

**DATA COLLECTION BY USING ACCESS DATABASE**

Version 2.3, August 10, 2014

**Data common to all tumours included in HR studies**

(in red variables common to the EURO CARE survival study)

	<i>Variable</i>	<i>Recommended coding of values</i>	<i>Format*</i>	<i>Definition/notes</i>
1.	<b>Registry</b>	registry name	A10	Missing not allowed
2.	<b>Identification code</b>	Necessary for possible corrections and later updating. Unique id code for both HR and low resolution study (to update life status through record linkage with EURO CARE)	A20	Missing not allowed
3.	<b>Tumour identification code</b>	If available, in addition to patient's id code	A20	
4.	<b>Gender</b>	1= male; 2= female	F1	Missing not allowed
5.	<b>Day of birth</b>	01-31	F2	Differently from ENCR or EURO CARE rules, the HR study collects the exact date of birth, to compute exactly the age at diagnosis
6.	<b>Month of birth</b>	01-12	F2	
7.	<b>Year of birth</b>	1900-1998	F4	
8.	<b>Day of incidence</b>	01-31	F2	Differently from ENCR or EURO CARE rules, the HR study collects the exact date of birth, to compute outcome indicators such as short term survival, operative mortality, disease-free interval.
9.	<b>Month of incidence</b>	01-12	F2	
10.	<b>Year of incidence</b>	2011-2013 (possible range)	F4	
11.	<b>Primary tumour site</b>	Topography coded according to the international classification of diseases for oncology (ICD-O-3) C00.0-C80.9	A5	See the ENCR recommendations (e.g. C50.9)  Missing not allowed
12.	<b>Tumour morphology</b>	Morphology coded according to the international classification of diseases for oncology (ICD-O-3) 8000/3-9989/3	A6	See the ENCR recommendations (e.g. 8000)  Missing not allowed; /2 is available only for breast cancer  Note: in the HR study on Lymphoma, only the following morphological codes are admitted: Diffuse Large B-cell lymphoma (9678-9680, 9684); Follicular lymphoma (9690-9691, 9695, 9698)
13.	<b>Behaviour</b>	It corresponds to the 5 <sup>th</sup> digit of ICD-O-3 code 2= in situ (available only for breast) 3= malignant	F1	Benign tumours not to be included  Missing not allowed  Note: Please, for Lymphomas record the following code: 3
14.	<b>Grading</b>	It corresponds to the 6 <sup>th</sup> digit of ICD-O-3 code 1= Grade I, well differentiated; 2= Grade II, moderately differentiated; 3= Grade III, poorly differentiated; 4= Grade IV, undifferentiated;	F1	<b>Note 1 for BREAST cancer:</b> In case of two different gradings (one at biopsy and one at the first surgery without -or before- neo-adjuvant chemotherapy), the highest grade should be collected

		5= T-cell; 6= B-cell; 7= Null cell; 8= NK cell; 9= Not determined, not graded;		<b>Note 2 for LYMPHOMAS:</b> Codes 1-4 have not to be recorded. Please record 5 to 8; the 6th digit of the morphology code can be added to the cell types of lymphomas that have been identified by surface marker studies. Code any statement of T-cell or B-cell involvement whether or not marker studies are documented in the patient record.
15.	<b>Basis of diagnosis</b>	0 = DCO; 1= clinical (clinical only, clinical investigation, tumour marker) 2= microscopic (histology of a primary tumour, cytology, histology of a metastasis); 9 = unknown	F1	See the ENCR recommendations
16.	<b>Incidental finding of cancer at the autopsy</b>	1= yes; 2= no; 9= not allowed	F1	
17.	<b>Multiple tumour</b>	In case of multiple tumour, please report the temporal ranking of the cancer under study (=that for which HR variables are being collected), e.g. 01, 02, 03, etc. This number corresponds to that actually collected by the CR, regardless the inclusion criteria of this study	A2	For synchronous bilateral breast cancer, keep the ENCR rule: fill in two records, although in the analyses only one case will be considered. Bilateral synchronous lung cancer will be considered as a single case.
18.	<b>Inclusion in controlled clinical trial (optional)</b>	1= yes; 2= no; 9= unknown	F1	
19.	<b>Multidisciplinary team consulting meeting (optional)</b>	1= yes; 2= no; 9= unknown	F1	“Yes” means that a multidisciplinary team meeting is documented in the clinical notes
<i>19 items for co-morbidities at diagnosis (Charlson index)</i>				
20.	<b>Charlson index (optional)</b>	00-90 99=unknown	A2	Record the total Charlson score if available in the clinical notes. However, score each item (see following diseases):  See Annex C for the definition
21.	<b>Myocardial infarct</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
22.	<b>Congestive heart failure</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
23.	<b>Peripheral vascular disease</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
24.	<b>Cerebrovascular disease</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
25.	<b>Dementia</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
26.	<b>Chronic obstructive pulmonary disease</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
27.	<b>Connective tissue disease/ Rheumatologic disease</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
28.	<b>Peptic ulcer disease</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
29.	<b>Mild liver disease</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
30.	<b>Diabetes without end organ damage</b>	1= yes; 2= no; 9= unknown	F1	1: score for Charlson index
31.	<b>Hemiplegia or Paraplegia</b>	1= yes; 2= no; 9= unknown	F1	2: score for Charlson index

32.	Moderate to severe renal disease	1= yes; 2= no; 9= unknown	F1	2: score for Charlson index
33.	Diabetes with end organ damage	1= yes; 2= no; 9= unknown	F1	2: score for Charlson index
34.	Any malignant solid tumour (additional to that in study) without metastasis	1= yes; 2= no; 9= unknown	F1	2: score for Charlson index
35.	Lymphoma	1= yes; 2= no; 9= unknown	F1	2: score for Charlson index
36.	Leukemia	1= yes; 2= no; 9= unknown	F1	2: score for Charlson index
37.	Moderate or severe liver disease	1= yes; 2= no; 9= unknown	F1	3: score for Charlson index
38.	Metastatic solid tumour	1= yes; 2= no; 9= unknown	F1	6: score for Charlson index
39.	AIDS/HIV	1= yes; 2= no; 9= unknown	F1	6: score for Charlson index
40.	Smoker (optional)	1= yes, currently; 2= yes, previously; 3= no, never; 9= unknown	F1	
41.	BMI (optional)	00.0-60.9 99.9= unknown  For the data collection, it was divided in two variables: 41a. BMIu: 00-60 41b. BMId:0-9	F4  A2 F1	Note: BMI could be also referred to the date of treatment  Please, report directly the BMI value calculated as ratio between weight in Kg and height in meters (Kg/m <sup>2</sup> ) (Ex: 15.9 or 45.0)  u=units d=decimals
<i>Performance status</i>				
42.	Type of scale (optional)	1= Karnofsky; 2= ECOG/WHO; 9= not available	F1	See Annex C for the definition
43.	Score of performance status (optional)	000-100 999= unknown	A3	Note: If ECOG or WHO scale are used, please record scores in the following way: 000, 001-005
<i>Follow-up</i> <i>- in the short term (e.g. 1-year or at the end of first treatment)</i> <i>- long-term follow-up will be updated in the future</i>				
44.	Relapse	<u>For SOLID TUMOURS:</u> 0= none; 1= local; 2= on regional nodes or adjacent tissues/organs; 3= distant metastases; 9= unknown  <u>For LYMPHOMAS:</u> 0= no relapse; 1= relapse; 9= unknown	F1	Note for Lymphomas: a relapse may only occur after a complete remission
45.	Day of relapse	01-31  If missing or not applicable, code: 99	F2	
46.	Month of relapse	01-12  If missing or not applicable, code: 99	F2	
47.	Year of relapse	2011-XXXX  If missing or not applicable, code: 9999	F4	

