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EUROPEAN HEALTH CARE OUTCOMES,
PERFORMANCE AND EFFICIENCY

EuroHOPE Breast Cancer: Material, Methods and Indicators

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Introduction and objectives

Breast cancer is the most common cancer in women and a significant cause of premature mortality amenable to healthcare intervention. It also occurs in men but occurs much less frequently. Previous studies have identified inter-country variation in survival but it has been difficult to obtain comparable data to analyse the impact of different patient characteristics and organisation of health care on access to and use of services as well as the outcomes such as survival and quality of life. This study will compare performance across countries against agreed standards, benchmarking outcomes, quality and costs. This will enable clinicians and policymakers to learn from best practice and will provide insight into the similarities and differences in health policy in relation to cancer and how it is enacted in different healthcare systems.

The objectives for EuroHOPE Breast cancer were:

- To define comparable patient care episodes for the diagnosis and treatment of breast cancer among women and for the analysis of process measures and outcomes of care.
- To develop agreed inclusion /exclusion criteria, definitions of the patient care episode including entry criteria), and risk adjustment, including measurement of co-morbidity.
- To produce national and / or regional level indicators for access and utilisation of services, treatment practices, costs and outcomes (each country can analyse lower level [iesubregional] data at their own discretion)
- To establish a pilot study on Health Related Quality of Life and patient experience in selected health systems in participating countries that builds on use of existing validated instruments
- To produce a report on care of breast cancer patients at national and regional levels in the participating countries. This included information on patients (number of patients, age structure, co-morbidity), disease course (disease severity), indicators on content of care (use of services and procedures, costs, treatment practices, process indicators) and indicators of outcomes.

This paper defines specific protocols for international comparisons that were based on the data of hospital discharge registers, mortality registers, and cancer registers. The protocol has been used in preparing both national Breast Cancer databases for each country and for an international

comparative Breast Cancer database which is produced from the national Breast Cancer databases. The comparative database has been used for basic reporting on care of Breast Cancer patients, and for research on reasons behind differences in performance. The protocol described in this paper defines how we have produced indicators at national and (within country) regional levels.

Definition of national databases

Definition of Breast Cancer: Breast cancer is recognised as a group of conditions that may present with symptoms, be found on physical examination undertaken for another purpose or detected following screening. Breast cancer is categorised by the International Agency on Research for Cancer as (IARC) as:

Invasive carcinoma: Invasive carcinoma of the breast is defined as a malignant tumour, part or allof which penetrates the basement membrane of the epithelial site of origin (i.e. the duct or lobule).

Invasive breast cancer can be identified using ICD-9 code 174 and ICD 10-code C50.

Carcinoma *in situ:* Two non-invasive forms of breast carcinoma in situ were recognized: DCIS and lobular carcinoma in situ (LCIS). Each arises from its respective epithelial cell population in the lobule or duct of the normal breast. However, the neoplastic cell population is confined within the parenchymal site of origin, and the cells do not infiltrate beyond the limiting basement membrane. **Breast cancer in situ** is defined using ICD-9 233.0 and ICD-10 D05 codes.

Definition of breast cancer stage and grade (see data description for more details)
Breast cancer stage is based on

1. Tumour size, whether invasive or non-invasive, lymph node involvement and metastatic spread.
2. The TNM staging system Classification (TNM Classification of Malignant Tumours, Sixth Edition, 2002)
   Grade is based on histological appearance

Screen detected cancers
Countries with data available categorised women as screen detected or symptomatic and compare health care use costs and outcomes for the different groups.

Development of linked databases of comparable summary data

Each country developed a **national breast cancer research database**. The database included all women with breast cancer registered from 2000-2009 (or a subset of this period) who were aged 25 years or over at the time of the first recorded episode of care or death from breast cancer. The age criterion is arbitrary but breast cancer is very rare under this age. The primary databases used were cancer registries, national hospital discharge data and mortality registers. The section below identifies the data sources from each project partner that were used to create datasets from each country. Patient information from different sources were linked using personal identification numbers or probabilistic linkage using person identifiers.

Data sources included were:

Scotland

- National hospital discharge database (SMR – Scottish Morbidity Records) 2000 - 2009
- National cancer register 2000 - 2009
- National mortality register 2000 - 2009

Other data sources

In addition, we explored the feasibility of linking data from national or regional breast cancer audit data and from the breast cancer screening programme

There were no national data available from outpatient services in primary care or from other institutions. Prescribing data may become available during the project.

Norway

- Hospital discharge data 2008-2010
- Cause of death register 1999-2010
- National cancer register 1999-2010

Other data sources

- Outpatient data from 2008-2010
- Possibly drug utilisation data for 2004-2010

Finland

- Hospital discharge register 1987-2009
- National mortality register 2000-2009
- National cancer register 2000-2009

https://cancer-fi.directo.fi/syoparekisteri/en/registration/forms-and-instructions/

  - name and PID,
  - municipality of residence,
  - primary site and date of diagnosis,
  - basis of diagnosis,
  - stage: localised, regional metastases, distant metastases,

- malignancy: malignant, in situ,
- histology/cell type,
- treatment: surgery, radiotherapy, cytotoxic drugs, hormones, other; specific codes for curative/palliative surgery or radiotherapy; specific codes for primary treatment and later treatment,
- follow-up: date of death or emigration, cause of death.

