluation and Monitoring of screening Programmes
- European guidelines for Quality Assurance in Cervical Cancer Screening Eur-J-Cancer 1993:29A(S4):S1-S38.

Suggestions to the European Commission

To recommend that the questions on the cytology examinations should be included in the National Health Surveys.

3Sc.3 Percentage of persons that have undergone a colo-rectal cancer screening test

Indicator context

This indicator shows the diffusion of the colo-rectal cancer screening tests (faecal occult blood examination, colonoscopy…) amongst the population aged 50-74. It considers the effects of both, organised and opportunistic screenings.

Indications on data collection

Data should be collected by survey and we need also information from regional programmes.
The question should refer to the last colo-rectal cancer screening test and also to the year of this test.
The question could be similar to: "When did you have the last colo-rectal cancer screening test (faecal occult blood examination, colonoscopy…)?"

Standardisation

No unresolved standardisation aspects recognised.

Variability within countries

No variability problems recognised.

Validity

No validity aspects recognised.

Bibliography

- IARC, ENCR (2000): Evaluation and Monitoring of screening Programmes
- European guidelines

Suggestions to the European Commission

To recommend that the questions on the colorectal cancer screening tests should be included in the National Health Surveys.

ANNEX 4: National evaluation in HMP of the organised screening process indicators

The «screening group» suggested that the process indicators of organised screening programmes' activities are included in HMP national evaluations.

The group specified the essential information necessary for this national evaluation:

Breast and colo-rectal cancer

Extension => Availability of the programmes in the population and coverage
Acceptance => Participation
Specificity => Recalled, benign operations (open surgical procedures)
Sensitivity => Detected by stage

Cervical cancer

Extension => Availability of the programmes in the population and coverage
Acceptance => Participation
Specificity => Recalled (anything non negative)
Sensitivity => Detected by CIN (histology) and invasive by stage

The indicators able to be calculated with this information are: volume, recall rate, detection rate, localized cancers, positive predictive value, specificity.

3Sc.4a Organised screening coverage

Indicator context

The indicator shows the coverage of the organised screening programmes.

Indications on data collection

Data could derive from the organised screening programme databases.

Standardisation

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Variability within countries

In countries without national organised screening it could be important to know the regional distribution of the indicator.

Validity

No validity aspects recognised.

Bibliography

- IARC, ENCR (2000): Evaluation and Monitoring of screening Programmes

Suggestions to the European Commission

No direct suggestions to the European Commission.

3Sc.4b Screening recall rate

Indicator context

The number of persons recalled for further assessment as a proportion of all persons who had a specific screening test.

Indications on data collection

Recall refers to the physical recall of the patient to the screening unit either because of a technical inadequacy (technical recall) or for the clarification of a perceived abnormality detected at the screening examination (recall for further assessment).

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Standardisation

No unresolved standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

- European Guidelines for Quality Assurance in Breast Cancer Screening. Luxembourg 2000, 3rd edition. ISBN 92-894-1145-7.
- European guidelines for Quality Assurance in Cervical Cancer Screening Eur-J-Cancer 1993:29A(S4):S1-S38.

Suggestions to the European Commission

3Sc.4c Screening detection rate

Indicator context

The number of cancers detected in the screening programme as a proportion of all the screening tests performed.

Indications on data collection

To calculate the overall detection rate, one should include cancers detected by screening round. Cancers detected in intermediate exploration should be assigned to a specific screening round.

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Standardisation

No unresolved standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

- European Guidelines for Quality Assurance in Breast Cancer Screening. Luxembourg 2000, 3rd edition. ISBN 92-894-1145-7.
- European guidelines for Quality Assurance in Cervical Cancer Screening Eur-J-Cancer 1993:29A(S4):S1-S38.
- "Data management in screening programmes" Publication as part of the project No EL 98/2/05191/PI/II.1.1.a/FPC of the Leonardo da Vinci programme-European Commission DG XXII co-ordinated by the Dept. of Hygiene and Epidemiology-Medical School University of Athens, eds Riza E, Linos A, Athens, 2001.

