GRANT NO:
DAMD17-94-J-4387

TITLE:
Adding Data Accessibility and Rule-Based Targeted Data Collection to the California Cancer Reporting System for Breast Cases

PRINCIPAL INVESTIGATOR:
Dr. Barry A. Gordon

CONTRACTING ORGANIZATION:
California Public Health Foundation
Berkeley, California 94704-1103

REPORT DATE:
September 13, 1995

TYPE OF REPORT:
Annual

PREPARED FOR:
U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for public release; distribution unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.
**4. TITLE AND SUBTITLE**

Adding Data Accessibility and Rule-Based Targeted Data Collection to the California Cancer Reporting System for Breast Cases

**6. AUTHOR(S)**

Dr. Barry Gordon

**7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)**

California Public Health Foundation
Berkeley, California 94704-1103

**9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES)**

U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

**12a. DISTRIBUTION / AVAILABILITY STATEMENT**

Approved for public release; distribution unlimited

**13. ABSTRACT (Maximum 200 words)**

The first phase of this 3-year project has been completed. The basic BBS hardware and software has been set up, and the data collection system has been fully implemented. This following was performed:

- Convened an advisory committee and chose additional data items for the first year of studies.
- Added 29 new data items for coding for 1995 California cancer cases, as initially proposed for this study.
- Implemented 17 additional data items proposed by data users for collection of comparison data.
- Modified our cancer registry software to collect, validate, store, and transmit these new fields.
- Prepared coding instructions and briefed hospital registrars on the new study.
- Distributed copies of the updated software to 251 hospitals in California.
- Designed the dataflow to receive these new data records at regional registries, and to pass them on to project staff for integration and analysis.
- Purchased hardware, setup the network, and setup the initial BBS with lookup of physicians' license numbers as a test resource.
- Pilot tested the HIRS software, which will be our query engine for online analysis.

**15. NUMBER OF PAGES**

24

**16. PRICE CODE**

Unlimited

**17. SECURITY CLASSIFICATION OF REPORT**

Unclassified

**18. SECURITY CLASSIFICATION OF THIS PAGE**

Unclassified

**19. SECURITY CLASSIFICATION OF ABSTRACT**

Unclassified

**20. LIMITATION OF ABSTRACT**

Unlimited
**GENERAL INSTRUCTIONS FOR COMPLETING SF 298**

The Report Documentation Page (RDP) is used in announcing and cataloging reports. It is important that this information be consistent with the rest of the report, particularly the cover and title page. Instructions for filling in each block of the form follow. It is important to stay within the lines to meet optical scanning requirements.

| Block 1. Agency Use Only (Leave blank). |
| Block 2. **Report Date.** Full publication date including day, month, and year, if available (e.g. 1 Jan 88). Must cite at least the year. |
| Block 3. **Type of Report and Dates Covered.** State whether report is interim, final, etc. If applicable, enter inclusive report dates (e.g. 10 Jun 87 - 30 Jun 88). |
| Block 4. **Title and Subtitle.** A title is taken from the part of the report that provides the most meaningful and complete information. When a report is prepared in more than one volume, repeat the primary title, add volume number, and include subtitle for the specific volume. On classified documents enter the title classification in parentheses. |
| Block 5. **Funding Numbers.** To include contract and grant numbers; may include program element number(s), project number(s), task number(s), and work unit number(s). Use the following labels: C - Contract  PR - Project  G - Grant  TA - Task  PE - Program  WU - Work Unit  Element  Accession No. |
| Block 6. **Author(s).** Name(s) of person(s) responsible for writing the report, performing the research, or credited with the content of the report. If editor or compiler, this should follow the name(s). |
| Block 7. **Performing Organization Name(s) and Address(es).** Self-explanatory. |
| Block 8. **Performing Organization Report Number.** Enter the unique alphanumeric report number(s) assigned by the organization performing the report. |
| Block 9. **Sponsoring/Monitoring Agency Name(s) and Address(es).** Self-explanatory. |
| Block 10. **Sponsoring/Monitoring Agency Report Number (If Known).** |
| Block 11. **Supplementary Notes.** Enter information not included elsewhere such as: Prepared in cooperation with...; Trans. of...; To be published in... When a report is revised, include a statement whether the new report supersedes or supplements the older report. |
| Block 12a. **Distribution/Availability Statement.** Denotes public availability or limitations. Cite any availability to the public. Enter additional limitations or special markings in all capitals (e.g. NOFORD, REL, ITAR). |
| Block 12b. **Distribution Code.** |
| DOD - See DoDD 5230.24, "Distribution Statements on Technical Documents." |
| DOE - See authorities. |
| NTIS - Leave blank. |
| Block 13. **Abstract.** Include a brief (Maximum 200 words) factual summary of the most significant information contained in the report. |
| Block 14. **Subject Terms.** Keywords or phrases identifying major subjects in the report. |
| Block 15. **Number of Pages.** Enter the total number of pages. |
| Block 16. **Price Code.** Enter appropriate price code (NTIS only). |
| Blocks 17. - 19. **Security Classifications.** Self-explanatory. Enter U.S. Security Classification in accordance with U.S. Security Regulations (i.e., UNCLASSIFIED). If form contains classified information, stamp classification on the top and bottom of the page. |
| Block 20. **Limitation of Abstract.** This block must be completed to assign a limitation to the abstract. Enter either UL (unlimited) or SAR (same as report). An entry in this block is necessary if the abstract is to be limited. If blank, the abstract is assumed to be unlimited. |
FOREWORD