Other data sources

- Outpatient services in specialist care / hospitals: Hospital register on outpatient visits in hospitals 2000-2009
- Outpatient services in primary care: Data for outpatient visits and outpatient services for older people from Helsinki, Espoo and Vantaa (for validation purposes) 2006-2009
- Data from other institutions (nursing homes etc.):2000-2009
- Drug utilisation: Registers of Social Insurance Institution (outpatient drug utilization (and use of private services) 2000-2009

Hungary

- Hospital discharge register 2004 -2009
- National mortality register: 2004 -2009 (dates only, not cause unless death in hospital)
- National cancer register 2004 -2009

Other data sources

- Outpatient services in specialist care / hospitals 2004-2009
- Data from other institutions (nursing homes etc.): hospital discharge data include also long term care, inpatient rehabilitation
- Drug utilisation: National dataset of outpatient drug utilization 2004-2009

There were no data available from Outpatient services in primary care or from quality of care registers

Italy

National data were not available so datawere provided from Liguria (1.6 million people) and two Italian provinces (Torino 2.2. million people and Rome 3.7 million people)

- Hospital discharge register 2003-2009
- National mortality register 2006
- Regional cancer registries 2006

Other data sources

- Outpatient services in specialist care / hospitals: 2004-2009
- Drug utilisation: national dataset of outpatient drugs; possibility of linking data with individual unique identification code only through regions 2004-2009

There were no data available from Outpatient services in primary care or from quality of care registers

Netherlands

Not taking part in the breast cancer work package

Sweden

- Hospital discharge register:2000-2009
- National mortality register: 2000-2009
- National breast cancer registers 2000-2009

Other data sources

- Outpatient services in specialist care / hospitals: National register on outpatient visits 2001-2009 (but data quality not good 2001-2003)
- Outpatient services in primary care: available for Stockholm County Council 2000-2009 (data quality not good 2000-2005)
- Drug utilisation: National register on drug utilization 2005-2009
- National breast cancer database for 2007
- Lund University Biobanking and cancer research (Swedish biobanking program)

There were no data available from other institutions.

Definitions to attain comparable data and episodes

We defined the "total episode of care" to extend from the date of diagnosis (or from the earlier date of referral where this is possible) to a point 2 years after diagnosis or to death, whichever was sooner. Full date may not be available and, where for example only month of diagnosis was known, diagnosis was assumed to have taken place on 15th of the month. This episode of care is shown in Figure 1 of the Data Description. It includes the following elements:

- Date and type (primary care/ screening) of first patient presentation (where available)
- Date of diagnosis of breast cancer
- Pre hospital treatment
- Hospital admission(s) or care episode(s)
- Hospital treatment procedure(s)
- Post discharge chemotherapy, radiotherapy and / or endocrine therapies
- Hospital episode(s) for reconstructive surgery

The total episode of care can start with either symptomatic patients seeking care or asymptomatic patients detected by breast screening programmes. However as the date of screening, attendance at primary care, referral to secondary care etc may not be available in all countries the date of diagnosis of breast cancer was used as the starting point for most analyses. We proposed that the total episode of care end at 2 years after diagnosis (or death) as we consider that this included all major care elements for the primary episode. We were aware that some patients receive endocrine therapy for many years after this but do not consider that it was possible to study this within the context of this project.

Exclusion criteria

The following exclusion criteria were applied:

- Women under 25 years of age at presentation of breast cancer,
- those with no unique ID (for example tourists and non- residents).
- Recurrence of breast cancer of same histology/ laterality first diagnosed before start of data collection

Risk adjustment (Case mix standardisation)

Case mix standardisation was used when comparing countries, regions, or years. Variables which were considered potential prognostic factors (and thus confounders) were used for adjustment. These were derived from primary and secondary diagnoses of previous discharge data and data on previously prescribed medicines. We used

- Age
- Stage of disease
- comorbidity as defined in the Appendix and also days in hospital during previous 365 days

Statistical methods for risk adjustment were developed in WP2 . This included e.g. how different factors were specified (i.e. age groups and interactions between the variables), statistical and practical relevance of variables as well as the models used in risk adjustment.

Descriptors of content of care (use of services and procedures, costs, treatment practices, process indicators).

We used the following indicators:

- Surgery (see data description for more details)
- Length of first hospital stay (i.e. index admission) based on definition described above
- Hospital days during follow-up
- Hospital days because of breast cancer (i.e. breast cancer identified as main diagnosis) during two years follow up.
- Cost of first hospital admission, first hospital episode, and all hospital care during follow-up

Each country defined how these were coded and provided the information (see table below). We asked clinical experts to evaluate whether they were comparable between the countries. This was based on definitions used by existing studies where possible.

The measurement and analysis of cost was developed in WP2 of the EuroHOPE project.

Measurement of Outcome

We used the following indicators (described in more detail in the data description at the end of this document):

- Mortality/ survival at 30 days post-surgery, 1, and where possible 5 years, from diagnosis using all-cause mortality and breast cancer mortality
- New breast cancer developing during follow-up (defined as breast cancer with different histology or different laterality from index cancer, which may be related to radiotherapy for first cancer) (www.ic.nhs.uk/webfiles/Services/.../appendixfor**breast**cancer.doc)
- Readmission to hospital during follow-up and description of reason for readmission (including primary diagnosis of breast cancer, side effects of treatment)

Information Governance and Data Protection

The information governance arrangements followed the detailed regulations established by each country to comply with data protection legislation and the requirements of ethics and other approval committees. Only named members of the project team in each country had access to de-identified data.

Data gathering

Where it was necessary to create new datasets, data were extracted from source registers by staff authorised to work with patient identifiable data and trained to standards required by their national statistical and health bodies to comply with Data Protection legislation.

Data linkage

Where necessary, additional data linkages were undertaken by staff authorised to do so, for example, those authorised by a proper statistical authority. Data were linked by unique patient identifier, supplemented where necessary against checks using gender, date of birth, area of residence and treatment centre.

Encryption and anonymisation

Once extracted and, where appropriate, linked, the unique patient identifier (in Scotland the CHI number) were encrypted. The key that links the encrypted and unencrypted unique patient identifier CHI were held securely. A randomly allocated study ID was then assigned to each record. The key that links the study ID and the encrypted CHI were held separately and securely in facilities authorised for this purpose.

