

CAHRES PROJECT : OVARIAN CANCER FOLLOW UP STUDY

Date: 1 June 2009

Rino Bellocco

Note: Need to be revised by Fall 2009

DATA DICTIONARY
V1

Note: variables are from FOUR different files

- | | | |
|------------|------------------------------------|---------------|
| (a) | Embla (medical abstracts): | Type 1 |
| (b) | Tomas (case control study): | Type 2 |
| (c) | Generated: | Type 3 |
| (d) | Death Registry | Type 4 |

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Variable	Format	Type
agefb	AGE AT FIRST BIRTH continuous variable	2
agelb	AGE AT LAST BIRTH continuous variable	2
bfdur	BREAST FEEDING DURATION IN MONTHS continuous variable	2
bmi	BODY MASS INDEX CALCULATED FROM HEIGHT (m) AND WEIGHT (kg) MEASURES continuous variable (wt/htxht)	2,3
bmi_cat	BODY MASS INDEX CATEGORICAL 1 = <= 18.5 underweight 2 = >= 18.5 but < 25 normal weight 3 = >= 25 but < 30 overweight 4 = >= 30 obese 9 = missing	2,3
cause_1	CAUSE OF DEATH among deaths before 31/12/2001 0 = NO OVARIAN 1 = ovarian cancer deaths only register code '1830' or 'C56'	3,4
cause_2	CAUSE OF DEATH among deaths before 31/12/2001 0 = No Ovarian 1 = ovarian cancer (as above) or related deaths	3,4
canin_mths	OVARIAN AND ENDOMETRIAL CANCER DIAGNOSED LESS THAN 1 MONTH OF EACH OTHER	

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0 = no

1 = yes

chemoy1

CHEMOTHERAPY LINE 1

0 = no

1 = yes

1

chemo1

TYPE OF CHEMOTHERAPY LINE 1

0 = platinum compounds

1 = cisplatin

2 = carboplatin

3 = taxol

4 = combination of 2 types from cisplatin, carboplatin or taxol

5 = other preparations

9 = no chemotherapy

1

chemoyes2

CHEMOTHERAPY LINE 2

0 = no

1 = yes

2 = not stated

9 = missing

1

chemoyes3

CHEMOTHERAPY LINE 3

0 = no

1 = yes

2 = not stated

9 = missing

1

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chemoyes4	CHEMOTHERAPY LINE 4 0 = no 1 = yes 2 = not stated 9 = missing	1
chemoyes5	CHEMOTHERAPY LINE 5 0 = no 1 = yes 2 = not stated 9 = missing	1
chemoyes6	CHEMOTHERAPY LINE 6 0 = no 1 = yes 2 = not stated 9 = missing	1
chemonow	CHEMOTHERAPY NOW 0 = no 1 = yes	1
cycles1	NUMBER OF TREATMENT CYCLES LINE 1	1
death	DEAD STATUS ACCORDING TO THE DEATH REGISTER 0 = no 1 = yes	3,4
deathdate	DATE OF DEATH ACCORDING TO DEATH REGISTER up to 31/04/2003	4
diagage	AGE AT DIAGNOSIS continuous variable	2
diagage_cat	AGE AT DIAGNOSIS CATEGORICAL 1 = 50 – 54 years 2 = 55 – 59 years 3 = 60 – 64 years 4 = 65 – 69 years 5 = 70 – 75 years	2,3

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diagdat	Date of diagnosis according to the National Cancer Registry	1
?diagtumor	TUMOR SIZE AT DIAGNOSIS Diameter in cm 1 = small <= 7cm 2 = medium > 7cm but <= 16cm 3 = large > 16cm 9 = missing	1,3
educ	EDUCATION 1 = folkskola 2 = grundskola 3 = gymnasium 4 = högskola/universitet	?
endo	ENDOCRINE THERAPY 0 = no 1 = yes 2 = not stated	1
enstd	ENDOCRINE THERAPY START DATE LINE 1	1
enendd	ENDOCRINE THERAPY LAST DATE LINE 1	1
?en_endd2	ENDOCRINE THERAPY LAST DATE LINE 2	1
ennow	ENDOCRINE THERAPY ONGOING 5 YEARS AFTER DIAGNOSIS 0 = no 1 = yes	1
eof1	time of overall death, as of April 2003	
eof2	five year time of -up	
eof3	OC time of death, as of December 2001	
eof4	five year OC time of -up	