Opinions, interpretations, conclusions and recommendations are those of the author and are not necessarily endorsed by the US Army.

Where copyrighted material is quoted, permission has been obtained to use such material.

Where material from documents designated for limited distribution is quoted, permission has been obtained to use the material.

Citations of commercial organizations and trade names in this report do not constitute an official Department of Army endorsement or approval of the products or services of these organizations.

In conducting research using animals, the investigator(s) adhered to the "Guide for the Care and Use of Laboratory Animals," prepared by the Committee on Care and Use of Laboratory Animals of the Institute of Laboratory Resources, National Research Council (NIH Publication No. 86-23, Revised 1985).

For the protection of human subjects, the investigator(s) adhered to policies of applicable Federal Law 45 CFR 46.

In conducting research utilizing recombinant DNA technology, the investigator(s) adhered to current guidelines promulgated by the National Institutes of Health.

In the conduct of research utilizing recombinant DNA, the investigator(s) adhered to the NIH Guidelines for Research Involving Recombinant DNA Molecules.

In the conduct of research involving hazardous organisms, the investigator(s) adhered to the CDC-NIH Guide for Biosafety in Microbiological and Biomedical Laboratories.
Table of Contents

Introduction .......................................................... 3
  Background .......................................................... 3
  Statement of the Problem ........................................ 3
  Purpose and Technical Objectives ............................... 4

Work Accomplished .................................................. 6
  Set up bulletin board ............................................. 6
  Add proposed new data items ................................... 6
  Announce new query bulletin board ............................ 8
  Install the HIRS query system .................................. 9

Conclusions .......................................................... 10

Appendix A
  Data Items Added for Army Study ............................... 11

Appendix B
  C/NET Screens with New 1995 Items ............................ 16

Appendix C
  Plan for Internet/BBS Cancer Query System .................. 19

Appendix D
  Examples of HIRS Query Screens ............................... 20
Introduction

Background
The California Cancer reporting system has been collecting data on all breast cancer cases (~20,000/year) for over seven years statewide, and for more than 25 years in some geographic areas. This pioneering system is built around mandatory electronic cancer case reporting, coupled with software specifically designed to carry out this mandatory reporting.

Hospital-based tumor registry software (C/NET) was developed by the California Public Health Foundation (CPHF) to achieve high-quality and efficient data collection. CPHF has distributed C/NET to 250+ hospitals and other cancer reporting facilities throughout the state. C/NET is also used on portable computers by to collect cases from the remaining, smaller hospitals around the state. C/NET currently handles autocoding, data entry, interfield edits, and the preparation of periodic transmit files for conveying new case reports and later case modifications or corrections to California's central cancer registry. Cases are first sent to one of eight regional intrastate registries, which carry out further editing, case matching, and quality control before sending the cases on to the state central registry.

