Original Article

Increasing the Use of the Kentucky Cancer Registry as a Research Tool: An Epidemiologic Pilot Study of Ovarian Cancer

Claudia Hopenhayn, PhD, MPH[a]; Maura Pieretti, PhD[b]; Thomas Tucker, Ph D, MPH[c]; Nada H. Khattar, PhD[d]; Jennifer Redmond, MPH[e]

Abstract: The Kentucky Cancer Registry (KCR) is a statewide, population-based registry. The goal of this study was to test the feasibility of increasing KCR's potential as a resource for research, utilizing a pilot investigation of ovarian cancer.

Information was obtained from ovarian cancer patients via an interview which included questions regarding their reproductive history and other risk factors. The responses were entered into the KCR database, using available data fields not routinely filled. Rapid case ascertainment methodology and the linkage of routine KCR data, interview data, and tumor biomarker analyses at one hospital were also tested.

During the study period, 23 ovarian cancer cases were interviewed and their responses coded and entered, providing additional information through the KCR database. The usual time between identifying a new case and abstracting the medical record into the KCR database was substantially reduced by the rapid case ascertainment methodology utilized. The linkage of interview data, KCR data, and tumor analyses was successful while retaining patient anonymity.

The study demonstrated how the KCR can be used to implement additional data collection for cancer studies through patient interview, and effective, systematic input into the KCR database. The rapid case ascertainment was successful, as was the linkage of the interview data, KCR data, and tumor analysis, while retaining the anonymity of the patients. The pilot study also showed the need for better coordination between interviewer and hospital staff to ensure that patients were identified and interviewed before they left the hospital.

This pilot study demonstrated the feasibility of using the methodology for a larger study, and utilizing the KCR effectively to increase patient-related information in an efficient, relatively simple and confidential manner.

Key words: *cancer registry, ovarian cancer, Kentucky Cancer Registry, pilot study, reproductive risk factors*

Background

Tumor registries routinely collect data on new cancer cases, but the breadth and completeness of the data varies across registries. The Kentucky Cancer Registry (KCR) was established in 1991 as a statewide, population-based registry, and as such collects data on all new incident cases. Additionally, KCR routinely updates the data on all existing KCR cancer cases through an active system until the cases die, or are lost to follow-up. The overall purpose of this pilot study was to test the feasibility of increasing the KCR's potential as a resource for research, by adding information into the user-defined fields in the KCR hospital-based computer software. This was accomplished by customizing the user-defined data fields to add interview responses, implementing a rapid case ascertainment methodology and linking KCR data with tumor biomarker analyses.

This pilot study focused on ovarian cancer, since the investigators had previously conducted work on this topic in the same hospital.[1] Previous studies show that reproductive and hormonal factors are associated with the risk of developing ovarian cancer.[2-10] Additionally, ovarian cancer is a heterogeneous disease in which different tumor types are associated with diverse morphological, molecular, and clinical characteristics, and there is evidence to suggest that different risk factors may be associated with different tumor types.[11]

The goals of this pilot study were to:

a. Investigate novel mechanisms for obtaining additional patient information on characteristics related to reproductive and hormone-use history, using available KCR user-defined fields to enter the additional information and integrating it with routinely collected patient information;

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Address correspondence to: Claudia Hopenhayn, PhD, MPH, Assistant Professor, School of Public Health and Markey Cancer Control Program, University of Kentucky, 2365 Harrodsburg Road, Suite B150, Lexington, KY 40504-3381, telephone: 859-296-6630 ext 229, Fax: 859-296-6737, e-mail: cmhope0@uky.edu

[a] Assistant Professor, School of Public Health and Markey Cancer Control Program, University of Kentucky, 2365 Harrodsburg Road, Suite B150, Lexington, KY 40504-3381

[b] Assistant Professor, Department of Pathology, University of South Alabama, 2451 Fillingim Street, Mobile, AL 36617

[c] School of Public Health and Markey Cancer Control Program, University of Kentucky, 2365 Harrodsburg Road, Suite A230, Lexington, KY 40504-3381

[d] Department of Internal Medicine, University of Kentucky, 800 Rose Street, Lexington, KY 40536-0096.