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eof5 OC-REL time of death, as of December 2001

eof6 OC-REL time of death, as of December 2001

eoreyrs ERT MEDIUM POTENCY ESTROGENS WITHOUT PROGESTINS – RECENCY , 2,3
-1 = never used
0 = current use
other number = number of years since use

eore_cat ERT MEDIUM POTENCY ESTROGENS WITHOUT PROGESTINS – RECENCY 2,3
CATEGORICAL
0 = never used
1 = current use
2 = <5 years ago
3 = >=5 years ago
. = missing

eotr HRT MEDIUM POTENCY ESTROGENS WITHOUT PROGESTINS - TREATMENT 2
0 = no
1 = yes
. = missing

eoduyrs DURATION OF ESTROGENS ONLY IN YEARS 2,3
(eodu/365.25)

eodu_cat DURATION OF ESTROGENS ONLY CATEGORICAL 2,3
0 = no eotr
1 = <1 yr
2 = >=1 yr to <2 yrs
3 = >=2 yrs to <5 yrs
4 = >=5 yrs to <10 yrs
5 = >=10 yrs
. = missing

eotr_only_pure eotr PURE USERS 2,3
(Takes the missing values from eotr as genuinely missing information. This variable is the most accurate)
0 = never user
1 = exclusive user
2 = non-exclusive user

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. = missing

eotr_only	SAME AS EOTR_ONLY_PURE, HOWEVER: (This variable takes the missing values from eotr interpreted as "0" or "no". This variable is only to be used in the analysis if there are insufficient numbers for the model to be fit) 0 = never user (missing = no) 1 = exclusive user 2 = non-exclusive user	2,3
eodu	HRT MEDIUM POTENCY ESTROGENS WITHOUT PROGESTINS – DURATION IN DAYS continuous variable	2

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eore **ERT MEDIUM POTENCY ESTROGENS WITHOUT PROGESTINS – RECENCY** **2**

-1 = never used

0 = current use

other number = number of days since use

epctre_cat **HRT MEDIUM POTENCY ESTROGENS WITH CONTINUOUS PROGESTINS 2,3 RECENCY CATEGORICAL**

0 = never used

1 = current use

2 = <5 years ago

3 = >=5 years ago

. = missing

epcyreys **HRT MEDIUM POTENCY ESTROGENS WITH CYCLIC PROGESTINS – RECENCY** **2,3**

-1 = never used

0 = current use

other number = number of years since use

epcyre_cat **HRT MEDIUM POTENCY ESTROGENS WITH CYCLIC PROGESTINS – RECENCY CATEGORICAL** **2,3**

0 = never used

1 = current use

2 = <5 years ago

3 = >=5 years ago

. = missing

epctreys **HRT MEDIUM POTENCY ESTROGENS WITH CONTINUOUS PROGESTINS – RECENCY** **2,3**

-1 = never used

0 = current use

other number = number of years since use

epcyduys **DURATION OF ESTROGENS & PROGESTINS (CYCLIC) ONLY IN YEARS (ep_cydu/365.25)** **2,3**

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epctduyrs	DURATION OF ESTROGENS & PROGESTINS (CONTINUOUS) ONLY IN YEARS (ep_ctdu/365.25)	2,3
epctdu_cat	DURATION OF ESTROGENS & PROGESTINS (CONTINUOUS) ONLY CATEGORICAL 0 = no ep_ctdu 1 = <1 yr 2 = >=1 yr to <2 yrs 3 = >=2 yrs to <5 yrs 4 = >=5 yrs to <10 yrs 5 = >=10 yrs . = missing	2,3
ep_cytr	HRT MEDIUM POTENCY ESTROGENS WITH CYCLIC PROGESTINS - TREATMENT 0 = no 1 = yes . = missing	2
ep_cytr_only_pure	ep_cytr PURE USERS (Takes the missing values from ep_cytr as genuinely missing information. This variable is the most accurate) 0 = never user 1 = exclusive user 2 = non-exclusive user . = missing	2,3
ep_cytr_only	SAME AS EP_CYTR_ONLY_PURE, HOWEVER: (This variable takes the missing values from ep_cytr interpreted as "0" or "no". This variable is only to be used in the analysis if there are insufficient numbers for the model to be fit) 0 = never user (missing = no) 1 = exclusive user 2 = non-exclusive user	2,3
ep_cydu	HRT MEDIUM POTENCY ESTROGENS WITH CYCLIC PROGESTINS – DURATION IN DAYS continuous variable	1