48.	Second cancer	C00.0-C80.9 C99.9, if unavailable; 999.9, if absent;	A5	Subsequent tumour diagnosed after the tumour under study to be coded according to ICD-O-3 code, if available;  (Ex: C50.9)
49.	Day of incidence of second cancer	01-31  If missing or not applicable, code: 99	F2	
50.	Month of incidence of second cancer	01-12  If missing or not applicable, code: 99	F2	
51.	Year of incidence of second cancer	2011-XXXX  If missing or not applicable, code: 9999	F4	
52.	Life status at last known contact	1= alive; 2= dead	F1	Missing not allowed
53.	Cause of death	Coded according to ICD-10 code for cause of death  A00.0 – Z99.9 if available; 999.9, if unavailable	A5	Note: ICD-10 covers years from 1999 to present
54.	Day of last known contact	01-31	F2	Missing not allowed
55.	Month of last known contact	01-12	F2	Missing not allowed
56.	Year of last known contact	2011-XXXX	F4	Missing not allowed

\*F=numeric; A=alphanumeric

## Additional data for BREAST CANCER (C50)

	<i>Variable</i>	<i>Recommended coding of values</i>	<i>Format*</i>	<i>Definition/notes</i>
57.	Menopausal status at diagnosis <b>(optional)</b>	1= pre-menopausal; 2= post-menopausal; 9= unknown	F1	If peri-menopausal status is mentioned in clinical records, please register as 1
58.	Modality of diagnosis /Mode of presentation	1= symptomatic tumour; 2= screened-detected; 9= unknown	F1	
59.	Laterality	1= left; 2= right; 9= unknown	F1	
60.	Multifocality	1= yes; 2= no; 9= unknown	F1	To be collected according to ENCR rules: Multifocal tumours – that is, discrete masses apparently not in continuity with other primary cancers originating in the same primary site or tissue - are counted as a single cancer.
<i>Diagnostic exams on the breast within 3 months (after or before) from diagnosis</i>				
61.	Mammography	1= done; 2= not done; 9= unknown	F1	
62.	Day of mammography	01-31 If missing or not applicable, code: 99	F2	To be collected as a proxy of the disease onset
63.	Month of mammography	01-12 If missing or not applicable, code: 99	F2	
64.	Year of mammography	2011-2014 If missing or not applicable, code: 9999	F4	
65.	Ultrasound	1= done; 2= not done; 9= unknown	F1	
66.	Biopsy (fine-needle aspiration, pre-surgery, core)	1= done; 2= not done; 9= unknown	F1	
67.	Mamotome	1= done; 2= not done; 9= unknown	F1	
68.	Magnetic resonance imaging (MRI)	1= done; 2= not done; 9= unknown	F1	
69.	Intra-surgery biopsy	1= done; 2= not done; 9= unknown	F1	
<i>Diagnostic exams for distant metastases within 3 months (after or before) from diagnosis</i>				
70.	Liver imaging	1= done; 2= not done; 9= unknown	F1	Each exam should be considered
71.	Lung imaging	1= done; 2= not done; 9= unknown	F1	
72.	Brain imaging	1= done; 2= not done; 9= unknown	F1	
73.	Skeleton imaging	1= done; 2= not done; 9= unknown	F1	
<i>Stage at diagnosis</i>				
74.	pT	Pathological T, according to TNM classification, 7th revision.  00=TX ; 01=T0 ; 02=Tis ; 03= Tis_DCIS; 04=Tis_LCIS; 05=Tis_Paget; 10=T1NOS ; 11=T1mic; 12=T1a; 13=T1b; 14=T1c; 20=T2; 30=T3NOS; 40=T4NOS; 41=T4a; 42=T4b; 43=T4c; 44=T4d; 99=Not available	A2	
75.	cT	Clinical T, according to TNM classification, 7th revision.  00=TX ; 01=T0 ; 02=Tis ; 03= Tis_DCIS; 04=Tis_LCIS; 05=Tis_Paget; 10=T1NOS ; 11=T1mic; 12=T1a; 13=T1b; 14=T1c; 20=T2; 30=T3NOS; 40=T4NOS; 41=T4a; 42=T4b; 43=T4c; 44=T4d; 99=Not available	A2	

76.	Pathological tumour diameter	Tumour size in mm. 000-900 988= >900 999= unknown	A3	In case of multifocality, the largest diameter should be collected. If there are invasive and in-situ cancers, the diameter of the invasive tumour should be collected.
77.	Clinical tumour diameter	Tumour size in mm. 000-900 988= >900 999= unknown	A3	
78.	pN	Pathological N, according to TNM classification, 7th revision.  00=N <sub>X</sub> ; 01=N <sub>0</sub> ; 02=N <sub>0</sub> (i-); 03=N <sub>0</sub> (i+); 04=N <sub>0</sub> (mol-); 05=N <sub>0</sub> (mol+); 06=N <sub>0</sub> (i-)(sn); 07= N <sub>0</sub> (i+)(sn); 08=N <sub>0</sub> (mol-)(sn); 09=N <sub>0</sub> (mol+)(sn); 10=N <sub>1</sub> NOS; 11=N <sub>1</sub> mic; 12=N <sub>1</sub> a; 13=N <sub>1</sub> b; 14=N <sub>1</sub> c; 15=N <sub>1</sub> (sn); 20=N <sub>2</sub> NOS; 21=N <sub>2</sub> a; 22=N <sub>2</sub> b; 30=N <sub>3</sub> NOS; 31=N <sub>3</sub> a; 32=N <sub>3</sub> b; 33=N <sub>3</sub> c; 40=N+NOS; 88=N <sub>X</sub> (sn); 99=Not available	A2	<u>Note</u> : “N+NOS” code is not allowed in the TNM, 7th revision, but allowed in this HR study as some cancer registries can only access this information
79.	cN	Clinical N, according to TNM classification, 7th revision.  00=N <sub>X</sub> ; 01=N <sub>0</sub> ; 10=N <sub>1</sub> NOS; 20=N <sub>2</sub> NOS; 21=N <sub>2</sub> a; 22=N <sub>2</sub> b; 30=N <sub>3</sub> NOS; 31=N <sub>3</sub> a; 32=N <sub>3</sub> b; 33=N <sub>3</sub> c; 40=N+NOS; 99=Not available	A2	For “N+NOS” code, see Note on pN stage
80.	Determination of nodal micrometastases (optional)	0= not done; 1= done, negative (pN0 micr); 2= done, positive (pN1 micr); 3= done, unknown (pNX micr); 9= unknown	F1	<u>Note</u> : it refers to either immunohistochemistry or gene expression, etc.
81.	Total number of examined nodes	000= not examined; 001-150 999= unknown	A3	<u>Note 1</u> : in case of consecutive surgeries within six months prior or after diagnosis, the number of lymph nodes should be summed.  <u>Note 2</u> : in case of biopsy of sentinel node, the total examined nodes should be summed to those examined during surgery
82.	Total number of metastatic nodes	000-150 999= unknown	A3	<u>Note 1</u> : in case of consecutive surgeries in the six months after diagnosis, the number of lymph nodes should be summed.  <u>Note 2</u> : if no nodal examination is carried out, the number of metastatic nodes should be 000
83.	pM	Pathological M, according to TNM classification, 7th revision.  0= M <sub>0</sub> ; 1= M <sub>0</sub> (i+); 2= M <sub>0</sub> (mol+); 3= M <sub>1</sub> ; 9= Not available	F1	
84.	cM	Clinical M, according to TNM classification, 7th revision.  0=M <sub>0</sub> ; 1=M <sub>1</sub> ; 9= Not available	F1	