Data Storage

Data were stored on secure servers in the country of origin and de-identified data extracts produced to answer specific research questions only.

Data Transfer

De-identified data were transferred using only secure routes such as secure file transfer protocol

Identification of adverse outcomes

Should the analysis indicate any concerns regarding the quality of clinical care, for example compliance with guidelines or unexpectedly high mortality rates, these were discussed with the clinical experts and a report outlining the concerns produced for the research governance body in the relevant country in line with their regulations.

Data collection and analysis

The Table indicates which of the following variables were available at individual patient level (Y=yes, N=No,DK = don't know or specific codes as indicated):

Definitions and categories of the following variables are in appendix A tick in the column indicates that the data were available in each country	Scotland	Norway	Finland	Hungary	Turin	Netherlands	Sweden
Type of presentation (S screening, P primary care, H hospital D diagnosis)	S,P, H, D	S,H	N	HD	N	S,P, H	S
Date(s) of first presentation if not diagnosis	Y	N	N	N	N	Y	N
Age(s) at first presentation if not diagnosis	Y	N	N	N	N	Y	Y
Date(s) of diagnosis	Y	Y	Y, Month	Y	Y	Y	Y
Age(s) at diagnosis	Y	Y	Y	Y	Y	Y	Y
Co-morbidity identified from hospital admissions in year prior to diagnosis (see below for EUROHOPE classification)	Y	Y	Y	Y (after 2004)	Y	DK	Y
Socio-economic status (if available – please give information) Area-based measure, Scottish Index of Multiple Deprivation, derived from postcode in Scotland	Y	DK,No index, but education , income, marital status	N	on basis of postal code	Y, based on both individual and area characteristics	on basis of postal code	??
Tumour pathology							
Screen/symptomatic detection	Y	Y	N	Y (szövettan, clinical, imaging, endoscopy, exploratio, etc.)	Y	Y	Y
Cancer type (Invasive (I)/In situ (IS) etc)	I, IS	I, IS	I, IS	I, IS	I,(no insitu data)	I,IS	I/IS

Size of tumour	Y	Y –not for T3/T4	Y, classified	N (only T status)	Y (32% missing)	Y	Y
Invasive type	Y	DK	DK	Y (organs near, organs far, systemic, spread to lymph node)	Y	Y	Y
TNM stage (or stage)	Y	Y – some missing data	Y-TNM missing to be obtained	Y (reliable?)	Y (frequently missing)	Y	Y
Stage type (C=clinical, P=pathological)	C, P	DK	DK	C	Some missing data	C,P	Y
ER/PgR status	Audit	Y	N	N	Some missing data	Y	no
HER2 status	Audit	Y	N	N	DK	Y	no
Nodal involvement	N	DK	DK	Y	Y (from hospital discharge, not complete in the register)	Y	Y
Treatment							
Diagnostic procedures	Y		Y	Y	Y	Y	Y
Surgery type	Y	Y	Y	Y	Y	Y	Y
Axillary surgery	Y	Y	Y	Y	Y	Y	Y
Re-excision	Y	Y	Y	Y	Y	Y	Y
Date of first surgery	Y	LIMITED	Y	Y	Y	Y	Y
Date of final surgery	Y	LIMITED	Y	Y	Y	Y	Y
Radiotherapy	Y	N	Y	Y	Y	Y	Y
Date of start of radiotherapy	Y	N	Y (approximately)	Y	Y	Y	?
Date of end of radiotherapy	Y	N	Y (approximately)	Y	Y	Y	?
Chemotherapy	Y	Y	Y (but not reliable)	Y	DK	Y	Y
Type of chemotherapy	? Audit	Y	Y (but not reliable)	Y	DK	Y	?
Date of start of chemotherapy	Y	LIMITED	N	Y	DK	Y	?
Date of end of chemotherapy	Y	LIMITED	N	Y	DK	Y	?
Hormone therapy – preoperative (including type and	? Audit	N	N	Y (from pharma database)	DK	Y	Y

duration)							
Hormone therapy – postoperative (including type and duration)	? Audit	N	Y (not reliable)	Y (from pharma database)	DK	Y	Y?
Reconstructive surgery	Y	Y	Y	Y	Y	Y	Y
Follow up							
Hospital admissions/discharge following diagnosis	Y	Y	Y	Y	Y	N	Y
Death (D=date, C=cause)	D,C	D,C	D, C	D, C (only in-hospital death)	D,C	D,C	D,C
Data in the following section is to be delivered on an episode by episode basis							
Timing							
Indicator of continuous stay	Y	Y (limited)	Y	Y	Y	N	Y
Date of start of hospital episode	Y	LIMITED	Y	Y	Y	N	Y
Date of end of hospital episode	Y	LIMITED	Y	Y	Y	N	Y
Codes for procedures during episode (see below for details)	Y	Y	Y	Y	Y	N	Y
Complications & recurrence (ICD10 codes)							
Post-surgical complications	Y	Y	Y	Y (depends on definition)	Y	N	Y
Recurrence type	Poor	N	N	Y (we do not know for sure that the tumour was eliminated beforehand)	DK	N	Y
Date of recurrence	Poor	N	N	Y	DK	N	Y
Metastases (location)	Poor	limited	N	Y	N	N	Poor

In addition, population data by sex and age group (and socio-economic status if available) for each year for which data were provided where required.

The following summary statistics were produced, for each year available and overall:

Study Population

- Descriptive statistics of the study populations including demographic, clinical, pathological and treatment data (mean/median and standard deviation or percentage, as dictated by the data), by age group and sex.