The C/NET hospital software is widely used and appreciated, as it carries out functions essential to hospital registries and their clinician staffs beyond case collection and reporting. Various versions of C/NET are in use in over 650 other hospitals outside of California. These have been distributed by the American College of Surgeons, and, more recently, by us, the California Public Health Foundation. C/NET software gathers data on cancer diagnoses, stage, treatment, and followup in national standard format. It includes all fields necessary for NCI's SEER Program and the American College of Surgeon's National Cancer Database. However, not all data items gathered at the hospitals have been uploaded to the central registry at present.

As the number of years of complete statewide coverage has increased, the California Cancer Registry has used it's statewide database for numerous studies and publications.

Statement of the Problem

Several factors have hindered wide usage of registry data for clinical and epidemiological studies in breast cancer. These problems include: lack easy access to the data, built-in delays in the reporting system, difficulty in pilot testing or adding new data fields targeted for breast cancer studies, and lack of rapid case ascertainment to support special studies. Many investigators have noted the unbalance in registry focus, with more attention to data collection than data usage. Analytical tables and reports are not available through a single, uniform access method. Instead they are scattered across many locally produced publications. This has meant that mainly insiders could use cancer registry data.
Most population-based registries must wait until complete years are closed out, including a time-consuming death clearance followup-back, before data can be shown. The delay is often two years. While the time to produce accurate cancer rates is difficult to shorten, faster pathways for reviewing preliminary data are needed. Breast cancers, in particular, may be identifiable to a large degree through fast channels such as path reports.

Interview studies are particularly sensitive to the timeliness of case identification. Because registry reporting is too slow at present, most special studies must mount a labor-intensive separate casefinding effort. A faster channel is needed.

The current cancer reporting systems are also slow in their ability to revise data collection to match changing clinical practices. Potential new methods of detection, staging, and treatment are constantly appearing and requiring evaluation. Although computers should facilitate the rapid deployment of new fields and codes for pilot testing, this is not happening. Rapid-turnaround studies require both faster methods for distributing data item revisions, as well as faster methods for reviewing early results.

**Purpose and Technical Objectives**

We propose to add significant new functions to the computerized reporting system now in place in order to solve these problems. We want to make the data available in highly useable form and foster studies not before possible on such a large and ethnically diverse population. Examples include testing whether access to care and quality of care are related to patient insurance status, ethnic, type of provider, or geographic factors.

Specific goals of the system enhancements include:

1. Provide a **dial-in user query system** open to all investigators, allowing user-defined tabulations, plots, and offline maps on a wide variety of breast case data. Databases open to queries would come from three sources: statewide data from 1988 to the current year, NCI SEER data from 1973 forward, and data from other states, by their agreement, who have submitted to the North American Association of Central Cancer Registries (NAACCR).

2. Facilitate the rapid, electronic communication of case-related information by adding **integrated telecommunications** to the C/NET hospital-based registry software. This would allow all 250 hospitals to easily submit case data, receive shared data, query the central statistical databases, carry out e-mail communication with their peers and their technical support personnel, and load comparison data counts which parallel their own in-house queries, to produce tables and graphs with direct comparisons.

3. Encourage cost-effective targeted patient interview studies by adding a flexible rule-
based rapid case-reporting channel for cases discovered in hospitals that potentially meet special patient interview study criteria, so the regional registries can conduct these studies for much reduced costs.

4. **Monitor and encourage enrollment in treatment protocols** by adding rule-based criteria to hospital registry software. The rules would flag cases meeting current criteria for one or more national treatment protocols. This helps track the rate of use of these protocols in the target patient population, and facilitates the recruitment of patients.

5. **Help solve at the hospital level the problem of incomplete treatment reporting** by adding Physician Data Query (PDQ) recommended treatment plans to the software. This will identify the most commonly recommended treatment for patients of a particular age, stage, and disease type. The software will also support the automatic mailing of physician letters to query whether this therapy has been carried out, if the medical record is incomplete.

6. Assure that a large cohort of breast cases has crucial staging and followup information by carrying out a one-time catch-up data upload of **AJCC stage and followup data** from hospitals to the regional and central registry. These data are mostly available in the hospital systems, but have not been fully communicated to the central registry. They will be transmitted on a regular basis thereafter.

7. Facilitate the timely flow of case-related data by setting up **regional registry bulletin board systems** to handle all communications with hospitals and other treatment facilities in eight regional centers. These BBS's would manage automatic information uploads and downloads, as well as e-mail, and would be tied together into a statewide network. They can also be used to update data collection software.