85.	Site of metastasis (in clear, optional)		A10	Please, report the site of metastasis.
86.	Sentinel lymph node biopsy	1= done; 2= not done; 9= unknown	F1	
87.	Number of examined sentinel nodes	00= not examined; 01-10 99= unknown	A2	
88.	Number of positive sentinel nodes	00-10 99= unknown	A2	In case of no sentinel node examination, the number of positive sentinel nodes should be 00
89.	pN stage sentinel lymph node	0= N0; 1= N1; 9= NX	F1	
90.	Axillary dissection after sentinel lymph node	1= done; 2= not done; 9= unknown	F1	
<i>Hormonal status</i> (in general obtained by immunohistochemistry. If other methods were used, please specified in a separate document)				
91.	Oestrogen (ER) receptors	(Range of) Percentage of positive cells:  000-100 or [000;100]  777= not done; 888= not available; 999= unknown	A9	
92.	ER positivity	<u>If the cells percentage is unavailable</u> , please report the receptor status synthesized in the clinical records:  1= positive; 2= negative; 3= weakly positive, 9= unknown	F1	
93.	Cut-off for ER positivity (optional)	<u>If either the cells percentage is unavailable or only the range of percentage of positive cells is available</u> , please report also the cut-off used to report the receptor status synthesized in the clinical records:  000-100  777= not done; 888= not available; 999= unknown	A3	
94.	Progesterone (PR) receptors	(Range of) Percentage of positive cells:  000-100 or [000;100]  777= not done; 888= not available; 999= unknown	A9	
95.	PR positivity	<u>If the cells percentage is unavailable</u> , please report the receptor status as synthesized in the clinical records:  1= positive; 2= negative; 3= weakly positive, 9= unknown	F1	

96.	Cut-off for PR positivity (optional)	<u>If either the cells percentage is unavailable or only the range of percentage of positive cells is available,</u> please report also the cut-off used to report the receptor status synthesized in the clinical records: 000-100 777= not done; 888= not available; 999= unknown	A3	
97.	Ki67 (or other cell proliferation marker)	(Range of) Percentage of positive cells: 000-100 or [000;100] 777= not done; 888= not available; 999= unknown	A9	
98.	Ki67positivity	<u>If the percentage of mitotic cells is unavailable,</u> please report the proliferation marker as synthesized in the clinical records: 1= high; 2= low; 9= unknown	F1	
99.	Cut-off for Ki67positivity (optional)	<u>If the percentage of mitotic cells is unavailable or only the range of percentage of positive cells is available,</u> please report also the cut-off used to report the receptor status synthesized in the clinical records: 000-100 777= not done; 888= not available; 999= unknown	A3	
100.	HER2	0= not done 1= 0 (negative) 2= 1+ (negative); 3= 2++ ; 4= 3+++ (positive); 9= unknown	F1	
101.	FISH	0= not done; 1= done, positive; 2= done, negative; 3= done, unknown result; 9= unknown	F1	
102.	HER2 percentage	(Range of) Percentage of HER2 positive cells at immunohistochemistry: 000-100 or [000;100] 777= not done; 888= not available; 999= unknown	A9	
103.	Cut-off for HER2 (optional)	<u>If either the percentage of HER2 positive cells at immunohistochemistry is unavailable or only the range of percentage of positive cells is available,</u> please report the cut-off used to report the HER2 status synthesized in the clinical records: 000-100 777= not done; 888= not available; 999= unknown	A3	



<i>Treatment</i>				
104.	<b>SURGERY</b>	0= not done; 1= breast conserving surgery (quadrantectomy, nodulectomy, resection); 2= mastectomy; 3= done, but unknown type of surgery; 9= unknown	F1	In case of consecutive surgical interventions for the primary cancer, sum up the total and positive lymph nodes of each intervention
105.	Day of surgery	01-31 If missing or not applicable, code: 99	F2	
106.	Month of surgery	01-12 If missing or not applicable, code: 99	F2	
107.	Year of surgery	2011-2014 If missing or not applicable, code: 9999	F4	
108.	Reasons for no surgery	1= medical contraindications; 2= patient refusal; 3= advanced cancer; 4= other; 8= no indication; 9= unknown	F1	
109.	Surgical radicality	1= R0, no residual tumour; 2= R1, microscopic residual tumour; 3= R2, macroscopic residual tumour; 4= R1/R2, presence of residual tumour but unknown if R1 or R2; 9= RX, presence of residual tumour cannot be assessed or information is not available	F1	
110.	Reconstruction	1= yes; 2= no; 9= unknown	F1	
111.	Day of reconstruction	01-31 If missing or not applicable, code: 99	F2	
112.	Month of reconstruction	01-12 If missing or not applicable, code: 99	F2	
113.	Year of reconstruction	2011-2014 If missing or not applicable, code: 9999	F4	
114.	<b>CHEMOTHERAPY</b>	1= done; 2= not done; 9= unknown	F1	
115.	Day starting chemotherapy	01-31 If missing or not applicable, code: 99	F2	
116.	Month starting chemotherapy	01-12 If missing or not applicable, code: 99	F2	
117.	Year starting chemotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
118.	Modality of chemotherapy	1= neo-adjuvant; 2= adjuvant; 3= palliative; 9= unknown	F1	
119.	Type of chemotherapy (optional)	1= anthracyclines (±CMF); 2= taxanes (±CMF); 3= anthracyclines+taxanes (±CMF); 4= CMF only; 5= other drugs and combinations; 9= unknown	F1	where CMF= cyclophosphamide, methotrexate and fluorouracil

120.	Conclusion of the treatment	1= yes; 2= no/interrupt; 9= unknown	F1	Note: This information can be collected only if the year of incidence and the year of data collection are different
121.	Reasons for no chemotherapy	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	
122.	ENDOCRINE TREATMENT	1= done; 2= not done; 9= unknown	F1	
123.	Day starting endocrine treatment	01-31 If missing or not applicable, code: 99	F2	
124.	Month starting endocrine treatment	01-12 If missing or not applicable, code: 99	F2	
125.	Year starting endocrine treatment	2011-2014 If missing or not applicable, code: 9999	F4	
126.	Type of endocrine treatment (optional)	1= tamoxifen; 2= aromatase inhibitors; 3= other; 9= unknown	F1	
127.	Reasons for no endocrine treatment	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	
128.	TARGETED TREATMENT	1= done; 2= not done; 9= unknown	F1	Note: It can be trastuzumab or any other monoclonal antibody
129.	Day starting targeted treatment	01-31 If missing or not applicable, code: 99	F2	
130.	Month starting targeted treatment	01-12 If missing or not applicable, code: 99	F2	
131.	Year starting targeted treatment	2011-2014 If missing or not applicable, code: 9999	F4	
132.	RADIOTHERAPY	1= done; 2= not done; 9= unknown	F1	
133.	Day starting radiotherapy	01-31 If missing or not applicable, code: 99	F2	
134.	Month starting radiotherapy	01-12 If missing or not applicable, code: 99	F2	
135.	Year starting radiotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
136.	Modality of radiotherapy	1= neo-adjuvant; 2= adjuvant; 3= palliative; 9= unknown	F1	