Cancer incidence

- **Incidence of new cancers** by cancer type per 100,000 population, crude and Europe/World standardised (new cancer as defined by a first cancer [of a specific histology and laterality] which does not meet the case definition of recurrence)

Surgical outcomes

- Rates of defined **complications within 30 days after surgery(re-admission or mortality within 30 days of date of surgery)** by age, sex, type of tumour and treatment (if there were sufficient events)

Cancer outcomes

- Crude and age standardised (to the European/World standard population) **1, and 5 year mortality and survival** rates

Health services outcomes

- Duration of **first hospital episode** (mean/median & standard deviation) [see Figure 1 and related episode definition]
- Duration of **total episode of care** (i.e. date of end of final treatment [defined as latest of last surgery for treatment not reconstruction, last date of radiotherapy or last chemotherapy] – date of first presentation) (mean/median & standard deviation) [see Figure 1 and related episode definition] **OR** 2 years from diagnosis where data were vague
- Cost of first hospital episode and total episode of care to final treatment

APPENDIX: Data description for Breast Cancer

APPENDIX A. General definitions and abbreviations for EuroHOPEbreast cancer

Total episode of care	The entire treatment patternfrom the beginning of the disease (which could be defined for breast cancer either at the point of referral to specialist services or date (may only be month and year) of diagnosis to the end of the treatment (defined as the latest of date of last surgery for treatment [excluding reconstruction surgery], date of last radiotherapy session or date of last chemotherapy session) or a maximum 2 year period [regardless of whether hormone therapy continues]. See figure 1.
First hospital episode	Hospital(includes also health care centre hospitals)inpatient treatment beginning on the index day including also possible discharge to another hospital and terminating on the first discharge home, death, or after one year of continuous inpatient care. See figure 1.
HDR	Hospital discharge register
Index admission	Thefirst hospital admission during the episode.
Index day	Admission day of the index admission.
LOS_index	Length of stay = (discharge day – index day) + 1LOS_all Total stay in hospital, including inpatient stays (overnight) and outpatient treatment (in and out on the same day)
Recurrence	Local recurrence occurs when cancer returns at the original tumour site over time Regional recurrence occurs when cancer spreads beyond the breast and lymph nodes ie breast cancer in chest muscles, internal mammary lymph nodes under breastbone and between ribs, or nodes in collarbone or surrounding the neck Distant recurrence refers to metastasis usually to the bone, more rarely to other sites (lungs, liver, brain or other organs)
Stages	**Stage 0**: Carcinoma in situ (DCIS, LCIS and Paget's Disease) **Stage 1a:** the tumour is 2cm or smaller and has not spread outside the breast **Stage 1b:** small areas of breast cancer cells are found in the lymph nodes close to the breast and either • No tumour is found in the breast **or** • The tumour is 2cm or smaller

Stage 2a: there is no tumour or a tumour 2cm or smaller in the breast and cancer cells were found in 1 to 3 lymph nodes in the armpit or in the lymph nodes near the breastbone **or** the tumour is larger than 2cm but not larger than 5cm and there is no cancer in the lymph nodes

Stage 2b: The tumour is larger than 2cm but not larger than 5cm and small areas of cancer cells are in the lymph nodes **or**

- The tumour is larger than 2cm but not larger than 5cm andthe cancer has spread to 1 to 3 lymph nodes in the armpit or to the lymph nodes near the breastbone **or**
- The tumour is larger than 5cm and has not spread to the lymph nodes

Stage 3a: No tumour is seen in the breast or the tumour may be any size and cancer is found in 4 to 9 lymph glands under the arm or in the lymph glands near the breastbone **or**

- The tumour is larger than 5cm and small clusters of breast cancer cells are in the lymph nodes **or**
- The tumour is more than 5cm and has spread into up to 3 lymph nodes in the armpit or to the lymph nodes near the breastbone
-

Stage 3b: The tumour has spread to the skin of the breast or to the chest wall, and made the skin break down (an ulcer) or caused swelling – the cancer may have spread to up to 9 lymph nodes in the armpit or to the lymph glands near the breastbone

Stage 3c: The tumour can be any size, or there may be no tumour, but there is cancer in the skin of the breast causing swelling or an ulcer and it has spread to the chest wall. It has also spread to

- 10 or more lymph nodes in the armpit
- Lymph nodes above or below the collar bone
- Lymph nodes in the armpit and near the breastbone

Stage 4: in stage 4 breast cancer

- The tumour can be any size
- The lymph nodes may or may not contain cancer cells
- The cancer has spread (metastasised) to other parts of the body such as the bones, lungs, liver or brain

It was considered sufficient to record only the stage number (eg stage3) and not all the divisions. (Definitions taken from the CRUK website http://www.cancerresearchuk.org/cancer-help/type/breast-cancer/treatment/number-stages-of-breast-cancer).