[e] Senior Information Specialist, Markey Cancer Control Program, University of Kentucky, 2365 Harrodsburg Road, Suite B150, Lexington, KY 40504-3381

b. Test the feasibility of conducting this procedure using a rapid case ascertainment methodology;
c. Obtain and analyze tumor samples from the same patients, by accessing the tissue archive of the Department of Pathology, and integrate results of genetic markers into the master database.

If successful, this methodology would be an efficient, economical, and anonymous way of gathering data necessary to link predisease risk factors with disease characteristics, and finally with genetic tumor markers using KCR as the centralizing and unifying structure.

Methods

A questionnaire was designed to obtain information on risk factors associated with ovarian cancer from newly diagnosed cases. The completed questionnaires were then abstracted into the KCR database.

Designing the questionnaire

The questionnaire was tailored to serve 2 purposes: a) obtain new information from ovarian cancer patients, and b) serve as a data coding form, so the data could be easily entered by the cancer registrars at the same time that other data from the medical record was abstracted into the KCR database.

The questions were aimed at obtaining information on risk factors associated with ovarian cancer, and to be administered via a personal interview to newly diagnosed ovarian cancer patients treated at the University of Kentucky Chandler Medical Center (hereafter referred to as UK Hospital) during the study period. The questionnaire included questions on reproductive history, use of contraception, estrogen replacement therapy (ERT) and other factors known or suspected to be related to ovarian cancer. Each question was linked to a numeric field with a specific variable name. Shortly after conducting the interview, the interviewer coded each question and subsequently delivered the entire document to the cancer registrar for direct data entry (a copy of the questionnaire/data entry form is included as Appendix A, pp.62-66).

Customizing KCR user-defined data fields

KCR routinely records information on every cancer case diagnosed in Kentucky (with the exception of *in situ* cervical cancer and noninvasive skin cancer). The information collected relates to the disease and its progression, as well as some limited demographic and lifestyle characteristics. In addition, KCR was designed with the built-in potential to allow researchers to collect additional information in a systematic, efficient, and anonymous manner by providing user-defined data fields. No previous attempts had been made at the UK Hospital to customize the user-defined fields for research purposes.

The user-defined data fields were customized directly in the registry data entry program at the UK Hospital, by naming 23 fields with the same names as those coded in the questionnaire. When the cancer registrars retrieved the medical record and entered the data for a new ovarian cancer case that was part of the pilot study, they also entered the data from the coded questionnaire directly into the newly-customized data fields.

Rapid case ascertainment

Another aspect of the study was to test the feasibility of rapid case ascertainment of study subjects. Normally, the entry of new cancer cases into the KCR database can take up to 6 months from the date of cancer diagnosis. This time can potentially be reduced by the active process of retrieving the medical records of all patients participating in a specific clinical or research study protocol. This applied to all newly-diagnosed ovarian cancer cases participating in the study. When the KCR abstractors in the hospital received a completed and coded questionnaire from the interviewer, it alerted them to the existence of a new ovarian cancer case who was a study participant in the pilot investigation. This prompted the active search and identification of the corresponding medical record, which, once retrieved, was immediately abstracted into the KCR database, along with the additional study variables from the questionnaire.

Training KCR abstractors

The UK Hospital cancer registry abstractors were trained for the additional tasks required for this study. In particular, this included customizing the user-defined data fields in the UK Hospital's data entry program for the KCR database, and using the questionnaire as both a prompt for rapid case ascertainment and as a data entry form for the new data fields. These were all new tasks assigned to KCR abstractors that had not been implemented before.

Recruitment of cases and interview methods

The patient recruitment and interviews were conducted by a UK genetics counselor, experienced at working with and interviewing cancer patients. The interviewer was also involved in other projects conducted by the UK Division of Gynecologic Oncology. Their staff alerted the interviewer when new ovarian cancer patients were being admitted to the UK Hospital and facilitated contact with the cases. Once patients were identified, the interviewer located them in the hospital, explained the study, obtained signed informed consent and conducted the interview.

Although the study was initially designed to include only cases that were available for interview while they were hospitalized, in several instances the patients had left the hospital before being identified as potential study subjects. In these cases, attempts were made to conduct the interview by telephone.