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ep_cyre	HRT MEDIUM POTENCY ESTROGENS WITH CYCLIC PROGESTINS – RECENCY -1 = never used 0 = current use other number = number of days since use	1
ep_ctr	HRT MEDIUM POTENCY ESTROGENS WITH CONTINUOUS PROGESTINS - TREATMENT 0 = no 1 = yes . = missing	2
ep_ctr_only_pure	ep_ctr PURE USERS (Takes the missing values from ep_ctr as genuinely missing information. This variable is the most accurate) 0 = never user 1 = exclusive user 2 = non-exclusive user . = missing	2,3
ep_ctr_only	SAME AS EP_CTR_ONLY_PURE, HOWEVER: 2,3 (This variable takes the missing values from ep_ctr interpreted as “0” or “no”. This variable is only to be used in the analysis if there are insufficient numbers for the model to be fit) 0 = never user (missing = no) 1 = exclusive user 2 = non-exclusive user	
ep_ctdu	HRT MEDIUM POTENCY ESTROGENS WITH CONTINUOUS PROGESTINS – DURATION IN DAYS continuous variable	1
ep_ctre	HRT MEDIUM POTENCY ESTROGENS WITH CONTINUOUS PROGESTINS – RECENCY -1 = never used 0 = current use other number = number of days since use	1

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fail1	overall death indicator, as of April 2003	3
fail2	five year overall death indicator	3
fail3	OC death indicator or death of death	3
fail4	five year OC death indicator of death	3

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fail5	OC- related death indicator of death	
fail6	five year OC- related death indicator of death	
f2	HEIGHT continuous variable	2
f4	WEIGHT ONE YEAR AGO continuous variable	2
f10	SMOKING – EVER/NEVER – MAIN QUESTIONNAIRE 1 = yes 2 = no . = missing	2
f11	SMOKING – ONE YEAR AGO – MAIN QUESTIONNAIRE 1 = yes 2 = no . = missing	2
f32_a	TUBAL LIGATION EVER 0 = no 1 = yes . = missing	2
f32_a1	TUBAL LIGATION YEAR	2
f35	OVARIAN CANCER IN MOTHER/SISTER 1 = yes 2 = no 3 = don't know . = missing	2
f35_a	OVARIAN CANCER IN MOTHER 1 = yes . = missing	2
f35_b	OVARIAN CANCER IN SISTER(S) 1 = yes . = missing	2
f37	AGE AT MENARCHE IN YEARS continuous variable	2

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f49	HRT CURRENT USE 1 = yes 2 = no . = missing	1
f43	HORMONAL CONTRACEPTIVES EVER 1 = no 2 = yes . = missing	1
figo	STAGE OF DISEASE ACCORDING TO FIGO 0 = not stated 1 = Ia 2 = Ib 3 = Ic 4 = Ix 5 = IIa 6 = IIb 7 = IIc 8 = IIX 9 = IIIa 10 = IIIb 11 = IIIc 12 = IIIx 13 = IVx	1,3
figo_cat	STAGE OF DISEASE ACCORDING TO FIGO COLLAPSED FIGO STAGES 0 = not stated 1 = (figo 1 – 4) 2 = (figo 5 – 8) 3 = (figo 9 – 12) 4 = (figo 13)	
fupdat	DATE OF LAST FOLLOW-UP Follow-up for at least 5 years after date of diagnosis	1
exclude	Exclusion criteria: 0 = not excluded (ALL in the ovarian follow up data set)	

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	1 = excluded	1
hrtany	HRT EVER USE before diagnosis 0 = no 1 = yes . = missing	2
hrtanynew	Any HRT Use 0 = never user 1= any user	2
hrt_rd	Combined effects of duration & recency 0 = never users 1 = current low 2 = current high 3 = former low 4 = former high	2,3
hrt_afterdx	Use of HRT after diagnosis 1= NEVER 2=USER 3=NOTSTATED	1,3
hrt_afterdx_missno	Use of HRT after diagnosis:NOT STATED 1= NEVER 2= USER	1,3
hist_0	TUMOR HISTOLOGICAL SUBTYPE ORIGINAL PAD 1 = serous 2 = mucinous 3 = endometrioid 4 = clearcell 5 = undifferentiated 6 = others 99 = reviewed as non-ovarian malignancy } *** 199 = other non-epithelial ovarian malignancy } *** 299 = other non-ovarian malignancy } *** . = missing NB: *** = THESE SHOULD NOT BE INCLUDED	