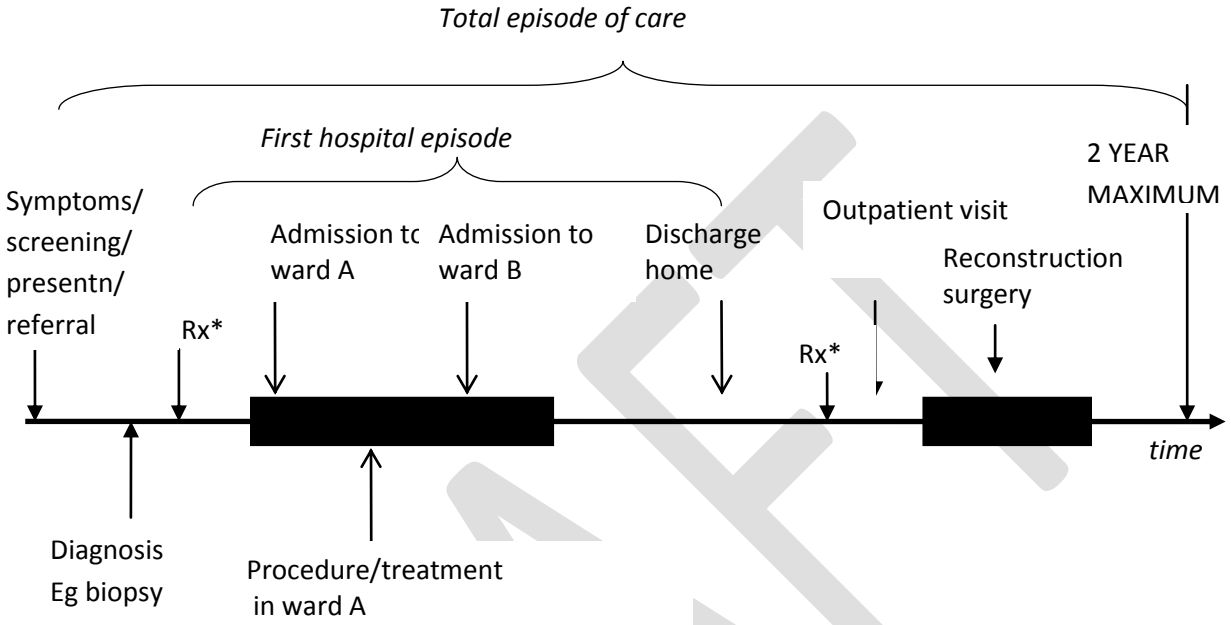
Pathological staging is based on the pathologist's study of the excised tissue and lymph nodes. Clinical staging is based on the clinicians examination and physical tests such as mammography. Pathological is the preferred method.

Grade

Grade 1 (low-grade) – The cancer cells look similar to normal cells and grow very slowly.
Grade 2 (moderate- or intermediate-grade) – The cancer cells look more abnormal and are slightly faster growing.

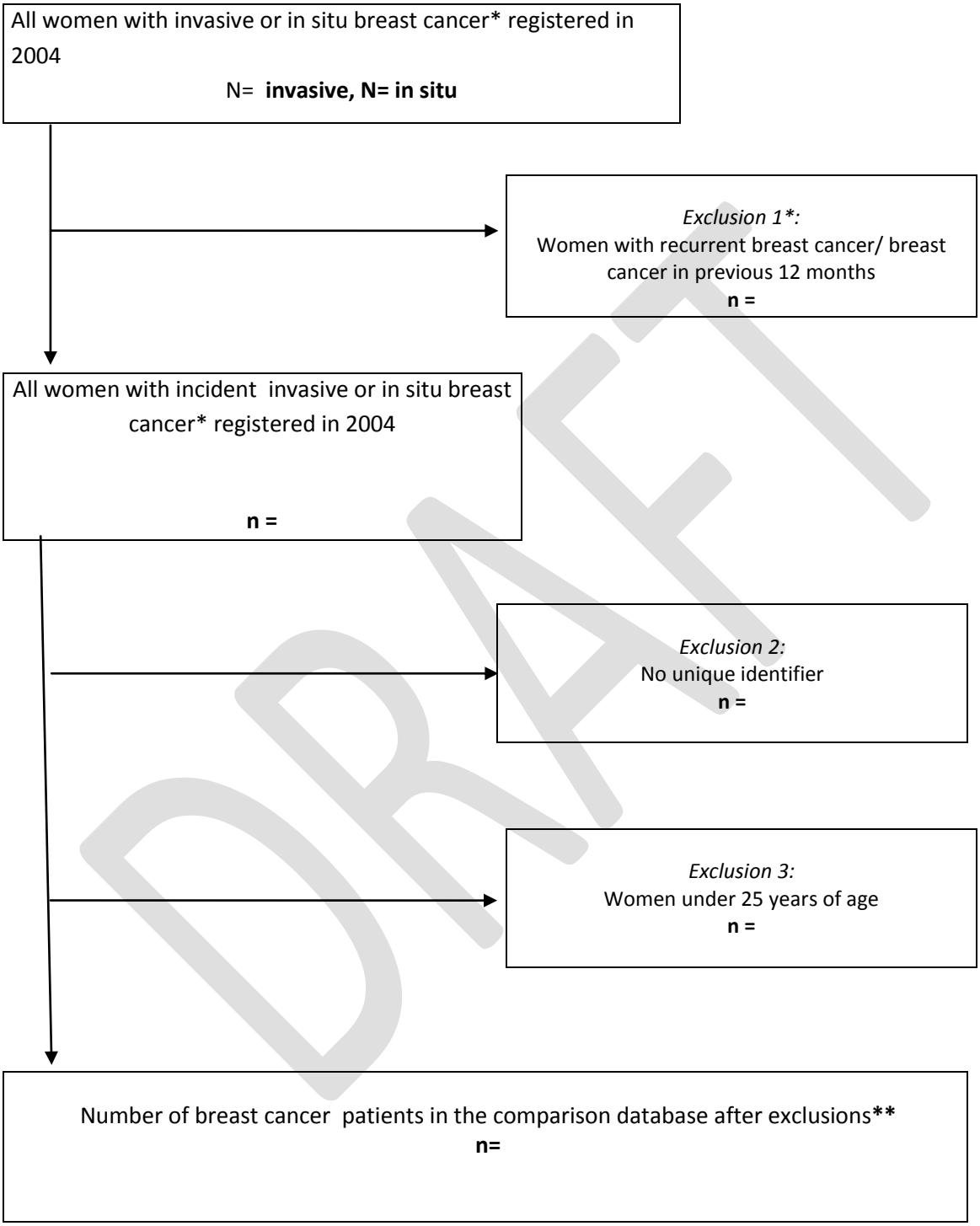
Grade 3 (high-grade) – The cancer cells look very different from normal cells and tend to grow quickly.

APPENDIX B: Events within an episode of care for breast cancer (Figure 1.)