Retrieval of tumor samples and tumor analysis

The Department of Pathology at the University of Kentucky collaborated in this study by identifying tumor samples from newly-diagnosed, histologically confirmed ovarian cancer cases who underwent surgery at the UK Hospital. To maintain anonymity of the patients' identity to the investigators, the interviewer contacted a collaborator in the Pathology Department, who in turn identified the

tumor specimen and subsequently provided the tissue samples to the investigator group conducting the molecular analyses. DNA was extracted from paraffin-embedded tissues, and mutational analyses were conducted on the P53 and K-RAS genes, which are often mutated in ovarian cancer. These data were integrated with the KCR data into one master database.

Results

During the study period, October 1998 to July 1999, 32 patients were identified as having a newly diagnosed, primary epithelial ovarian cancer surgically removed at the UK Hospital.

Interviews were conducted with 23 patients. Face-to-face interviews were successfully completed with 9 patients while they were still in the hospital. Telephone interviews were conducted with 14 patients who were identified after they were discharged. Of the remaining 9 cases, one died before she could be reached, one did not speak English and one refused to speak to anyone from UK. Repeated attempts were made to contact the other 6 women by telephone, on different days and times, but they were never reached.

Due to logistical limitations of study, the identification and subsequent interviews of about half of the cases were delayed. In several instances, weeks or months elapsed since the patient had been released from the UK Hospital, and the case information had been entered into the KCR database by the routine reporting method. These were primarily the cases that were interviewed by telephone. Therefore, the assessment of the rapid case ascertainment should be based only on those patients interviewed and coded shortly after hospital admission; in these cases, the coded interview alerted the cancer registrar of a study participant and the need to retrieve and abstract the completed medical record. The mean time between interview and data entry into the KCR (both routine data and interview results) was 33 days. In contrast, among the cases which had already been entered into KCR, the average time between admission date and KCR data entry was 135 days. The effectiveness of the rapid case ascertainment in the former group is clear.

Twenty-one of the 23 interviewed patients were confirmed ovarian cancer cases entered into the KCR database; the remaining 2 were not reportable to KCR.* Tumor samples were obtained and analyzed for 14 of the 21 KCR cases. The 7 cases for which pathology material was not obtained included 2 cases for which there were linkage problems between the study interviewer and the different clinical departments, resulting in coding errors, and 5 cases were diagnosed and/or initially treated at other institutions so that tumor biopsy material was not stored with the UK Department of Pathology. In 3 cases, K-RAS gene mutations were identified and in 5 cases P53 gene mutations were found.

The summary results of the interview and the molecular studies are presented in Table 1. Since this was a small pilot study, the data are not conducive to be analyzed extensively or to be used to generate conclusions regarding the case group. Similarly, no associations can be attempted between specific risk factors and specific tumor subtypes, and/or mutational status. This would be the goal of a larger-scale study.†

Discussion

The study succeeded in demonstrating how the KCR can be used to implement additional data collection for cancer studies through patient interview and input into the KCR database. The interview itself did not present any problems, the coding of the answers was straightforward, and the data entry by the cancer abstractors proceeded very smoothly. The rapid case ascertainment was successful, and throughout the study the investigators remained blinded to the identity of the cases. This proved that the linkage of the interview data, KCR data, pathology reports and tumor analysis was successful while retaining the anonymity of the patients to nonclinical personnel.

The 32 patients identified during the study period represented a lower number of cases than anticipated for the duration of the study based on estimates from the KCR, which predicted 50 cases. Further investigation indicated that those identified in the initial estimate in the KCR included nonepithelial cancers (around 10%), some nonsurgical patients (e.g., consultation or treatment subsequent to diagnosis at another institution), and some that were not primary ovarian tumors, which were excluded from this study. The lower than expected number of cases was a useful finding to consider in future study planning, as it enables investigators to have a more accurate and realistic expectation of the case load.

One limitation of the study involved the interviewer's availability to reach and interview cases while they were hospital inpatients. The specific problems encountered were: the limited availability of time of the trained interviewer; the relatively short amount of time spent by many ovarian cancer patients in the hospital after surgery; and the difficulties encountered with the flagging of new patients by the physicians and their staff. These problems resulted in a number of cases leaving the hospital before they were identified as potential study subjects or before they could be contacted by the interviewer. Although 14 patients were interviewed by telephone, finding these women and arranging a convenient interview time was difficult and time-consuming. Additionally, for 9 of the 23 identified cases no tumor sample could be obtained.