Suggestions to the European Commission

3Sc.4d Screening localised cancers

Indicator context

Proportion of localised cancers of the total screen-detected cancers.

Indications on data collection

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Standardisation

No unresolved standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

Suggestions to the European Commission

3Sc.4e Positive predictive value

Indicator context

The proportion of persons who have the cancer in question and who are screened positive.

Indications on data collection

In practice, the denominator refers to the patients recalled for further assessment following a positive screening examination.

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Standardisation

No unresolved standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

- European Guidelines for Quality Assurance in Breast Cancer Screening. Luxembourg 2000, 3rd edition. ISBN 92-894-1145-7.
- European guidelines for Quality Assurance in Cervical Cancer Screening Eur-J-Cancer 1993:29A(S4):S1-S38.
- "Data management in screening programmes" Publication as part of the project No EL 98/2/05191/PI/II.1.1.a/FPC of the Leonardo da Vinci programme-European Commission DG XXII co-ordinated by the Dept. of Hygiene and Epidemiology-Medical School University of Athens, eds Riza E, Linos A, Athens, 2001.

Suggestions to the European Commission

3Sc.4f Screening benign/malignant biopsy ratio

Indicator context

The ratio of pathologically-proven benign cases to the malignant ones surgically removed within the screening programme.

Indications on data collection

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Standardisation

No unresolved standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

- European Guidelines for Quality Assurance in Breast Cancer Screening. Luxembourg 2000, 3rd edition. ISBN 92-894-1145-7.

Suggestions to the European Commission

3Sc.4g Screening interval cancers

Indicator context

A primary cancer which has been diagnosed in the time interval between the most recent screening test which was negative for malignancy and the next screening test, or within the specified time interval for the next screening test in the case of the woman reaching the screening age upper limit.

Indications on data collection

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Standardisation

No unresolved standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

- European Guidelines for Quality Assurance in Breast Cancer Screening. Luxembourg 2000, 3rd edition. ISBN 92-894-1145-7.
- "Data management in screening programmes" Publication as part of the project No EL 98/2/05191/PI/II.1.1.a/FPC of the Leonardo da Vinci programme-European Commission DG XXII co-ordinated by the Dept. of Hygiene and Epidemiology-Medical School University of Athens, eds Riza E, Linos A, Athens, 2001.

Suggestions to the European Commission

3Sc.4h Screening specificity

Indicator context

The probability that a screening test correctly identifies people without the preclinical disease as negative.

Indications on data collection

It is calculated as the ratio of true negative screening tests to the total of true negatives and false positives.

The screening group gave the following definition of "organised screening programme": Population-based system with a structure for quality control and assurance including quantitative information on screening performance indicators of which absolutely necessary: target population, participation, recall (for any reason) and detected lesions, evaluation and training, addressing general population at average risk

Standardisation

No unresolved standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

- European Guidelines for Quality Assurance in Breast Cancer Screening. Luxembourg 2000, 3rd edition. ISBN 92-894-1145-7.
- "Data management in screening programmes" Publication as part of the project No EL 98/2/05191/PI/II.1.1.a/FPC of the Leonardo da Vinci programme-European Commission DG XXII co-ordinated by the Dept. of Hygiene and Epidemiology-Medical School University of Athens, eds Riza E, Linos A, Athens, 2001.

Suggestions to the European Commission

ANNEX 5: specification of the various phases of the disease history

The treatment group has recommended that Cancer Registries (for breast, prostate, colon, rectum, lung cancers) have to collect dates of 1st diagnosis, 1st surgery, 1st radiotherapy, 1st chemotherapy or 1st endocrine therapy (for breast and prostate)
These dates are necessary for the indicator "Delay of cancer treatment" so defined "Average difference between 1st diagnosis and 1st treatment (among surgery, chemotherapy, radiotherapy or other therapy)

The group tried to specific definitions for the dates of first diagnosis and of first treatment for 5 cancer sites: breast, colon, rectum, lung and prostate.