137.	Reasons for no radiotherapy	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	
<i>Stage after neo-adjuvant treatment (if any)</i>				
138.	ypT	Pathological T, according to TNM classification, 7th revision.  00=TX ; 01=T0 ; 02=Tis ; 03= Tis_DCIS; 04=Tis_LCIS; 05=Tis_Paget; 10=T1NOS ; 11=T1mic; 12=T1a; 13=T1b; 14=T1c; 20=T2; 30=T3NOS; 40=T4NOS; 41=T4a; 42=T4b; 43=T4c; 44=T4d; 99=Not available	A2	
139.	ypN	Pathological N, according to TNM classification, 7th revision.  00=NX; 01=N0; 02=N0(i-); 03=N0(i+); 04=N0(mol-); 05=N0(mol+); 06=N0(i-)(sn); 07= N0(i+)(sn); 08=N0(mol-)(sn); 09=N0(mol+)(sn); 10=N1NOS; 11=N1mic; 12=N1a; 13=N1b; 14=N1c; 15=N1(sn); 20=N2NOS; 21=N2a; 22=N2b; 30=N3NOS; 31=N3a; 32=N3b; 33=N3c; 40=N+NOS; 88=NX(sn); 99=Not available	A2	<b>Note 2: “N+NOS” code is not allowed by the TNM, 7th revision, but allowed in this HR study as some cancer registries can only access this information</b>
140.	yM	Stage M, according to TNM classification, 7th revision.  0=M0; 1=M1; 9=Not available	F1	

\*F=numeric; A=alphanumeric

## Additional data for COLORECTAL CANCER (C18-C21)

	<i>Variable</i>	<i>Recommended coding of values</i>	<i>Format*</i>	<i>Definition/notes</i>
57.	Modality of diagnosis /Mode of presentation	1= symptomatic tumour; 2= screened-detected; 9= unknown	F1	
58.	Multifocality	1= yes; 2= no; 9= unknown	F1	<b>To be collected according to ENCR rules:</b> Multifocal tumours – that is, discrete masses apparently not in continuity with other primary cancers originating in the same primary site or tissue - are counted as a single cancer.
<i>Diagnostic exams on the colorectum within 3 months (after or before) from diagnosis</i>				
59.	Colonoscopy	0= not done; 1= done, complete; 2= done, incomplete; 9= unknown	F1	
60.	Barium enema	1= done; 2= not done; 9= unknown	F1	
61.	CT MRI colonography	1= done; 2= not done; 9= unknown	F1	
<i>Diagnostic exams for distant metastases within 3 months (after or before) from diagnosis</i>				
62.	Liver imaging	1=done; 2=not done; 9=unknown	F1	Each exam should be considered
63.	Lung imaging	1=done; 2=not done; 9=unknown	F1	
64.	Brain imaging	1=done; 2=not done; 9=unknown	F1	
65.	Skeleton imaging	1=done; 2=not done; 9=unknown	F1	
<i>Stage at diagnosis</i>				
66.	pT	Pathological T, according to TNM classification, 7th revision.  00=TX ; 01=T0 ; 02=Tis; 10=T1NOS; 20=T2NOS; 30=T3NOS; 40=T4NOS; 41=T4a; 42=T4b; 99= Not available	A2	
67.	cT	Clinical T, according to TNM classification, 7th revision.  00= TX ; 1= T0; 02= Tis; 10= T1NOS; 20= T2NOS; 30= T3NOS; 40= T4NOS; 41= T4a; 42= T4b; 99= Not available	A2	<b>To be collected only for rectal cancer including MRI or echo-endoscopy</b>
68.	Pathological tumour diameter (optional)	Tumour size in mm. 000-900 988= >900 999=unknown	A3	
69.	Clinical tumour diameter (optional)	Tumour size in mm. 000-900 988= >900 999= unknown	A3	
70.	pN	Pathological N, according to TNM classification, 7th revision.  00=NX; 01=N0; 10=N1NOS; 11=N1a; 12=N1b; 13=N1c; 20=N2NOS; 21=N2a; 22=N2b; 30=N+NOS; 99= Not available	A2	<b>Note:</b> “N+NOS” code is not allowed in the TNM, 7th revision, but allowed in this HR study as some cancer registries can only access this information

71.	cN	Clinical N, according to TNM classification, 7th revision. 00=NX; 01=N0; 10=N1NOS; 11=N1a; 12=N1b; 13=N1c; 20=N2NOS; 21=N2a; 22=N2b; 30=N+NOS; 99= Not available	A2	To be collected only for rectal cancer including MRI or echo-endoscopy  For “N+NOS” code see Note on pN stage
72.	Total number of examined nodes	000= not examined; 001-150 999= unknown	A3	
73.	Total number of metastatic nodes	000-150 999= unknown	A3	In case of no nodal examination, the number of metastatic nodes should be 000
74.	pM	Pathological M, according to TNM classification, 7th revision.  0=M0; 1=M1; 9=Not available	F1	
75.	cM	Clinical M, according to TNM classification, 7th revision. 0= M0; 10= M1a; 11= M1a, liver carcinomatosis; 12= M1a, lung carcinomatosis; 13= M1a, non-regional nodes; 14= M1a, other sites; 20= M1b; 21= M1b, liver+other(s) site(s); 22= M1b, multiple sites not including liver; 23= M1b, peritoneal carcinomatosis;  99= Not available	F2	
<i>Pre-operative work-up</i>				
76.	Echography	1= done; 2= not done; 9= unknown	F1	
77.	Thoracic X-ray	1= done; 2= not done; 9= unknown	F1	
78.	Thoracic CT	1= done; 2= not done; 9= unknown	F1	
79.	Abdominal CT	1= done; 2= not done; 9= unknown	F1	
80.	Magnetic resonance imaging (MRI)	1= done; 2= not done; 9= unknown	F1	
81.	Echoendoscopy	1= done; 2= not done; 9= unknown	F1	To be collected only for rectal cancer
<i>Treatment</i>				
82.	SURGERY	00= not done; 01= endoscopic resection/endoscopic polypectomy; 02= transanal resection; 03= anterior resection; 04= Hartman; 05= abdomino-perineal resection; 06= right hemicolectomy; 07= left hemicolectomy; 08= segmental resection; 09= total colectomy; 10= done, but unknown type of resection;  99= unknown	A2	
83.	Type of hospital admission	1= planned; 2= emergency (for obstruction or perforation); 9= unknown	F1	
84.	Mode of surgery	1= open surgery; 2= laparoscopic surgery; 9= unknown	F1	

85.	Day of surgery	01-31 If missing or not applicable, code: 99	F2	
86.	Month of surgery	01-12 If missing or not applicable, code: 99	F2	
87.	Year of surgery	2011-2014 If missing or not applicable, code: 9999	F4	
88.	Reasons for no surgery	1= medical contraindications; 2= patient refusal; 3= advanced cancer; 4= other; 8= no indication; 9= unknown	F1	
89.	Involvement of surgical margins	1= without microscopic involvement of distal surgical margin (R0 resection); 2= with microscopic involvement of distal surgical margin (R1 resection); 9= unknown	F1	To be recorded ONLY for stages I-III
90.	Resection of distant metastases (for stage IV / M1 only)	1= complete resection of both primary cancer and metastasis (R0 resection); 2= complete resection of cancer, but presence of metastasis (R2 resection); 3= no resection of either cancer or metastasis (R2 resection) 9= unknown	F1	To be recorded ONLY if surgery was carried out in stage IV/ M1
91.	COLOSTOMY	1= done; 2= not done; 9= unknown	F1	
92.	Type of colostomy	1= permanent (after resection); 2= temporary (after resection); 3= colostomy alone with no resection of the tumour; 9= unknown	F1	
93.	CHEMOTHERAPY	1= done; 2= not done; 9= unknown	F1	
94.	Day starting chemotherapy	01-31 If missing or not applicable, code: 99	F2	
95.	Month starting chemotherapy	01-12 If missing or not applicable, code: 99	F2	
96.	Year starting chemotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
97.	Modality of chemotherapy	1= neo-adjuvant; 2= adjuvant; 3= peri-operative; 4= palliative; 9= unknown	F1	
98.	Type of chemotherapy (in clear, optional)		A20	Please, report the therapeutic scheme or the drug(s) used. Otherwise, insert as many “_” as necessary to reach the accepted 20-character string
99.	Reasons for no chemotherapy	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	