It should be noted that the rapid case ascertainment in this study was limited to patients identified through the interviews and at the specific hospital where the pilot work was undertaken. For other types of research in which rapid case ascertainment is used as a means of identifying cases in population-based research, other methodologies would need to be implemented across all participating institutions. However, this study does show the feasibility of alerting KCR abstractors to the appearance of new cases,

* These two ovarian cases may not have been invasive cancer or may not have been a primary ovarian tumor.

† The tumor analyses performed for this study were grouped with additional cases for a separate study (unpublished).

Table 1. Selected Variables from Ovarian Pilot Study Subjects (from interview and tumor markers)

Case #	Menarche Age	Menopause Age	Cause of Menopause	Tubal Ligation	Pregnancies	OC Use	Duration OC	Talcum Powder Use	ERT Use	Family History of Breast or Ovarian Cancer	P53 Mutation	K-RAS Mutation
1	15	51	natural	yes	3	no		yes	yes	no	yes	yes
2	13	43	natural	no	1	yes	1 week	no	no	no	n/a	n/a
3	12	unknown	hysterectomy	no	2	yes	1-2 mths	no	no	breast	n/a	n/a
4	17	42	natural	no	0	no		yes	no	no	yes	no
5	12	53	natural	no	2	no		yes	no	breast	no	no
6	14	45	natural	no	2	no		yes	no	both	no	yes
7	15	53	natural	yes	1	yes	5 yrs	no	yes	no	no	no
8	11	47	natural	yes	6	yes	2 yrs	no	no	no	no	no
9	11	no menopause		no	0	no		no	no	no	n/a	n/a
10	15	53	natural	no	3	no		no	yes	no	n/a	n/a
11	14	50	natural	no	1	yes	2 weeks	no	no	no	yes	no
12	12	52	natural	no	0	yes	6 mths	no	no	no	no	no
13	12	47	natural	yes	5	yes	10 yrs	no	yes	no	no	no
14	12	no menopause		yes	3	yes	1.5-2 yrs	yes	yes	no	n/a	n/a
15	14	42	natural	no	2	yes	10 yrs	yes	yes	no	no	no
16	12	no menopause		no	2	yes	3 yrs	no	no	no	n/a	n/a
17	14	52	natural	no	1	no		unknown	no	no	n/a	n/a
18	9	no menopause		no	2	yes	1 yr	yes	no	breast	n/a	n/a
19	16	48	natural	yes	3	no		no	no	no	yes	yes
20	10	52	hysterectomy	no	4	yes	8 yrs	yes	yes	unknown	yes	no
21	14	35	natural	no	2	yes	20 yrs	no	yes	no	n/a	n/a
22	13	unknown	hysterectomy	no	3	yes	20 yrs	no	yes	no	no	no
23	13	52	natural	no	9	no		no	yes	breast	no	no

n/a = not available

which could be achieved by alternate but similar methods (such as flagging new cases by attending physicians or other health professionals).

Future studies using this methodology would likely necessitate that interviews be conducted immediately after a patient is admitted. This would require excellent collaboration and communication among investigators, staff, and treating physicians and nurses, as well as the availability of an interviewer every day of the week, in order to minimize the likelihood of missing a case. Ensuring that most patients be contacted and interviewed in person while they are still in the hospital would be an important goal of a study using the methodology proposed. Attempting telephone interviews with patients who were missed in the hospital did not prove to be an effective alternative, since many patients may not be reachable, or may be too ill or even die within weeks after ovarian cancer surgery.

Conclusion

The significant results of this study include the feasibility of using the methodology for embarking on a large study and using the KCR as an effective tool for increasing patient-related information in an efficient, relatively simple and confidential manner. Additionally, the lessons learned, including both strengths and limitations of the pilot study, provide important feedback for the development of any larger study.

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Appendix A

Survey #_____ Medical Record # _____ Admission Date: _____

OVARIAN CANCER SUPPLEMENTAL QUESTIONNAIRE

1) What is your approximate normal weight (before this illness)?