8. Broaden the kinds of research questions that can be studied statewide by **adding new fields** to the recommended state data set, and adding rapid-turnaround study fields that would change every year. To study protocol enrollment, protocol # or reason for no protocol would be coded. To study financial limitations on care for breast patients, insurance status/source of payment would be tracked. In order to study treatment success, disease free interval would be calculated. Fields will also be added to collect co-morbidities, and to pass on the clinical indicators for breast cancer required by the JCAHO starting in 1995. To encourage hospital studies in more detail, optional fields would include procedures performed and their costs, and detail on radiation and chemotherapy performed or the reason none was given. These fields would be evaluated and revised yearly.
Work Accomplished

The following list corresponds to the first year workplan submitted in the original proposal.

1. **Set up bulletin board hardware and LAN for the central registry node, and install BBS software.** A Netware LAN server was purchased and installed, using Netware 3.15 running on a 486 with 2 1-Gbyte hard disks and ethernet linking a number of computers. No problems were encountered.

A bulletin board system (Mustang) was installed on a dedicated computer, with access to an 800 number telephone line. To test the BBS in use, a simple information system was developed that looks up California physician license numbers by searching on physician name. This service facilitates the proper coding of physicians attached to cancer cases by hospital registrars, who can dial in to find the codes for MD's that are not a part of their known staff. The lookup software was programmed in Foxpro, and installed as a 'door' that BBS users can invoke via a menu choice when they call in. This system has been in use for the past four months, and receives on average 6-8 calls per day from California hospitals. It shows that at least some hospitals can set up modem communication with our BBS, and make use of its initial services.

We have also designed an Internet access path to the data query system. Since this grant was first proposed, the Internet has become a much more important and available connection method. We wanted to be able to provide access to the same features via the Internet as through the dial-up bulletin board. We have completed the plan for accomplishing this (see Appendix C). We will be running an Internet Web server, which will handle e-mail and information publication, as well as running our HIRS cancer data query system. Separate funding for the Internet connection is being sought.

2. **Add proposed new data items to C/NET hospital registry software and distribute to all registry hospitals in California.**

In the proposal, a number of new fields were listed which would significantly add to the ability of researchers to study the dissemination of treatments, the use of protocols, and the reasons for no-treatment decisions. These fields have been added to our C/NET data collection software.

A number of these fields are being considered by the American College of Surgeons as part of their 1996 dataset. Although the College needs to proceed slowly with the approval and implementation of these items, we believe they are of such obvious importance for breast cancer that they should be implemented as soon as possible on a trial basis. We have
implemented them for 1995 case collection.

The added fields are as follows:

Protocol number
This is a single national number chosen from the nationally maintained list, to be filled in if the patient is known to be on a national protocol.

Reason not on protocol
This field is used when a patient is apparently eligible for a national protocol to code why no such treatment was begun (co-morbidity factors, patient declined, other patient status factors, or unknown). Codes have been developed.

Date patient disease free (from which disease free interval will be calculated).
This field is proposed by the College of Surgeons Data Task Force.

Reason for no radiation.
This field is proposed by the College of Surgeons Data Task Force to parallel the field "Reason for no surgery", to track type of reason proposed radiation was not administered (patient refusal, etc).

Reason for no chemotherapy
The same logic and coding applies as for the above Reason for no Radiation.

Patient history of cancer
This field is proposed by the College of Surgeons Data Task Force. It will provide specific information on history of breast cancer in the immediate family.

JCAHO Oncology Indicators for breast cancer.
These indicators, currently in beta test, may be required of hospitals by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). They need to be evaluated by registries for relevance to patient outcome.

Co-morbidity.
We provide two fields to code co-morbidity factors. The codes used are ICD9, and the instructions ask the coders to give first priority to those factors that may influence the management and success of breast cancer treatment. Examples include diabetes and hypertension.

In addition, a some other fields were proposed by our C/NET Advisory Committee as
candidates for the one-year trial period. The ones selected for inclusion with 1995 cases are as follows:

Global Clinical Guidelines
These are 12 fields which can track the presence or absence of 12 standard diagnostic tests, such as MRI's, and CT scans. Hospitals can set their own standards for different cancers, and monitor their own compliance. They can also compare their data with grouped data from other hospitals of comparable type.