*Rx – treatment might include hormonal treatment, chemotherapy or radiotherapy

APPENDIX C: Creation of the Scottish comparison database for breast cancer for 2004 in first instance (the complete database will be for 2000-2009) (Figure 2.)



*** defined using ICD codes** (ICD-9 codes 174 / ICD 10-code C50) for invasive breast cancer and (ICD-9 233.0/ ICD-10 D05) for in situ breast cancer.

APPENDIX D: Coding of co-morbidity (derived from other EUROHOPE documents)

Co-morbidity	ICD-9*	ICD-10*	ATC-code*
Hypertension	40	I10 to I15	C03, C07 (if no coronary heart disease or atrial fibrillation), C08, C09
Coronary heart disease	410 to 414	I20 to I25	
Atrial fibrillation	4273	I48	
Cardiac failure	428	I50	
Diabetes	250	E10 to E14	A10A, A10B
Alcoholism/drug abuse	291, 304, 305	F10 to F19	
Peripheral artery disease	440	I70	
Cancer	140-208	C00 to C99, D00 to D09	L01 except for L01BA01
COPD and asthma	4912 , 496 , 493	J44 to J46	R03
Dementia	290, 3310	F00 to F03, G30	N06D
Depression	296.2, 296.3	F32 to F34	N06A
Parkinson's disease	332	G20	N04B
Mental disorder	295 to 298 except for 2962 and 2963	F20 to F31	N05A except for N05AB01 and N05AB04 and no dementia

- * Abbreviations: ICD-9, International classification of diseases Finnish version 9 (years 1986-1995); ICD-10, International classification of diseases Finnish version
- 10 (years 1996 onwards); ATC, Anatomical Therapeutic Chemical Classification System

APPENDIX E. Preliminary list of Indicators

National and Regional level

Basic information on patients – for single year, 2004

- Age distribution of incident cases by invasive and in situ cancers
- Incidence of all invasive + in situ breast cancers per 100,000 population, (directly age and sex standardised to the European standard population)

Indicators of content of care

- Mean length of first hospital stay:
- Mean number of hospital days during two years follow-up from diagnosis
- Mean number of hospital days because of breast cancer during two years follow up
- Cost of first hospital admission and hospital care within one and two years after diagnosis : in local currency , Euros (using exchange rate /or PPP)
- Number of patients receiving specific procedures: diagnostic tests, chemotherapy, radiotherapy, types of surgery (total mastectomy) reconstruction given to patients stratified by first month, three months, six months and 12 months after first presentation for diagnostic tests and by first month, three months, six months and 12 months after diagnosis for treatments
- Construction of patient pathway with location and costs of care

Indicators of outcomes

- Mortality/ survival at 30 days post-surgery one year, (and five years where available)
- Readmission (and primary diagnostic codes) within 30 days, one year, and five years (if available)

APPENDIX F: Procedure codes for breast cancer (source of OPCS-4 codes used in Scotland):*http://www.ic.nhs.uk/webfiles/Services/Datasets/cancer/appendixforbreastcancer.pdf)*

Diagnostic procedures

Procedure	OPCS-4 code	Norway and Sweden	Finland	Hungary
Clinical FNA (Aspiration of lesion of breast)	B37.1	THA99	HA2XT	18590
Guided FNA (Percutaneous approach to organ under image control) For radiological, add into second position For ultrasonic, add into second position For CAT scan, add into second position	B37.1 Y53.1 Y53.2 Y53.3		HA2DT	18592 81553
Clinical Core Biopsy Percutaneous biopsy of lesion of breast Biopsy of lesion of breast	 B32.1 B32.2	 HAA10	 THA00 HAA10	
Guided core biopsy Percutaneous biopsy of lesion of breast Biopsy of lesion of breast For radiological, add into second position For ultrasonic, add into second position For CAT scan, add into second position	 B32.1 B32.2 Y53.1 Y53.2 Y53.3	 HAA10/THA10	HA1AT -with ultrasound guidance HA1DT - with MRI guidance HA1MT - with X-ray guidance HA1ST - with sterotacticguidanc	14821 14824

			e Use of cat scan very rare in Finland	

Main surgical procedures

Procedure	OPCS-4 code	Norway and Sweden	Finland	Hungary
Simple mastectomy	B27.4	HAC25/HAC99	HAC20 Total mastectomy HAC99 Other mastectomy	58610
Subcutaneous mastectomy	B27.5	HAC10/HAC15	HAC10 HAC15	58651
Total mastectomy + excision of both pectoral muscles + part of chest wall	B27.1	HAC25	HAC25 Radical mastectomy + GAE16/GAE20/GAE23/ GAE40/GAE50/GAE96	58641
Total mastectomy + excision of pectoralis muscle	B27.3		HAC25	58631
Wide local excision	B28.2		HAB99/HAB40	-
Excision biopsy (lumpectomy) (Excision of lesion of breast)	B28.3	HAF00?	HAB00/HAB99	58600
Segmentectomy (under discussion)	B28.8		HAB40 Wedge excision of mammary gland	58602

Procedure	OPCS-4 code	Norway and Sweden	Finland	Hungary
Quadrantectomy	B28.1		HAB40	-
Sub-areola excision of mammary duct (Hadfield's procedure)	B34.1		HAB20	58605
Excision of mammillary duct nec	B34.2	HAB20	HAB20	58600
Excision of lesion of mammillary duct	B34.3		HAB20	-
Microdochotomy	B34.4	HAB10	Not performed in Finland	-
Exploration of mammillary duct nec	B34.5		HAB20	-
Transposition of nipple	B35.1		HAD41	-
Excision of nipple	B35.2	HAD45	HAB30 (Excision of mamilla or areola) HAC30 (Excision of supernumerary mammary gland or mamilla)	58721
Extirpation of lesion of nipple	B35.3		HAB30/QBE10	-
Biopsy of lesion of nipple	B35.5		THA10/QBE00	-
Eversion of nipple	B35.6		HAD45	-
Re-excision for clearance of margins (BASO)	B28.8 + Y71.3		HAB99	-
Frozen section	?S05.2		Not used	