DATE	BREAST	COLON	RECTUM	LUNG	PROSTATE
First diagnosis	1st FNA (Fine needle aspiration) or 1st histological confirmation	1st histological confirmation or 1st biopsy	1st histological confirmation or 1st biopsy	1st histological or 1st cytological confirmation	1st histological confirmation
Surgery	1st Surgical resection or 1st neo-adjuvant therapy	1st surgical resection	1st surgical resection	1st surgical resection	1st radical prostatectomy or 1st other surgery
Radiotherapy	1st adjuvant radiotherapy		1st adjuvant radiotherapy	1st curative radiotherapy treatment	1st radical radiotherapy (external beam and/or brachytherapy)
Chemotherapy	1st adjuvant chemotherapy			1st chemotherapy treatment	
Other therapy	1st Adjuvant endocrine therapy				1st endocrine therapy

4Tr.1 Delay of cancer treatment

Indicator context

Phases of the disease history:

- Symptoms: there is not an event and for this reason it is not strictly defined on time
- First medical attendance: date on which patient reports his symptoms to the Health System (general practitioner, hospital ...)
- Diagnosis: date defined specifically site per site
- First treatment: date of the beginning of primary treatment defined specifically site per site .

The date of first symptoms is not intrinsically defined as an event and for this reason we suggest to use the date of the first diagnosis as a reference.

The treatment group suggests specific definitions for the dates of first and of first treatment for 5 cancer sites: breast, colon, rectum, lung and prostate.
To define these indicators, the Cancer Registries have to collect the dates of first treatment (with particular attention to surgery, chemotherapy, radiotherapy or endocrine therapy)

Indications on data collection

The sources are the Cancer Registries. For frequent cancer sites a sample of cases could be studied.
To define these intervals, Cancer Registries have to collect data in the form DD/MM/YYYY with consequent attention paid to the problem of privacy. However, the indicator is an average interval without any problem of privacy.

Standardisation

Pilot studies should be organised to determine the exact definitions of the dates for each cancer site.
For the first medical attendance, the date should be defined operationally.

Variability within countries

It is important to monitor different areas within one country. This includes those countries with a with a national cancer registration.

Validity

The time intervals are very short (months or fraction of months), so the intrinsic uncertainty of the dates can become a major problem.

Bibliography

- Sant M, Gatta G (1995): The EUROCARE Database. Survival of cancer patients in Europe. The EUROCARE Study. IARC Scientific Publications N° 132
- Coleman MP, Démaret E (1988): Cancer Registration in the European Economic Community

Suggestions to the European Commission

To subsidise pilot studies to define exactly the date of first diagnosis and first treatment for each cancer site considered (breast, colon, rectum, lung and prostate).

4Tr.2 Percentage of radio-therapy systems on population

Indicator context

The indicator refers to the number of linear accelerators on population. At present, it is an indicator for the degree of high-tech. According to the new technologies, this indicator will probably need to be changed in the next years.

Indications on data collection

Survey on health structures and services in which we have to ask about all linear accelerators, linear accelerators with multi-leaf collimator and linear accelerators installed within the last 10 years

Standardisation

The Linear Accelerators have to be working on 31st December of the year prior to the survey.

Variability within countries

In countries where the distribution is not uniform, the indicator should be given by regional areas.

Validity

No validity aspects recognised.

Bibliography

Suggestions to the European Commission

To subsidise a survey on health structures and services

4Tr.3 Percentage of diagnostic Computed Axial Tomographies (CTs) on population

Indicator context

The indicator refers to the number of diagnostic CT (Computed Axial Tomography or computed tomography scanners) systems. At present, it is an indicator for the degree of high-tech. According to the new technologies, this indicator will probably need to be changed in the next years.