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hyst1	HYSTERECTOMY OCCASSION 1 0 = no 1 = yes	1
lgllbuk1	ABDOMINAL CAVITY LYMPH NODE CLEARANCE OCCASION 1 0 = no 1 = yes	1
lastd1	LAST DATE OF CHEMOTHERAPY LINE 1	1
lastd2	LAST DATE OF CHEMOTHERAPY LINE 2	1
lopnr	LÖPNUMMER subject ID in the study	1,2
malig	MALIGNANCY: CLASSIFICATION ON TUMOR TISSUE, PATHOLOGY & CYTOLOGY 1 = borderline 2 = invasive	1,3
mpage	AGE AT MENOPAUSE continuous variable	2
mpage_50	TO BE DOCUMENTED	
mptype	TYPE OF MENOPAUSE 0 = premenopausal 1 = natural 2 = surgical . = missing	2
Mpdate	DATE OF MENOPAUSE	2
?metast	DISTANT METASTASIS 0 = no 1 = yes 9 = missing	1
metdat	DATE OF DIAGNOSIS OF FIRST DETECTED DISTANT	

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METASTASIS

mult_spt	MULTIPLE SIMULTANEOUS PRIMARY TUMORS	1
	0 = not present but have a new primary gynaecological cancer	
	1 = yes	
	9 = no multiple simultaneous primary tumors or new primary cancer	
myses	SOCIOECONOMIC STATUS OF FAMILY, dichotomized	
	based on SES, see P:\OCS\data\tomas\doc\data dictionary.doc	
	0 = low (ses=0-3)	
	1 = high (ses = 4-7)	
npcy	NEW PRIMARY GYNAECOLOGICAL CANCER	
	0 = no	
	1 = yes	1
npcd	DATE OF DIAGNOSIS OF NEW PRIMARY GYNAECOLOGICAL CANCER	
		1

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npgova	NEW PRIMARY CANCER OVARIAN 0 = no 1 = yes	1
npgend	NEW PRIMARY CANCER ENDOMETRIAL 0 = no 1 = yes	1
npgcrx	NEW PRIMARY CANCER CERVICAL 0 = no 1 = yes	1
npgvag	NEW PRIMARY CANCER VAGINAL 0 = no 1 = yes	1
oment1	OMENECTOMY OCCASSION 1 0 = no 1 = yes	1
occombtr	ANY COMBINED ORAL CONTRACEPTIVES – TREATMENT 0 = no 1 = yes . = missing	1
occombdu	ANY COMBINED ORAL CONTRACEPTIVES – DURATION IN DAYS continuous variable	1
occombre	ANY COMBINED ORAL CONTRACEPTIVES – RECENCY -1 = never used 0 = current use other number = number of days since use	1
opy1	OPERATION: PRIMARY SURGERY 0 = no 1 = yes	1
opy2	OPERATION OCCASION 2 0 = no 1 = yes	1

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opdat1	OPERATION DATE OCCASSION 1 Primary surgery procedure	1
opdat2	OPERATION DATE OCASSION 2 Second-look surgery procedure	1
opother1	OTHER SURGICAL PROCEDURE OCCASION 1 text description	1
parity	NUMBER OF FULL-TERM PREGNANCIES 0 - 7 (range) . = missing	1
para0	PARITY CATEGORICAL 0 = no (parous) 1 = yes (nulliparous) . = missing	1
parnew	to be documented	

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pnr	Personal Registration Number	1,2
potr	HRT PROGESTIN ONLY – TREATMENT 0 = no 1 = yes . = missing	2
potr_only_pure	potr PURE USERS (Takes the missing values from potr as genuinely missing information. This variable is the most accurate) 0 = never user 1 = exclusive user 2 = non-exclusive user . = missing	2,3
potr_only	SAME AS POTR_ONLY_PURE, HOWEVER: (This variable takes the missing values from potr interpreted as “0” or “no”. This variable is only to be used in the analysis if there are insufficient numbers for the model to be fit) 0 = never user (missing = no) 1 = exclusive user 2 = non-exclusive user	2,3
podu	HRT PROGESTIN ONLY – DURATION IN DAYS continuous variable	2
pore	PROGESTIN ONLY – RECENCY -1 = never used 0 = current use other number = number of since of use	2
poreyr	PROGESTIN ONLY – RECENCY -1 = never used 0 = current use other number = number of years since use	2,3
poduyrs	DURATION OF PROGESTINS ONLY IN YEARS (podu/365.25)	2,3
podu_cat	DURATION OF PROGESTINS ONLY CATEGORICAL 0 = no potr 1 = <1 yr 2 = >=1 yr to <2 yrs	2,3