_____
Pounds

In pounds – LEFT JUSTIFIED Ex: 1 2 5___

25A WEIGHT ☐☐☐☐

2) How tall are you?

_____ _____ = _____
ft. *in.* *inches*

In total inches – LEFT JUSTIFIED Ex: 7 0 ___ ___

25B HEIGHT ☐☐☐☐

3) How old were you when you first got your period?

_____
Years Old

❍	Never	(0)	☛7a
❍	Did Not Know	(9999)	
❍	Refused	(8888)	

In years – LEFT JUSTIFIED Ex: 1 2 ___ ___

25C STARTPERIOD ☐☐☐☐

4) Up until this surgery, had you stopped having periods?

❍	Yes	(1)	
❍	No	(0)	☛7a
❍	Did Not Know	(9999)	☛6
❍	Refused	(8888)	☛6
❍	N/A	(5555)	☛6

As coded above LEFT JUSTIFIED

25D ENDPERIOD ☐☐☐☐

5) For which of these reasons did your period stop?

❍	Naturally	(1)
❍	Surgical Hysterect.	(2)
❍	Other Surgery	(3)
❍	Other Reasons	(4)
❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

As coded above LEFT JUSTIFIED

25E CAUSEMENOP ☐☐☐☐

6) At what age did you reach menopause?

_____
Years Old

❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

In years – LEFT JUSTIFIED Ex: 45 ___ ___

25F AGEMENOP ☐☐☐☐

OCSQ05/04/04 Date of Interview: _____ Date Received:_____ Date Abstracted:_____

Survey #_____ Medical Record # _____ Admission Date: _____

OVARIAN CANCER SUPPLEMENTAL QUESTIONNAIRE

7) Did you have a tubal ligation?

- ❍ Yes ☛ (Code Question #7b)
- ❍ No (0) ☛ 8
- ❍ Did Not Know (9999) ☛ 8
- ❍ Refused (8888) ☛ 8

7b) How old were you when you had your tubal ligation

_____
Years Old

- ❍ Did Not Know (7777)
- ❍ Refused (6666)

As coded above LEFT JUSTIFIED Ex: 4 6 ___ ___

109A TUBALIGAT ☐☐☐☐

8) How many times have you been pregnant? (Counting all pregnancies, even if they ended as miscarriages, abortions, ectopic pregnancies, etc.)

_____
 # Pregnancies

- ❍ Never (0) ☛13
- ❍ Did Not Know (9999)
- ❍ Refused (8888)

All pregnancies – LEFT JUSTIFIED Ex: 3___ ___ ___

109B PREGNANCIES ☐☐☐☐

9) How many live births did you have?

_____
 # Live Births

- ❍ None (0) ☛11
- ❍ Did Not Know (9999)
- ❍ Refused (8888)
- ❍ N/A (5555)

LEFT JUSTIFIED Ex: 1 ___ ___ ___

109C LIVEBIRTH ☐☐☐☐

10) How many months did you breast feed each child?

1st. Baby	_____	*Months*
2nd. Baby	_____	*Months*
3rd. Baby	_____	*Months*
4th Baby	_____	*Months*
5th Baby	_____	*Months*
TOTAL	_____	*Months*

- ❍ None (0)
- ❍ Did Not Know (9999)
- ❍ Refused (8888)
- ❍ N/A (5555)

Months– LEFT JUSTIFIED Ex: 4 ___ ___ ___

109D BREASTFEED ☐☐☐☐

11) How many miscarriages or abortions did you have?

_____
 # Early Losses

- ❍ None (0)
- ❍ Did Not Know (9999)
- ❍ Refused (8888)
- ❍ N/A (5555)

LEFT JUSTIFIED Ex: 1 ___ ___ ___

109E EARLYLOSS ☐☐☐☐

OCSQ05/04/04 Date of Interview: _____ Date Received:_____ Date Abstracted:_____

Survey #_____ Medical Record # _____ Admission Date: _____

OVARIAN CANCER SUPPLEMENTAL QUESTIONNAIRE

12) How many stillbirths did you have?

_____
 # Stillbirths

❍	None	(0)
❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

LEFT JUSTIFIED Ex: 1 ___ ___ ___

109F STILLBIRTH ☐☐☐☐

13) Have you ever used the pill?