Indications on data collection

Survey on health structures and services

Standardisation

The CT has to be working on 31st December of the year prior to the survey.

Variability within countries

In countries where the distribution is not uniform, the indicator should be given by regional areas.

Validity

No validity aspects recognised.

Bibliography

Suggestions to the European Commission

To subsidise a survey on health structures and services

4Tr.3 Percentage of Positron Emission Tomographies (PETs) on population

Indicator context

The indicator refers to the number of PETs (Positron Emission Tomography) systems. In the future this indicator should substitute the other indicators on resources.

Indications on data collection

Survey on health structures and services

Standardisation

The PET has to be working on 31st December of the year prior to the survey.

Variability within countries

In countries where the distribution is not uniform, the indicator should be given by regional areas.

Validity

No validity aspects recognised.

Bibliography

Suggestions to the European Commission

To subsidise a survey on health structures and services

4Tr.3 Percentage of diagnostic magnetic resonances on population

Indicator context

The indicator refers to the number of magnetic resonance systems. In the future this indicator should substitute the other indicators on resources.

Indications on data collection

Survey on health structures and services

Standardisation

The magnetic resonance has to be working on 31st December of the year prior to the survey.

Variability within countries

In countries where the distribution is not uniform, the indicator should be given by regional areas.

Validity

No validity aspects recognised.

Bibliography

Suggestions to the European Commission

To subsidise a survey on health structures and services

4Tr.6 Compliance with best oncology practice

Indicator context

The indicator is aimed at reflecting the compliance with best practices in oncology.
The Treatment Group of Specialists defined specific items to study for breast, colon, rectum, cervix and lung cancers.
The indicator should change in the future following the diffusion of new treatments and new guidelines.

As an example, Sant (2001) showed that in Southern Italy a very low proportion of breast cancer patients T1N0M0 were treated with conservative surgery while the majority received Hastled mastectomy's. This is a clear deviation from the guidelines, although was motivated by the lack of radiotherapy centres in the area.

Indications on data collection

The sources should be the Cancer Registries. We suggest specific studies on sample of cases in order to collect information on therapy and stage, such as the EUROCARE High Resolution Studies

Standardisation

Specific studies should be conducted using a common protocol and the analysis should be performed centrally with common criteria on guidelines. These criteria have to be defined .

Variability within countries

The differences are strongly relevant.

Validity

This indicator has a high specificity, but a low sensibility.

Bibliography

- Sant M, and the EUROCARE Working Group: *Differences in stage and therapy for breast cancer across Europe*. International Journal of Cancer 93: 894-901 (2001)
- Gatta G, Capocaccia R, Sant M, Bell CMJ, Coebergh JWW, Damhuis RAM, Faivre J, Martinez-Garcia C, Pawlega J, Ponz de Leon M, Pottier D, Raverdy N, Williams EMI, Berrino F: *Understanding variations in survival for colorectal cancer in Europe: a EUROCARE high resolution study*. GUT 47-4: 533-538 (2000)

Suggestions to the European Commission

To subsidise specific studies in the areas covered by Cancer Registries.
Cancer Registries have to do these studies, ideally, every 5 years with an annual report.

ANNEX 6: Various specifications from "Compliance with best oncology practice"

The treatment group suggested some items for different cancer sites:

- BREAST
  - Proportion of patients receiving post-operative breast radiotherapy after breast conserving surgery
  - Proportion of breast conservation surgery in pT1 cases (multiple cancers excluded)
- COLON
  - Proportion of patients with Dukes C (or TNM Stage 3) receiving adjuvant chemotherapy
  - Proportion of patients with Dukes B (or TNM Stage 2) not receiving adjuvant chemotherapy
- RECTUM
  - Proportion of patients receiving pre-operative radiotherapy
- LUNG
  - Proportion of patients with non small cell undergoing radical surgery
  - Proportion of patients undergoing staging with thoracic CT scanning
- CERVIX
  - Proportion of patients with FIGO-stage III/IV in cervical cancer receiving combined chemo-radiotherapy
  - Proportion of patients with FIGO-stage "Ia2" and "Ib" in cervical cancer undergoing hysterectomy with pelvic lymphonodatectomy (WERTHEIM-MEIGS hysterectomy)