Surgical approach
This field has been proposed by the American College of Surgeons for 1996 cases, and monitors the use of the newer scope-based surgeries.

Referral to support services
This allows the coding of up to four kinds of referrals to support services for each patient. This will help monitor the use of a variety of ancillary and support services, from support groups to rehabilitation, hospice, and pain management.

Tumor Markers
We are adding fields to track breast S-phase %, DNA level, and for prostate, the PSA value and level. Comparison data on these values will help facilities evaluate and compare their use of these prognostic indicators.

For a complete list of the fields added, and their allowed codes, see Appendix A. The data fields were added to C/NET screens, validity edits, and the case database. In addition, the transmit records were modified to include the new items, so that comparison data can be accumulated.

The revised software was then distributed to 251 hospitals in California, who use it to report cases to the state as well as manage their cancer registries. Software updates were also distributed to the eight regional cancer registries, which receive and collate cases from the hospitals in their area before sending them to the state. The hospitals are now using the revised software, with the new fields, for coding their 1995 cases. The fields are not required by the states. However, hospitals' own interest in carrying out quality of care monitoring, and the opportunity to receive comparison data has made participation in the data collection an attractive choice.

3. Announce new query bulletin board, provide user documentation, and demonstrate its use to groups of potential users.
   We have written and distributed several documents explaining the mission of the bulletin
board and describing the new data items involved. We have also presented this information to several regional meetings of cancer registry staff, who will not only be providing the data but will be helping facilitate its use by their medical and administrative staffs.

4. **Install the HIRS query system, and load California registry data.**
The HIRS query system has been obtained from the Centers for Disease Control and Prevention, and successfully installed and tested. We have loaded 1988-1990 California breast cancer cases for testing. See Appendix D for example screens and reports.

5. **Implement e-mail and case transmit bulletin boards in 7 regional registries.**
We have held discussions with the regional center technicians, making sure the design is feasible and the proper hardware is available to run the new BBS's. We are setting up a test link with the Sacramento region, to make sure the email sharing works correctly. We will also be improving the user interface to make it easier for hospitals to transmit and receive data files. When testing is completed, software will be distributed to all the remaining regions.

6. **Carry out one-time upload of patient followup and AJCC staging data**
This has not yet been carried out, since the regional systems have not yet been modified to receive the data. When this is accomplished (under separate funding) in the next 3-6 months, we will implement the one-time upload.

7. **Load 1993 case data into query system when available.**
The data are not yet available.

8. **Load NCI SEER data into HIRS.**
Not completed yet.
Conclusions
We have learned several things during this startup year:

1. There is considerable interest on the part of hospitals in receiving comparison data, and in expanding the data collected on their cancer cases.

2. Hospitals can make good use of a dial-in bulletin board, even when only the simplest information is available (such as physician license numbers).

3. Enhancing a bulletin board system with a statistical query system like HIRS is feasible.

4. There is considerable interest among potential users and providers in using the Internet via a Web server to access our comparison data query system.

Thus, the basic premises of our project are proving to be sound. The only change we will make in the next year's plan will be to implement a full Internet connection to our query system.
Appendix A  
Data Items Added for Army Study

Co-Morbidity #1 and #2  two 4-digit fields #591

Purpose: to help interpret treatment given in light of the primary co-morbidities that might affect it, such as diabetes, high blood pressure, etc. Allow two fields, to list two conditions.

Codes:  ICD9 diagnosis codes.  
Leave blank if don’t know (default)  
0000 = none

Discovered by Screening  #592 (1)

Purpose: to track which patients were diagnosed via screening programs, especially for breast, cervical, prostate, and colo-rectal cancers. This will help analyze changes in reporting trend due to screening alone. Will be most easily available in registries which help carry out screening themselves.