❍	Yes	(1)
❍	No	(0) ☛17
❍	Did Not Know	(9999) ☛17
❍	Refused	(8888) ☛17

As coded above LEFT JUSTIFIED

109G PILLUSE ☐☐☐☐

14) How old were you when you first took the pill?

_____
Years Old

❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

In years – LEFT JUSTIFIED Ex: 1 8 ___ ___

109H FIRSTPILL ☐☐☐☐

15) Can you estimate the total amount of years you were on the pill?

_____
Years

❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

In years – LEFT JUSTIFIED Ex: 1 8 ___ ___

109I TIMEPILL ☐☐☐☐

16) How old were you when you last took the pill?

_____
Years Old

❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

In years - LEFT JUSTIFIED Ex: 3 6 ___ ___

109J LASTPILL ☐☐☐☐

17) Have you ever used an IUD?

❍	No	(0)
❍	Yes	(1)
❍	Did Not Know	(9999)
❍	Refused	(8888)

As coded above LEFT JUSTIFIED

109K IUD ☐☐☐☐

OCSQ05/04/04 Date of Interview: _____ Date Received:_____ Date Abstracted:_____

Survey #_____ Medical Record # _____ Admission Date: _____

OVARIAN CANCER SUPPLEMENTAL QUESTIONNAIRE

18) Have you ever used talcum powder around your vaginal area on a regular basis?

❍	No	(0)
❍	Yes	(1)
❍	Did Not Know	(9999)
❍	Refused	(8888)

As coded above LEFT JUSTIFIED

109L TPOWDER ☐☐☐☐

19) Have you ever been on Estrogen Replacement Therapy?

❍	Yes	(1)
❍	No	(0) ☛22
❍	Did Not Know	(9999) ☛22
❍	Refused	(8888) ☛22

As coded above LEFT JUSTIFIED

109M ERTUSE ☐☐☐☐

20) How old were you when you first took estrogen replacement therapy?

_____
Years Old

❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

As coded above LEFT JUSTIFIED

109N STARTERT ☐☐☐☐

21) How old were you when you last took estrogen replacement therapy?

_____
Years Old

❍	Has not stopped	(0)
❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

As coded above LEFT JUSTIFIED

109O ENDERT ☐☐☐☐

22) Were you ever diagnosed with Pelvic Inflammatory Disease or PID?

❍	No	(0)
❍	Yes	(1)
❍	Did Not Know	(9999)
❍	Refused	(8888)

As coded above LEFT JUSTIFIED

109P PID ☐☐☐☐

23) Have you ever had problems getting pregnant?

❍	No	(0)
❍	Yes	(1)
❍	Did Not Know	(9999)
❍	Refused	(8888)

As coded above LEFT JUSTIFIED

109Q INFERT ☐☐☐☐

OCSQ05/04/04 Date of Interview: _____ Date Received:_____ Date Abstracted:_____

Survey #_____ Medical Record # _____ Admission Date: _____

OVARIAN CANCER SUPPLEMENTAL QUESTIONNAIRE

24) Were you ever prescribed pills so that you could increase your chances of getting pregnant?

❍	Yes	(1)
❍	No	(0) ☛26
❍	Did Not Know	(9999) ☛26
❍	Refused	(8888) ☛26

As coded above LEFT JUSTIFIED

109R TXINFERT ☐☐☐☐

25) Can you tell me the name of the fertility medication you took?

❍	Clomid	(1)
❍	Pergonal	(2)
❍	Lupron	(3)
❍	Other	(4)
	_____	
❍	Did Not Know	(9999)
❍	Refused	(8888)
❍	N/A	(5555)

As coded above LEFT JUSTIFIED

If more than one medication, please code one number in each box.

109S RXINFERT ☐☐☐☐ *Ex: 1 _ _ _ OR 1 2 _ _.*

26) Do you have a family history of Ovarian or Breast cancer?

❍	No	(0)
❍	Yes OVARIAN	(1)
❍	Yes BREAST	(2)
❍	Yes BOTH	(3)
❍	Did Not Know	(9999)
❍	Refused	(8888)

As coded above LEFT JUSTIFIED

109T FHISTORY ☐☐☐☐

OCSQ05/04/04 Date of Interview: _____ Date Received:_____ Date Abstracted:_____