100.	<b>TARGETED TREATMENT</b> (e.g. monoclonal antibody)	1= done; 2= not done; 9= unknown	F1	
101.	Day starting targeted treatment	01-31 If missing or not applicable, code: 99	F2	
102.	Month starting targeted treatment	01-12 If missing or not applicable, code: 99	F2	
103.	Year starting targeted treatment	2011-2014 If missing or not applicable, code: 9999	F4	
104.	Type of targeted treatment (in clear, optional)		A20	Please, report the drug(s) used.
105.	<b>RADIOTHERAPY</b>	1= done; 2= not done; 9= unknown	F1	
106.	Day starting radiotherapy	01-31 If missing or not applicable, code: 99	F2	
107.	Month starting radiotherapy	01-12 If missing or not applicable, code: 99	F2	
108.	Year starting radiotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
109.	Modality of radiotherapy	1= neo-adjuvant; 2= adjuvant; 3= palliative (radiotherapy alone); 9= unknown	F1	
110.	Reasons for no radiotherapy	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	
<i>Stage after neo-adjuvant treatment (if any)</i>				
111.	ypT (optional)	Pathological T, according to TNM classification, 7th revision.  00=TX ; 01=T0 ; 02=Tis; 10=T1NOS; 20=T2NOS; 30=T3NOS; 40=T4NOS; 41=T4a; 42=T4b; 99= Not available	A2	
112.	ypN (optional)	Pathological N, according to TNM classification, 7th revision.  00=NX; 01=N0; 10=N1NOS; 11=N1a; 12=N1b; 13=N1c; 20=N2NOS; 21=N2a; 22=N2b; 30=N+NOS; 99=Not available	A2	<u>Note:</u> “N+NOS” code is not allowed in the TNM, 7th revision, but allowed in this HR study as some cancer registries can only access this information
113.	yM (optional)	Stage M, according to TNM classification, 7th revision.  0=M0; 1=M1; 9= Not available	F1	

\*F=numeric; A=alphanumeric

### Additional data for LUNG CANCER (C34)

	<i>Variable</i>	<i>Recommended coding of values</i>	<i>Format*</i>	<i>Definition/notes</i>
57.	Laterality	1 = left; 2 = right; 3 = bilateral; 9 = unknown	F1	
58.	EGFR mutation	1= present; 2= absent; 9= unknown	F1	To be collected for non-small cell cancer ONLY
<i>Diagnostic exams on the lung within 3 months (after or before) from diagnosis</i>				
59.	Conventional thorax Imaging (radiography, stratigraphy, CT scan)	1= done; 2= not done; 9= unknown	F1	
60.	Spiral CT	1= done; 2= not done; 9= unknown	F1	
61.	Positron emission tomography (PET)	1= done; 2= not done; 9= unknown	F1	
62.	Magnetic resonance imaging (MRI)	1= done; 2= not done; 9= unknown	F1	
63.	Bronchoscopy	1= done; 2= not done; 9= unknown	F1	
64.	Mediastinoscopy	1= done; 2= not done; 9= unknown	F1	
65.	Endobronchial ultrasound guided bronchoscopy	1= done; 2= not done; 9= unknown	F1	
<i>Diagnostic exams for distant metastases within 3 months (after or before) from diagnosis</i>				
66.	Liver imaging	1= done; 2= not done; 9= unknown	F1	Each exam should be considered
67.	Lung imaging	1= done; 2= not done; 9= unknown	F1	
68.	Brain imaging	1= done; 2= not done; 9= unknown	F1	
69.	Skeleton imaging	1= done; 2= not done; 9= unknown	F1	
<i>Stage at diagnosis</i>				
70.	pT	Pathological T, according to TNM classification, 7th revision.  00=TX ; 01=T0 ; 02=Tis; 10=T1NOS; 11=T1a; 12=T1b; 20=T2NOS; 21=T2a ; 22=T2b ; 30=T3NOS; 40=T4NOS; 99= Not available	A2	
71.	cT	Clinical T, according to TNM classification, 7th revision.  00=TX ; 01=T0 ; 02=Tis; 10=T1NOS; 11=T1a; 12=T1b; 20=T2NOS; 21=T2a ; 22=T2b ; 30=T3NOS; 40=T4NOS; 99= Not available	A2	
72.	Pathological tumour diameter	Tumour size in mm. 000-900 988= >900 999= unknown	A3	
73.	Clinical tumour diameter	Tumour size in mm. 000-900 988= >900 999= unknown	A3	
74.	pN	Pathological N, according to TNM classification, 7th revision.  00=NX; 01=N0; 10=N1NOS; 20=N2NOS; 30=N3NOS; 40=N+NOS; 99=Not available	A2	<b>Note:</b> “N+NOS” code is not allowed in the TNM, 7th revision, but allowed in this HR study as some cancer registries can only access this information
75.	cN	Clinical N, according to TNM classification, 7th revision.  00=NX; 01=N0; 10=N1NOS; 20=N2NOS; 30=N3NOS; 40=N+NOS; 99=Not available	A2	For “N+NOS” code, see Note on pN stage



76.	pM	Pathological M, according to TNM classification, 7th revision. 0=M0; 1=M1; 9= Not available	F1	
77.	cM	Clinical M, according to TNM classification, 7th revision. 0= M0; 10= M1; 11= M1a; 12= M1b; 99= Not available	F2	
78.	Site of metastasis (in clear, optional)		A10	Please, report the site of metastasis.
<i>Treatment</i>				
79.	SURGERY	0= not done; 1= lobectomy 2= pneumectomy; 3= partial resection; 4= segmentectomy; 8= done, but unknown type of surgery; 9= unknown	F1	
80.	Day of surgery	01-31 If missing or not applicable, code: 99	F2	
81.	Month of surgery	01-12 If missing or not applicable, code: 99	F2	
82.	Year of surgery	2011-2014 If missing or not applicable, code: 9999	F4	
83.	Reasons for no surgery	1= medical contraindications; 2= patient refusal; 3= advanced cancer; 4= other; 8= no indication; 9= unknown	F1	
84.	Surgical radicality	1 = R0, no residual tumour; 2 = R1, microscopic residual tumour; 3 = R2, macroscopic residual tumour; 4 = R1/R2, presence of residual tumour but unknown if R1 or R2; 9 = RX, presence of residual tumour cannot be assessed or information is not available	F1	
85.	CHEMOTHERAPY	1= done; 2= not done; 9= unknown	F1	
86.	Day starting chemotherapy	01-31 If missing or not applicable, code: 99	F2	
87.	Month starting chemotherapy	01-12 If missing or not applicable, code: 99	F2	
88.	Year starting chemotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
89.	Modality of chemotherapy	1= neo-adjuvant; 2= adjuvant; 3= palliative; 9= unknown	F1	