Codes:  0 - no  
1 - routine screening exam  
2 - hospital screening program (targeted to a particular cancer)  
3 - state-sponsored screening program  
4 - nationally-sponsored screening program  
5 - other type of screening  
9 - unknown if via screening (default)

Family history (1st degree) of any cancer (1) #521  
Family history (1st degree) of this cancer (1) #522

First degree relatives include brothers, sisters, parents, and children

Family history (2nd degree) of any cancer (1) #523  
Family history (2nd degree) of this cancer (1) #524

Second degree relatives include grandparents, aunts, uncles, cousins

Codes:  0 stated as none  
1 one relative  
2 two relatives  
...  
8 8 or more  
9 unknown if any

Protocol Number (10) #584

Codes:  alphanumeric, prefixed by study initials
Protocol Eligibility Status (1) #585
Codes (from DAM)
0  no protocol available
1  on protocol (enrolled and started rx)
2  ineligible (age, stage, etc)
3  ineligible (co-morb, pre-existing condition)
4  withdrawn after entering
6  eligible but didn’t start, reason unknown
7  patient refused, though eligible
9  unknown if on protocol

Date patient disease free (6) #562
Codes: mmddyy

Reason for no Radiation #567 (1)
Purpose: to help track which cases may have unreported treatment, vs which ones were known to have refused, etc.

The following codes are to be used to record the reason the patient did not undergo radiation:
0  Radiation treatment performed.
1  Radiation treatment not recommended.
2  Radiation contraindicated because of other conditions; autopsy only cases
3  Patient not referred for radiation consultation
6  Reason unknown for no radiation therapy.
7  Patient or patient’s guardian refused radiation.
8  Radiation recommended, unknown if done.
9  Unknown if radiation recommended or performed; death certificate only cases.

Reason for no Chemotherapy #577 (1)
Purpose: to help track which cases may have unreported treatment, vs which ones were known to have refused, etc.

The following codes are to be used to record the reason the patient did not undergo chemotherapy:
0  Chemotherapy treatment performed.
1  Chemotherapy treatment not recommended.
2  Chemotherapy contraindicated because of other conditions; autopsy only cases.
6  Reason unknown for no chemotherapy.
7  Patient or patient’s guardian refused chemotherapy.
8  Chemotherapy recommended, unknown if done
9  Unknown if chemotherapy recommended or performed; death certificate only cases.

Reason for no Hormone Therapy #581 (1)

The following codes are to be used to record the reason the patient did not undergo hormone therapy:
0    Hormone therapy performed.
1    Hormone therapy not recommended.
2    Hormone therapy contraindicated because of other conditions; autopsy only cases.
6    Reason unknown for no hormone therapy.
7    Patient or patient’s guardian refused hormone therapy.
8    Hormone therapy recommended, unknown if done.
9    Unknown if hormone therapy recommended or performed; death certificate only cases.

JCAHO Clinical Indicators. (15) #266-#280

Codes:        0 or blank   Does not apply
             1 - met       Requirements met
             2 - not met   Requirements not met
             3 - exception Justifiable Exception
             9 - unknown

Ind 16 for breast, lung, colorectal
1. PTN noted (were T and N in the surgical path report?)
2. Margins Status Doc (Status of margins documented?)
3. Histology in Path Rpt: (Histologic type reported in path report?)
4. Extension documented: (In Situ or invasive type noted in path report)
5. Size doc in Path Rpt: (Size of tumor documented in path report?)
6. Nodes documented (Lymph node examine documentation?)
7. Surg Path Consult Rpt: (Surgical path consult report present?)

Ind 17 - female breast, lung, colorectal
8. Staged by managing MD: (Stage of tumor designated by a managing physician?)

Ind 18 for female breast ca stage >= 1
9. ER analysis documented (Estrogen receptor analysis documented?)

Ind 19 for non-small cell lung ca undergoing thoractotomy

Ind 20 for colorectal patients undergoing resection.
12. Barium Enema within 6 wks (prior to resection for colorectal ca)
13. Colonoscopy within 6 wks (prior to resection for colorectal ca)
14. Obstructed/Perforated (Obstructed or perforated colorectal cancer?)
15. Proctosigmoidoscopy 6 wks (within 6 weeks prior to resection for colorectal ca)
Chemotherapy Completion Status #597 (1)

This field is to be used for recording whether the patient completed chemotherapy or not according to treatment plan. The following codes are to be used:

0  No chemotherapy
1  Treatment completed
2  Chemotherapy not complete, patient health
3  Chemotherapy not complete, patient expired
4  Chemotherapy not complete, patient choice
5  Chemotherapy not complete, family choice
6  Chemotherapy not complete, complications
7  Chemotherapy not complete, cytopenia
8  Chemotherapy not complete, other reason
9  Chemotherapy not complete, reason unknown