5Mv.08 Anti–tobacco regulations

Indicator context

The indicator refers to the description of the anti-tobacco regulation regarding smoking at school, in hospital, at work place, on public transports, in public areas, sales to children/teenagers, taxes, advertising and sponsorship.
It is a multiple-indicator indicating presence or absence (Y/N) of a set of specific laws on anti-tobacco regulation. These laws should refer to:

- restrictions in public places
- prohibition in hospitals, school (or universities) and and on public transports
- on-pack warnings
- indications of nicotine on pack
- limits on tar content
- employees protection law (ETS)
- prohibition of TV and radio advertising
- prohibition on national airline flights
- sales to children/teenagers
- tobacco smoke labeled as a carcinogen

Indications on data collection

Information is already collected by "Tobacco country profiles" (Corrao 2000)

Standardisation

No standardisation aspects are recognised

Variability within countries

No variability problems are recognised

Validity

No validity aspects are recognised

Bibliography

- Corrao MA *et al*. *Tobacco Control Country Profiles*. American Cancer Society, Atlanta, GA, (2000)

Suggestions to the European Commission

5Mv.09a Public expenditure for cancer prevention on anti-tobacco activity

Indicator context

The indicator refers to public expenditure on every action aimed at reducing smoking.
Specifically, the indicator refers to:
−1 campaigns against smoking initiation
−2 facilities for treatment of smokers, including training of health professionals in smoking cessation techniques
−3 free nicotine-replacement therapy
−4 special attention to smoking during pregnancy
We have to define exactly the boundaries of expenses to be included in the indicator.

Indications on data collection

Health ministries and local administrations.

Standardisation

The quality of the measurement of public expenditure is expected to vary between European countries.

Variability within countries

No variability problems recognised.

Validity

The indicator is not exhaustive on the real expenses spent on reducing smoking. Some countries should subsidise campaigns aimed at changing general lifestyles, not solely against smoking.

Bibliography

Suggestions to the European Commission

To subsidise a survey to ministries and/or regions.

5Mv.09b Total expenditure for population-based Cancer Registries

Indicator context

The indicator refers to the total expenditure devoted to supporting population-based cancer registration.
The expenditures should solely refer to the operational costs (permanent support for the registry to operate).

Indications on data collection

Survey on Cancer Registries

Standardisation

The expenditure should be underestimated.
The robustness of the data depends upon economical validation systems.
The survey has to refer to the previous year

Variability within countries

The variability may exist and may be relevant

Validity

No validity aspects recognised

Bibliography

Suggestions to the European Commission

To subsidise a survey on Cancer Registries

5Mv.09c Total expenditure on organised cancer screening programmes

Indicator context

The indicator refers to the total expenditure devoted to supporting organised cancer screening programmes Subdivided by site.

Indications on data collection

European Breast Cancer Network

Standardisation

No standardisation aspects recognised

Variability within countries

The variability may exist and may be relevant. The costs could be different between town and country.

Validity

No validity aspects recognised

Bibliography

Suggestions to the European Commission

To subsidise a survey on EBCN

5Mv.09e Total Expenditure on cancer research

Indicator context

The indicator refers to national (governmental) public expenditure on cancer research and to the expenditure on cancer research by charity organisations reviewing research projects and controlling fund requests.

The indicator does not include grants and subsidising from International Institutes, European Commission, etc

Indications on data collection

Ministries of health and/or research and survey cancer charity organisations reviewing research projects and controlling fund requests.

Standardisation

In some situations the expenditure on cancer research is not well defined within a general expenditure for research.

Variability within countries

No variability problems recognised

Validity

No validity aspects recognised

Bibliography

Suggestions to the European Commission