90.	Type of chemotherapy (in clear, optional)		A20	Please, report the therapeutic scheme or the drug(s) used.
91.	TARGETED TREATMENT (e.g. monoclonal antibody)	1= done; 2= not done; 9= unknown	F1	
92.	Day starting targeted treatment	01-31 If missing or not applicable, code: 99	F2	
93.	Month starting targeted treatment	01-12 If missing or not applicable, code: 99	F2	
94.	Year starting targeted treatment	2011-2014 If missing or not applicable, code: 9999	F4	
95.	Type of targeted treatment (in clear, optional)		A20	Please, report the drug(s) used.
96.	RADIOTHERAPY	1= done; 2= not done; 9= unknown	F1	
97.	Modality of radiotherapy	1= neo-adjuvant; 2= adjuvant; 3= palliative; 9= unknown	F1	
98.	Day starting radiotherapy	01-31 If missing or not applicable, code: 99	F2	
99.	Month starting radiotherapy	01-12 If missing or not applicable, code: 99	F2	
100.	Year starting radiotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
101.	Reasons for no radiotherapy	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	

\*F=numeric; A=alphanumeric

**Additional data for SKIN MELANOMA (C44)**

	<i>Variable</i>	<i>Recommended coding of values</i>	<i>Format*</i>	<i>Definition/notes</i>
57.	Modality of diagnosis /Mode of presentation	1= symptomatic tumour; 2= screened-detected; 9= unknown	F1	
58.	Laterality	1= left; 2= right; 3= bilateral; 9= unknown	F1	
59.	Multifocality	1= yes; 2= no; 9= unknown	F1	<b>To be collected according to ENCR rules:</b> Multifocal tumours – that is, discrete masses apparently not in continuity with other primary cancers originating in the same primary site or tissue - are counted as a single cancer.
60.	Source of data	1= only clinical notes; 2= pathological report; 3= pathological report unavailable; 9= unknown	F1	
61.	Pattern of neoplastic growth	1= vertical; 2= horizontal; 3= mixed (vertical/horizontal); 8= not mentioned in the pathological report; 9= unavailable pathological report to CR	F1	
62.	Lymphocytic infiltration	0= absent; 1= present, brisk 2= present, not brisk; 8= not mentioned in the pathological report; 9= unavailable pathological report to CR	F1	
63.	Associated nevo	1= yes; 2= no; 9= unknown	F1	
64.	BRAF mutation	1= present; 2= absent; 9= unknown	F1	
65.	Regression	1= yes; 2= no; 9= unknown	F1	
66.	Microscopic involvement	0=absent; 1= vascular; 2= perineural; 3=both (vascular and perineural); 9= unknown	F1	
<i>Diagnostic exams for distant metastases within 3 months (after or before) from diagnosis</i>				
67.	Liver imaging	1= done; 2= not done; 9= unknown	F1	<b>Each exam should be considered</b>
68.	Lung imaging	1= done; 2= not done; 9= unknown	F1	
69.	Brain imaging	1= done; 2= not done; 9= unknown	F1	
70.	Skeleton imaging	1= done; 2= not done; 9= unknown	F1	
<i>Stage at diagnosis</i>				
71.	pT	Pathological T, according to TNM classification, 7th revision.  00=TX ; 01=T0; 02=Tis; 10=T1NOS; 11=T1a; 12=T1b; 20=T2NOS; 21=T2a; 22=T2b; 30=T3NOS; 31=T3a; 32=T3b; 40=T4NOS; 41=T4a; 42=T4b; 99=Not available	A2	cT is not allowed in the TNM, 7th revision
72.	Ulceration	1= present; 2= absent; 8= not mentioned in the pathological report; 9= unavailable pathological report to CR	F1	
73.	Breslow thickness	Tumour size in mm. 000.0-900.0 9880= >900.0 9999= unknown	A5	Ex: In case of 0.6mm, please report 000.6
74.	pN	Pathological N, according to TNM classification, 7th revision.  00=NX; 01=N0; 2=N0(sn); 10=N1NOS; 11=N1a; 12=N1b; 13=N1(sn); 20=N2NOS; 21=N2a; 22=N2b; 23=N2c; 30=N3NOS; 40=N+NOS; 88=NX(sn); 99=Not available	A2	<b>Note:</b> “N+NOS” code is not allowed in the TNM, 7th revision, but allowed in this HR study as some cancer registries can only access this information

75.	cN	Clinical N, according to TNM classification, 7th revision. 00=NX; 01=N0; 10=N1NOS; 11=N1a; 12=N1b; 20=N2NOS; 21=N2a; 22=N2b; 23=N2c; 30=N3NOS; 40=N+NOS; 99=Not available	A2	For “N+NOS” code, see Note on pN stage
76.	Determination of nodal micrometastases (optional)	0= not done; 1= done, negative; 2= done, positive; 3= done, unknown result; 9= unknown	F1	
77.	Total number of examined nodes	000= not examined; 001-150 999= unknown	A3	
78.	Total number of metastatic nodes	000-150 999= unknown	A3	In case of no nodal examination, the number of metastatic nodes should be 000
79.	pM	Pathological M, according to TNM classification, 7th revision. 0= M0; 1= M1; 9= Not available	F1	
80.	cM	Clinical M, according to TNM classification, 7th revision. 0= M0; 10= M1; 11= M1a; 12= M1b; 13= M1c;  99 = Not available	F2	
81.	Site of metastasis (in clear, optional)		A10	Please, report the site of metastasis.
82.	Sentinel lymph node biopsy	1= done; 2= not done; 9= unknown	F2	
83.	Number of examined sentinel nodes	00= not examined; 01-90 99= unknown	A2	
84.	Number of positive sentinel nodes	00-90 99= unknown	A2	In case of no sentinel node examination, the number of positive sentinel nodes should be 00
85.	pN stage sentinel lymph node	0= N0; 1= N1; 9= NX	F1	
86.	Mitotic index	1= <1 per mm <sup>2</sup> 2= ≥1 per mm <sup>2</sup> ; 8= not mentioned in the pathological report; 9= unavailable pathological report to CR	F1	
87.	CLARK level (to be used only for tumours ≤1 mm)	1= Clark I, in situ melanoma; 2= Clark II, invasive melanoma, up to the papillar derma; 3= Clark III, invasion of papillar derma; 4= Clark IV, invasion of reticularis derma; 5= Clark V, invasion of subcutaneous adipose tissue; 8= Clark level not reported in the pathological report; 9= unavailable pathological report to CR	F1	