GLOBAL CLINICAL GUIDELINES [C/NET Screen 4]
These fields are to be entered using the following codes:

0  No
1  Yes
9  Unknown

Fields:
Chest X-Ray
MRI of Primary
CT Chest/Lung
CT Abdomen/Pelvis
CT Liver/Spleen
Imaging Bone
Imaging Brain
CBC
Multichannel Chemistry
Surgical Consultation
Radiation Oncology Consultation
Medical Oncology Consultation

Surgical approach #566 (1)
The following codes are to be used to record the method used to approach the surgical field:

0  No surgery performed
1  Open approach, endoscopy not used
2  Open approach, assisted by laparoscope
3  Laparoscopic approach only
4  Laparoscopy, NOS (unknown if with or without open approach)
5  Video Assisted Thoracoscopy (VAT)
6  Thoracoscopy, NOS
8  Endoscopy, NOS
9  Unknown approach
Referral to support services #532 (4 2-digit codes)

Codes:

00  No Support services
05  Pain management
10  Patient Services (ACS)
19  Patient Services (other)
20  Support Group (ACS)
25  Support Group (Hosp)
29  Support Group (other)
30  Enterostomal/stomal therapy
31  Infusion/parenteral therapy
32  Respiratory therapy
40  Nutritionist
41  Occupational therapy
42  Physical therapy
43  Speech therapy
50  Home care
51  Visiting nurse
60  Rehabilitation facility
70  Social Services
80  Hospice
98  Other
99  Unknown if referred

Breast: S-phase % (4) #593
2-digits, plus decimal point and 1 decimal place, from 00.0 to 99.9, e.g. 10.2 or 09.0

DNA Level (1) #594

0  not done
1  diploid
2  aneuploid
3  tetraploid
9  unknown

PSA Value (6) #595
4-digits plus decimal point and 1 decimal place, from 0000.0 to 9999.9

PSA Level (1) #596 (pre-treatment)

0  not done
1  normal
2  abnormal
3  borderline
8  ordered, results not in chart
9  unknown
**ABSTRACT: (4) PE/SCANS**

<table>
<thead>
<tr>
<th>Text-Physical Exam:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>X-rays/Scans:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

**GLOBAL CLINICAL GUIDELINES**

<table>
<thead>
<tr>
<th>Chest Xray</th>
<th>Imaging Brain</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRI of Primary</td>
<td>CBC</td>
</tr>
<tr>
<td>CT Chest/Lung</td>
<td>Multichannel Chemistry</td>
</tr>
<tr>
<td>CT Abdomen/Pelvis</td>
<td>Surgical Consult</td>
</tr>
<tr>
<td>CT Liver/Spleen</td>
<td>Radiation Onc. Consult</td>
</tr>
<tr>
<td>Imaging Bone</td>
<td>Medical Onc. Consult</td>
</tr>
</tbody>
</table>

**ABSTRACT: (4A) LAB/SCOPES/MARKERS**

<table>
<thead>
<tr>
<th>Scopes:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lab:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

**MARKERS**

<table>
<thead>
<tr>
<th>Breast Estrogen:</th>
</tr>
</thead>
<tbody>
<tr>
<td>S-phase Value:</td>
</tr>
<tr>
<td>DNA Value:</td>
</tr>
</tbody>
</table>

| Prostate PSA Value: | Level: |
| Ovarian CA-125 Value: | Level: |
**ABSTRACT: (5) OPERATIVE/PATHOLOGY FINDINGS**

Text - Operative Findings:

Text - Pathology:

Path Rpt# (Diag/Path):...
Path Rpt# (Surgery):...

Regional Nodes Positive:...
Regional Nodes Examined:...
Tumor Size(mm):...
Residual Tumor:...
Date of Diagnosis:../../...
Diagnostic Confirm:...

Pediatric Stage:...
Pediatric Stage System:...

ENTER TEXT NOTES

---

**ABSTRACT: (7) FIRST COURSE OF TREATMENT**

**SURGERY**

Summary:...

At this Hospital:...

Reason for no surgery:...

Surgical Approach:...

Date of Initial Therapy:../../...

Date First Disease Free:../../...

Surgery Date:../../...

Protocol Eligibility Status:...