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3 = ≥ 2 yrs to < 5 yrs

4 = ≥ 5 yrs to < 10 yrs

5 = ≥ 10 yrs

. = missing

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pore_cat	PROGESTIN ONLY – RECENCY CATEGORICAL 0 = never used 1 = current use 2 = <5 years ago 3 = >=5 years ago . = missing	2,3
prfdat	RECURRENCE DATE	1
q3	Reason for Diagnosis 0 = not stated 1 = gynaecological routine examination 2 = symptoms 3 = other reasons	1,3
?q5_1	OPERATIONS, CURATIVE & PALLIATIVE: OCCASION 1 0 = not stated 1 = radical 2 = non-radical 9 = missing	?
?q5_2	OPERATIONS, CURATIVE & PALLIATIVE: OCCASION 2 0 = not stated 1 = radical 2 = non-radical 9 = missing	1
rad	RADIATION THERAPY LINE 1 0 = no 1 = yes 2 = not stated	1
rad2	RADIATION THERAPY LINE 2 0 = no 1 = yes 2 = not stated 9 = missing	1
?recur	LOCOREGIONAL RECURRENCE 0 = no	

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	1 = yes 9 = missing	1
residual1	RESIDUAL TUMOR SIZE OCCASION 1 0 = < 2 cm 1 = > 2 cm 2 = non-measurable 3 = not stated . = missing	1,3
residual2	RESIDUAL TUMOR SIZE OCCASION 2 0 = < 2 cm 1 = > 2 cm 2 = non-measurable 3 = not stated . = missing	1
residual3	RESIDUAL TUMOR SIZE OCCASION 3 0 = < 2 cm 1 = > 2 cm 2 = non-measurable 3 = not stated . = missing	1
sekopy1	SECONDARY SURGERY FOR PALLIATIVE PURPOSES OCCASION 1 0 = no 1 = yes	1
sekopd1	SECONDARY SURGERY FOR PALLIATIVE PURPOSES OCCASION 1 DATE	1
sekopy2	SECONDARY SURGERY FOR PALLIATIVE PURPOSES OCCASION 2 0 = no 1 = yes	1
sekopd2	SECONDARY SURGERY FOR PALLIATIVE PURPOSES OCCASION 2 DATE	1
sekopy3	SECONDARY SURGERY FOR PALLIATIVE PURPOSES OCCASION 3 0 = no 1 = yes	1

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sekopd3	SECONDARY SURGERY FOR PALLIATIVE PURPOSES OCCASION 3 DATE	1
ses	SOCIO-ECONOMIC STATUS 0 = lowest ses 1 = 2 = 3 = 4 = 5 = 6 = 7 = highest ses . = missing	2
smoy	SMOKING ONE YEAR AGO FROM MAIN AND PHONE QUESTIONNAIRES 1 = yes 2 = no . = missing	2,3
sm	EVER SMOKERS FROM MAIN AND PHONE QUESTIONNAIRES 1 = yes 2 = no . = missing	2,3
smoke	SMOKE, never/current/former (probably from f10 and f11, same as sm and smoy) 0 = never 1 = current 2 = former	
smdu	SMOKING DURATION – MAIN AND PHONE QUESTIONNAIRES IN YEARS	2
soebil1	SALPINGO-OOPHORETOMY OCCASSION 1 BILATERAL 0 = no 1 = yes	1
soeuni1	SALPINGO-OOPHORETOMY OCCASSION 1 UNILATERAL 0 = no	

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	1 = yes	1
startd	START DATE OF RADIATION LINE 1	1
startd1	START DATE OF CHEMOTHERAPY LINE 1	1
startd2	START DATE OF CHEMOTHERAPY LINE 2	1
?startd2_r	START DATE OF RADIATION LINE 2	1
?std2_end	ENDOCRINE THERAPY START DATE LINE 2	1
subhyst1	SUBTOTAL HYSTERECTOMY OCCASSION 1 0 = no 1 = yes	1
?tistyp	TISSUE TYPE: TISSUE ORIGIN OF TUMOR 1 = epithelial 2 = non-epithelial	1,3
who	GRADE OF DIFFERENTIATION ACCORDING TO WHO 0 = not stated 1 = highly differentiated 2 = medium differentiated 3 = lowly differentiated	1,3

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