<i>Treatment</i>				
88.	<b>SURGERY</b> (First excision)	0= not done; 1= done in a specialized hospital; 2= done in a general hospital; 3= done, outpatient; 4= done, but unknown place of excision; 9= unknown if done	F1	A specialized hospital is an oncological hospital/department or a Comprehensive Cancer Centre, or a dermatological hospital.
89.	Day of surgery	01-31  If missing or not applicable, code: 99	F2	
90.	Month of surgery	01-12  If missing or not applicable, code: 99	F2	
91.	Year of surgery	2011-2014  If missing or not applicable, code: 9999	F4	
92.	Reasons for no surgery	1= medical contraindications; 2= patient refusal; 3= other; 4= advanced cancer; 8= no indication; 9= unknown	F1	
93.	Surgical radicality	1= R0, no residual tumour; 2= R1, microscopic residual tumour; 3= R2, macroscopic residual tumour; 4= R1/R2, presence of residual tumour but unknown if R1 or R2; 9= RX, presence of residual tumour cannot be assessed or information is not available	F1	
94.	<b>CHEMOTHERAPY</b>	1= done; 2= not done; 9= unknown	F1	
95.	Day starting chemotherapy	01-31  If missing or not applicable, code: 99	F2	
96.	Month starting chemotherapy	01-12  If missing or not applicable, code: 99	F2	
97.	Year starting chemotherapy	2011-2014  If missing or not applicable, code: 9999	F4	
98.	Modality of chemotherapy	1 = neo-adjuvant; 2= adjuvant; 3= palliative; 9= unknown	F1	
99.	Type of chemotherapy (in clear, optional)		A20	Please, report the therapeutic scheme or the drug(s) used.
100.	Reasons for no chemotherapy	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	
101.	<b>TARGETED TREATMENT</b>	1= done; 2= not done; 9= unknown	F1	Note: For example, monoclonal antibody
102.	Day starting targeted treatment	01-31  If missing or not applicable, code: 99	F2	

103.	Month starting targeted treatment	01-12 If missing or not applicable, code: 99	F2	
104.	Year starting targeted treatment	2011-2014 If missing or not applicable, code: 9999	F4	
105.	Type of targeted treatment (in clear, optional)		A20	Please, report the drug(s) used.
106.	RADIOTHERAPY	1= done; 2= not done; 9= unknown	F1	
107.	Day starting radiotherapy	01-31 If missing or not applicable, code: 99	F2	
108.	Month starting radiotherapy	01-12 If missing or not applicable, code: 99	F2	
109.	Year starting radiotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
110.	Modality of radiotherapy	1= neo-adjuvant; 2= adjuvant; 3= palliative; 9= unknown	F1	
111.	Reasons for no radiotherapy	1= medical contraindications; 2= patient refusal; 3= other; 8= no indication; 9= unknown	F1	

\*F=numeric; A=alphanumeric

## Additional data for LYMPHOMA

(ICD-O-3 morphology: DLBCL= 9678-9680, 9684; FL= 9690-9691, 9695, 9698)

	<i>Variable</i>	<i>Recommended coding of values</i>	<i>Format*</i>	<i>Definition/notes</i>
<i>Work-up at diagnosis</i>				
57.	Bone marrow exam	0= not done; 1= done, positive; 2= done, negative; 3= done, unknown result; 9= unknown if done or not	F1	
58.	CT scan (above and below the diaphragm)	0= not done; 1= done, positive; 2= done, negative; 3= done, unknown result; 9= unknown if done or not	F1	
59.	Day performing CT scan	01-31 If missing or not applicable, code: 99	F2	
60.	Month performing CT scan	01-12 If missing or not applicable, code: 99	F2	
61.	Year performing CT scan	2011-2014 If missing or not applicable, code: 9999	F4	
62.	Positron emission tomography (PET)	0= not done; 1= done, positive; 2= done, negative; 3= done, unknown result; 9= unknown if done or not	F1	
63.	Day performing PET scan	01-31 If missing or not applicable, code: 99	F2	
64.	Month performing PET scan	01-12 If missing or not applicable, code: 99	F2	
65.	Year performing PET scan	2011-2014 If missing or not applicable, code: 9999	F4	
<i>Blood test at diagnosis</i>				
66.	Serum haemoglobin	Please, refer to the nearest value to diagnosis, however before starting primary treatment. To be collected as gr/dL. 00.0-50.9  99.9, if unavailable;	A4	Example: Serum haemoglobin= 12.3 gr/dL Code: 12.3
67.	LDH test category	Please, refer to the nearest value to diagnosis, however before starting primary treatment.  1= normal; 2= higher than upper normal limit; 3= LDH test done, unknown result; 9= unknown if done or not	F1	
68.	LDH value (optional)	Please, report the nearest value to diagnosis, however before starting primary treatment. To be collected as U/l: 0000-2000  9888= >2000 9999, if unavailable	A4	To be collected ONLY IF the LDH test category was not available

69.	Higher LDH (optional)	Upper normal limit for LDH. To be collected as U/l. 0000-2000  9888= >2000 9999, if unavailable	A4	To be collected ONLY IF the LDH test category was not available
70.	β2 microglobulin category	Please, refer to the nearest value to diagnosis, however before starting primary treatment.  1= normal; 2= higher than upper normal limit; 3= β2 microglobulin test done, unknown result; 9= unknown if done	F1	
71.	β2 microglobulin value (optional)	Please, report the nearest value to diagnosis, however before starting primary treatment. To be collected as mg/dl. 00.00-20.00  98.88= >20.00 99.99, if unavailable	A4	To be collected ONLY IF the β2 microglobulin category was not available
72.	Higher β2 microglobulin (optional)	Upper normal limit for β2 microglobulin. To be collected as mg/dl. 00.00-20.00  98.88= >20.00 99.99, if unavailable	A4	To be collected ONLY IF the β2 microglobulin category was not available
<i>Stage at diagnosis</i>				
73.	B symptoms	1= present; 2= absent; 9= unknown	F1	B symptoms consist of fever (greater than 38°C) or night sweats or weight loss (>10% in less than 6 months). Code present if any of them was present
74.	Reported ANN ARBOR stage	1= Stage I: lymphoma localized in one region /organ; 2= Stage II: lymphoma in 2 distinct lymph-node regions, in the same side of diaphragm, or multiple localisations in one organ with nodal involvement in the same side of diaphragm; 3= Stage III: involvement of two regions, both sides of diaphragm; 4= Stage IV: massive involvement of more than one organ, with distal node involvement; 9= unknown	F1	Please, report the Ann Arbor stage reported in the clinical records
75.	Reconstructed ANN ARBOR stage	1= Stage I: lymphoma localized in one region /organ; 2= Stage II: lymphoma in 2 distinct lymph-node regions, in the same side of diaphragm, or multiple localisations in one organ with nodal involvement in the same side of diaphragm; 3= Stage III: involvement of two regions, both sides of diaphragm; 4= Stage IV: massive involvement of more than one organ, with distal node involvement; 9= unknown	F1	Note 1: Please, report the Ann Arbor stage reconstructed by using all the information found in the clinical records <u>ONLY IF the original stage was not available</u> in medical record  Note 2: Liver and bone marrow involvements should be classified as stage IV



<i>Nodal localisation at diagnosis FOR FL as a prognostic factor (within 3 months -after or before- from diagnosis)</i>				
76.	The largest diameter of lymph nodes	Tumour size in mm. 000-900 988= >900 999= unknown	A3	To be used as a proxy of presence or absence of bulk disease
77.	Number of nodal regions involved	00-50 99= unknown	A2	
78.	Day of first detection of nodal involvement	01-31 If missing or not applicable, code: 99	F2	
79.	Month of first detection of nodal involvement	01-12 If missing or not applicable, code: 99	F2	
80.	Year of first detection of nodal involvement	2011-2014 If missing or not applicable, code: 9999	F4	
81.	FLIPI (only for Follicular Lymphoma)	0= 0 points; 1= 1 point; 2= 2 points 3= 3 points; 4= 4 points; 5= 5 points; 9= unknown	F1	See Annex C for the definition
82.	FLIPI origin	0= reported in the clinical record 1= derived from the information needed to score	F1	
<i>Extranodal localisations at diagnosis (to be established by examining clinical documentation, especially imaging) ONLY FOR DLBCL as a prognostic factor (within 3 months -after or before- from diagnosis)</i>				
83.	Lung or respiratory tract	1= present; 2= absent; 9= unknown	F1	
84.	Serosae (pleura, pericardium, vaginalis testis)	1= present; 2= absent; 9= unknown	F1	
85.	Liver	1= present; 2= absent; 9= unknown	F1	
86.	Nervous system (brain, spinal cord)	1= present; 2= absent; 9= unknown	F1	
87.	Stomach	1= present; 2= absent; 9= unknown	F1	
88.	Colorectum	1= present; 2= absent; 9= unknown	F1	
89.	Skin and subcutaneous, soft tissues	1= present; 2= absent; 9= unknown	F1	
90.	Skeleton	1= present; 2= absent; 9= unknown	F1	
91.	Urinary organs	1= present; 2= absent; 9= unknown	F1	