Sub-procedures (not valid for main procedure position)

Procedure	OPCS-4 code	Norway and Sweden	Finland	Hungary
Axillary sample	T86.2		PJA10 /PJD42 Exploration of lymph nodes	
Axillary clearance	T85.2	TPJ00	PJD52	58600
Sentinal node biopsy	T87.3	TPJ05?	PJA12	
Level 'n' axillary clearance (n=1, 2, 3) No OPCS code for this: it was decided to add a supplementary code to the OPCS code. Therefore: Level 1 axillary clearance (Level 1 =Lymph nodes lying lateral to the lateral border of the pectoralis muscle. Level 1 represents the tissue between the latissimusdorsi muscle and the lateral border of the pectoralis minor muscle) Level 2 axillary clearance (Level 2 = Lymph nodes lying behind pectoralis minor muscle. Level 2 is the axillary tissue between and inferior to the lateral and medial borders of the pectoralis minor muscle) Level 3 axillary clearance (Level 3 = Lymph nodes located medial to the medial border of the pectoralis muscle. Level 3 is the tissue between the medial border of the pectoralis minor and the apex of the axilla)	 T85.21 T85.22 T85.23	 PJD42?	 1 level PJD42 II-III level PJD52	

Reconstruction procedures

Procedure	OPCS-4 code	Norway and Sweden	Finland	Hungary
Tissue expander (Insertion of skin expander into subcutaneous tissue of breast)	S48.2		HAE00,ZZS50 (very rare)	01350
Implant (Insertion of prosthesis for the breast)	B30.1	HAE00/05	HAE00 HAD60 Also sometimes ZZS60	58651
Latissmus Dorsi flap	B29.1	|	HAE10,ZZR10	58732
Latissmus Dorsi flap+ implant	B29.1 + B30.1	|	HAE05,ZZR10	58732
DIEP flap (not coded by OPCS - supplementary code added)	B29.83	|	HAE10,ZZQ00	
DIEP flap + implant (not coded by OPCS - supplementary code added)	B29.83 + B30.1	| FLAP10	HAE05,ZZQ00	
Pedicle flap	B29.3	|	HAE10,ZZR00	
Pedicle flap + implant	B29.3 + B30.1	|	HAE05,ZZR00	
Tram flap	B29.8	|	HAE10,ZZR10	
Free tram flap (not coded by OPCS – supplementary code added)	B29.81		HAE10,ZZQ10	

Mini-flap (not coded by OPCS - supplementary code added)	B29.82		HAE10,ZZR10	
Reduction (Reduction mammoplasty)	B31.1	HAD30/35	HAD30	
Nipple reconstruction (Plastic operations on nipple)	B35.4	HAE20	HAE20	58733

Finland reconstruction procedures codes
HAE00 Reconstruction of breast using prosthesis
HAE05 Reconstruction of breast using soft tissue and prosthesis
HAE10 Reconstruction of breast using graft or flap
HAE20 Reconstruction of areola and mamilla using graft or flap
HAE99 Other reconstruction of breast
HAB50 Partial excision of mammary gland with reconstructive operation * Includes: Oncoplastic resection

APPENDIX G: Suggested simplified breast cancer procedure codes

*International procedure name given first, then if different (Scottish name given in brackets) &**ICD-CM name in bold**

Broad group	**Detailed procedure***	**Scottish codes**	**Scandinavian codes Sweden (S), Norway (N) Finland (F)**	**Hungary**	**ICD-CM codes - Italy**
Diagnostic	Aspiration of lesion	B37.1	Sweden/Norway THA99 Fin HA2XT	18590 18592 81553	**85.91**
	Biopsy of lesion	B32.1/B32.2	S/N HAA10THA10 F -THA00/HAA10		**85.11**
Therapeutic	Simple mastectomy	B27.4	S/N HAC25/HAC99 F- HAC20/HAC99	58610	**85.41**
	Subcutaneous mastectomy	B27.5	S/N/F HAC10/HAC15	58651	
	Radical mastectomy (total mastectomy + excision of both pectoral muscles + part of chest wall)	B27.1	S/N/F HAC25		**85.45** **85.47 (nodes too)**
	Total mastectomy (total mastectomy + excision of pectoralis muscle)	B27.3	N/F HAC25	58631	
	Wide local excision	B28.2	F- HAB99/HAB40		

Broad group	Detailed procedure*	Scottish codes	Scandinavian codes	Hungary	ICD-CM codes - Italy
	Excision biopsy (lumpectomy) (Excision of lesion of breast)	B28.3	F - HAB00/HAB99	58600	**85.21**
	Wedge excision of mammary gland (segmentectomy)	B28.8	F - HAB40	58602	
Additional prognostic/ therapeutic procedures	Exploration of lymph nodes (axillary sample)	T86.2	F - PJA10/PJD42		
	Excision of axillary lymph nodes/ Block dissection of axillary lymph nodes (axillary clearance) **(Simple mastectomy with excision of regional lymph nodes)**	T85.2 (includes further digits 1-3 to specify level)	S/N TPJ00 F - PJD52/or PJD42 (level1)		**85.43**
	Sentinel node biopsy	T87.3	S/N TPJ05? F - PJA12		
Reconstruction	Implant (Insertion of prosthesis for the breast)	B30.1	N/F HAE00/HAD60	58651	**V50.1**
	Reconstruction of breast using graft or flap	B29.1, B29.3, B29.8	N/F HAE10/HAE05	58732	**85.7**