92.	Salivary / lacrimal glands	1= present; 2= absent; 9= unknown	F1	
93.	Spleen	1= present; 2= absent; 9= unknown	F1	
94.	Other	1= present; 2= absent; 9= unknown	F1	
95.	IPI (only for Diffuse B-cell lymphoma)	0= 0 points; 1= 1 point; 2= 2 points; 3= 3 points; 4= 4 points; 5= 5 points; 9=unknown	F1	See Annex C for the definition
96.	IPI origin	0= reported in the clinical record 1= derived from the information needed to score	F1	
<i>Treatment</i>				
97.	SURGERY	1= done; 2= not done; 9= unknown	F1	Only for extranodal Non-Hodgkin lymphoma.  For example, surgery can be carried out for colon lymphoma or stomach lymphoma (although guidelines do not recommend surgery as treatment)
98.	CHEMOTHERAPY	1= done; 2= not done; 9= unknown	F1	
99.	Day starting chemotherapy	01-31  If missing or not applicable, code: 99	F2	
100.	Month starting chemotherapy	01-12  If missing or not applicable, code: 99	F2	
101.	Year starting chemotherapy	2011-2014  If missing or not applicable, code: 9999	F4	
102.	Type of chemotherapy (optional)	Most common regimens/drugs:  01= COP (cyclophosphamide, oncovin, prednisone); 02=COPP (Cyclophosphamide, Oncovin (vincristine), procarbazine, prednisone); 03= CHOP (Cyclophosphamide, Hydroxydaunorubicin (also called doxorubicin or Adriamycin), Oncovin (vincristine), Prednisone or prednisolone); 04= CHOP-Bleo (Cyclophosphamide, adriamycin, vincristine, bleomycin and prednisolone); 05= CHOEP/EPOCH (CHOP+etoposide); 06= C(X)OP21; 07= CVP (Cyclophosphamide, (vincristine), prednisone); 08= MCP (mitoxantrone, chlorambucil and prednisolone); 09= CHVP (cyclophosphamide, adriamycin, etoposide, prednisolone); 10= FCM (fludarabine, cyclophosphamide, mitoxantrone);	F2	CHOP includes CHOP14, CHOP21, miniCHOP

		<p>11= Chlorambucil;  12= bendamustine;  13= ICE (Ifosfamide, carboplatin, etoposide (VP-16))  14= CBV (Cyclophosphamide, BCNU (carmustine), etoposide);  15 =DHAP (dexamethasone, cytarabine, cisplatin) ;  16 = CEBOPP (Cyclophosphamide, epirubicin, bleomycin, vincristin, prednisone, procarbazine);  17 = BEAM (carmustine, etoposide, cytarabine, melphalan);</p> <p>88= other;  99= unknown</p>		
103.	Reasons for no chemotherapy	<p>1= medical contraindications;  2= patient refusal;  3= watch and wait;  4= other;  9= unknown</p>	F1	
104.	TARGETED THERAPY	<p>1= done;  2= not done;  9= unknown</p>	F1	
105.	Type of targeted therapy (optional)	<p>List of most commonly used targeted drugs:</p> <p><i>CD20 Targeted Drugs</i>  01= Rituximab*;  02= Tositumumab*;  03= Ibritumomab Tiuxetan*;</p> <p><i>HDAC inhibitors</i>  04= Vorinostat*;</p> <p><i>CD20 Targeted Drugs</i>  05= Ofatumumab (also called HuMax-CD20);  06= Veltuzumab;</p> <p><i>Bcl-2 Targeted Drugs</i>  07= Oblimersen sodium;  08= Gossypol (levo gossypol);  09= Obatoclax;</p> <p><i>mTOR inhibitors</i>  10= Everolimus;  11= Rapamycin;  12= Temsirolimus;  13= Deforolimus;</p> <p><i>Akt inhibitors</i>  14= Perifosine;  15= Triciribine;</p> <p><i>HDAC inhibitors</i>  16= Belinostat;  17= Entinostat;  18= Panobinostat;  19= Romidepsin (also called depsipeptide);</p> <p>88= other;  99= unknown</p>	F2	Note: drugs without * are those still under study in controlled clinical trials

106.	Day starting targeted therapy	01-31 If missing or not applicable, code: 99	F2	
107.	Month starting targeted therapy	01-12 If missing or not applicable, code: 99	F2	
108.	Year starting targeted therapy	2011-2014 If missing or not applicable, code: 9999	F4	
109.	RADIOTHERAPY	1= done; 2= not done; 9= unknown	F1	
110.	Day starting radiotherapy	01-31 If missing or not applicable, code: 99	F2	
111.	Month starting radiotherapy	01-12 If missing or not applicable, code: 99	F2	
112.	Year starting radiotherapy	2011-2014 If missing or not applicable, code: 9999	F4	
113.	Bone marrow transplantation	1= done; 3= not done; 9= unknown	F1	
114.	Type of bone marrow transplantation	1= autologous; 2= eterologous; 9= unknown	F1	
115.	Day of bone marrow transplantation	01-31 If missing or not applicable, code: 99	F2	
116.	Month of bone marrow transplantation	01-12 If missing or not applicable, code: 99	F2	
117.	Year of bone marrow transplantation	2011-2014 If missing or not applicable, code: 9999	F4	
118.	Patient status after completion of primary treatment	1= complete remission (no symptoms, nor nodal or extranodal localisations); 2= partial remission (reduction of measurable parameters, e.g. of bulky, with no new localisations); 3= stable disease (no substantial modifications of measurable parameters, or no response to primary treatment); 4= progression; 8= not evaluable because of interruption of treatment; 9= unknown	F1	<b>Note:</b> it finishes with treatment done to consolidate, e.g. if planned at diagnosis  There is a progression in case of absent response or partial remission to the 1st line treatment
119.	Day of patient status evaluation	01-31 If missing or not applicable, code: 99	F2	
120.	Month of patient status evaluation	01-12 If missing or not applicable, code: 99	F2	
121.	Year of patient status evaluation	2011-2014 If missing or not applicable, code: 9999	F4	

*Follow-up in addition to the first common part*

122.	<b>Transformation (from FL to DLBCL)</b>	<b>1= no transformation; 2= transformation; 9= unknown</b>	<b>F1</b>	
123.	<b>Day of transformation</b>	<b>01-31 If missing or not applicable, code: 99</b>	<b>F2</b>	
124.	<b>Month of transformation</b>	<b>01-12 If missing or not applicable, code: 99</b>	<b>F2</b>	
125.	<b>Year of transformation</b>	<b>2011-2014 If missing or not applicable, code: 9999</b>	<b>F4</b>	

\*F=numeric; A=alphanumeric