Broad group	Detailed procedure*	Scottish codes	Scandinavian codes	Hungary	ICD-CM codes - Italy
	Nipple reconstruction (Plastic operations on nipple)	B35.4	N/F HAE20	58733	**85.87**
	Partial excision of mammary gland with reconstructive operation * Includes: Oncoplastic resection	-	N/F HAB50		

APPENDIX H : TNM classification

(source: *http://www.ic.nhs.uk/webfiles/Services/Datasets/cancer/appendixforbreastcancer.pdf)*

T CATEGORY EXTENDED (PATHOLOGICAL) [Local invasion – tumour extent]

TX(i)	Primary tumour cannot be assessed
T0	No evidence of primary tumour
Tis	Carcinoma in situ: intraductal carcinoma, or lobular carcinoma in situ, or Paget disease of the nipple with no tumour
T1(i)	**T1** - Tumour 20mm or less in greatest dimension **T1mic** - micro-invasion 10mm or less
T1(ii)	**T1a** - tumour >1 and <5mm
T1(iii)	**T1b** - tumour >5 and <10mm
T1(iv)	**T1c** - tumour >10 and <20mm
T2(i)	Tumour more than 20mm but not more than 50mm in greatest dimension
T3(i)	Tumour more than 50mm in greatest dimension

T4(i)	**T4** - Tumour of any size with direct extension to chest wall or skin **T4a** -Tumour extends to chest wall
T4(ii)	**T4b** - Oedema - peau d'orange
T4(iii)	**T4b** - Skin ulceration
T4(iv)	**T4b** - Satellite skin nodules
T4(v)	**T4c** - T4a and T4b
T4(vi)	**T4d** - Inflammatory carcinoma

N - REGIONAL LYMPH NODES

NX	NX Regional lymph nodes cannot be assessed (eg previously removed
N0	No regional lymph node metastasis
N1	Metastasis to movable ipsilateral axillary node(s)
N2	Metastasis to ipsilateral axillary node(s) fixed to one another or to other structures
N3	Metastasis to ipsilateral internal mammary lymph node(s)

M CATEGORY EXTENDED (PATHOLOGICAL) [Distant metastases]

MX	Distant metastases cannot be assessed
M0	No distant metastases
M1(i)	Distant metastases in supraclavicular, cervical or contralateral internal mammary lymph nodes
M1(vii)	Liver metastases present
M1(viii)	Other distant metastases present

<u>Breast cancer staging</u>

Stage 1 The cancer is smaller than, or equal to, 2cm and has not spread to axillary lymph nodes

Stage 2A– Either the lump is smaller than 2cm and has spread to lymph nodes in the armpit OR it's bigger than 2cm (but under 5cm) and hasn't spread to the lymph nodes OR the cancer can't be found in the breast but is in the lymph nodes in the armpit.

Stage 2B– Either the lump is smaller than 5cm and has spread to the lymph nodes in the armpit OR it's bigger than 5cm but hasn't spread to the lymph nodes in the armpit.

Stage 3A– Either the cancer can't be found in the breast or the lump is under 5cm and the cancer is in the lymph nodes in the armpit, which are stuck together OR the lump is bigger than 5cm and has spread to the lymph nodes.

Stage 3B– The cancer has spread to tissue near the breast and may be attached to surrounding skin or muscle. There are usually cancer cells in the lymph nodes in the armpit as well.

Stage 3C– The cancer has spread to lymph nodes in the armpit, below the breastbone, near the neck or under the collarbone.

Stage 4– The cancer has spread to other parts of the body such as the bones, liver or lungs. This is called secondary or metastatic breast cancer.

Grading

- **Grade 1 (low-grade)–** The cancer cells look similar to normal cells and grow very slowly.
- **Grade 2 (moderate- or intermediate-grade)–** The cancer cells look more abnormal and are slightly faster growing.
- **Grade 3 (high-grade)–** The cancer cells look very different from normal cells and tend to grow quickly.

APPENDIX I: Coding for post-operative complications (ICD-10)

Major complications

Leak if caused by graft/implant/prosthesis	T85.4
Abscess unless caused by implant/graft/prosthesis	T81.4
Abscess caused by implant/graft/prosthesis	T85.7
Bleed unless caused by implant/graft/prosthesis	T81.0
Bleed caused by implant/graft/prosthesis	T85.8

Other complications

Wound infection Without prosthesis graft With prosthesis	 T81.4 T85.7
Lower chest infection	J22(X)
Upper chest infection	J06.9
Urinary infection Post-operative	N39.0 +Y83.2

Excision of an organ	+Y83.3
Thromboembolic	T81.7
MRSA	
Cardiac	I97.8
Breakdown of reconstruction	
Haematoma	T81.0
Skin necrosis	

APPENDIX J : Participating countries and persons in WP6.

Country Code	Country	WP contact	WP contact e-mail	Corresponding clinical expert(s)	clinical expert(s)e-mail
P1	Finland	Mikko Peltola	Mikko.Peltola@thl.fi	TiinaJahkola TiinaSaarto	Tiina.Jahkola@hus.fi Tiina.Saarto@hus.fi
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P2	Italy	Giovanni Fattore Dino Numerato	giovanni.fattore@unibocconi.it dino.numerato@unibocconi.it	??	
P4	Netherlands	Data not available to allow participation			
P5	Norway	Eline Aas	eline.aas@medsin.uio.no	Ellen Schlichting	ellen.schlichting@ous.no
P7	Scotland WP leader	Harry Campbell and Sarah Wild (lead) via Anne Douglas Team: Eilidh Fletcher, Colin Simpson, Linda Williams, Joel Smith, John Forbes	anne.douglas@ed.ac.uk	Elaine Anderson David Cameron David Brewster	elaine.anderson@luht.scot.nhs.uk D.Cameron@ed.ac.uk David.brewster@nhs.net
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