Protocol Number:...

Co-morbidity #1:...

Co-morbidity #2:...

Cancer Conference Date:../../...

Support Services:...

#2:...

#3:...

#4:...

ENTER THE APPROPRIATE SITE SPECIFIC SURGERY WHICH SUMMARIZES THE PATIENTS' FIRST COURSE OF RX
**ABSTRACT: (I) JCAHO CLINICAL INDICATORS**

<table>
<thead>
<tr>
<th>PTN noted:</th>
<th>BREAST, LUNG, OR COLORECTAL (IND 16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Margins Status Doc:</td>
<td>FEMALE BREAST, LUNG, COLORECTAL (IND 17)</td>
</tr>
<tr>
<td>Histology in Path Rpt:</td>
<td>FEMALE BREAST, STAGE &gt;=1 (IND 18)</td>
</tr>
<tr>
<td>Extension documented:</td>
<td>LUNG CANCER, NON SMALL CELL (IND 19)</td>
</tr>
<tr>
<td>Size doc in Path Rpt:</td>
<td>COLORECTAL UNDERGOING RESECTION (IND 20)</td>
</tr>
<tr>
<td>Nodes documented:</td>
<td></td>
</tr>
<tr>
<td>Surg Path Consult Rpt:</td>
<td></td>
</tr>
</tbody>
</table>

**WAS PTN NOTED? (WERE T & N IN THE SURGICAL/PATH REPORT)?**

0 = NOT APPLICABLE, 1 = REQUIREMENTS MET, 2 = REQ NOT MET, 3 = JUSTIFIABLE EXCEPTION, 9 = UNKNOWN
PLAN FOR INTERNET/BBS CANCER QUERY SYSTEM

Incoming Telephone Lines/Modems

Internet Service Provider

THE INTERNET

WINDOWS NT SERVER
- BBS Software
- WWW Server
- FTP Server
- File Serving
- TCP/IP Routing
- Mail Gateway

HIRS Server (runs data queries)

Existing E-mail Server

EXISTING OFFICE NETWORK
Appendix D
Examples of HIRS Query Screens

<table>
<thead>
<tr>
<th>Age</th>
<th>(n)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-14</td>
<td>1</td>
<td>0.00</td>
</tr>
<tr>
<td>15-19</td>
<td>5</td>
<td>0.01</td>
</tr>
<tr>
<td>20-24</td>
<td>77</td>
<td>0.09</td>
</tr>
<tr>
<td>25-29</td>
<td>491</td>
<td>0.54</td>
</tr>
<tr>
<td>30-34</td>
<td>1751</td>
<td>1.94</td>
</tr>
<tr>
<td>35-39</td>
<td>3794</td>
<td>4.19</td>
</tr>
<tr>
<td>40-44</td>
<td>6655</td>
<td>7.36</td>
</tr>
<tr>
<td>45-49</td>
<td>8483</td>
<td>9.38</td>
</tr>
<tr>
<td>50-54</td>
<td>7987</td>
<td>8.83</td>
</tr>
<tr>
<td>55-59</td>
<td>8516</td>
<td>9.41</td>
</tr>
<tr>
<td>60-64</td>
<td>10335</td>
<td>11.42</td>
</tr>
<tr>
<td>65-69</td>
<td>12460</td>
<td>13.77</td>
</tr>
<tr>
<td>70-74</td>
<td>10995</td>
<td>12.15</td>
</tr>
<tr>
<td>75-79</td>
<td>8917</td>
<td>9.86</td>
</tr>
<tr>
<td>80-84</td>
<td>5757</td>
<td>6.36</td>
</tr>
<tr>
<td>85+</td>
<td>4249</td>
<td>4.70</td>
</tr>
</tbody>
</table>

Total 90473 100.00
(HIRS 1.0d (OSG) 03/31/94) 09/13/95 09:56:41 Query Time: 0.07 seconds

File Edit Window Help Options Format
Query

Dataset: California 1988-1992 Breast Cases
Statistic: Count
Display Rows By: Age
Cols By: None

Year of Diagnosis: All
Summary Stage: All
Age: All
Breast Sub-site: All
Race/Ethnicity: All

Press Enter or Q to run the query
California 1988-1992 Breast Cases
-----COUNT-----

<table>
<thead>
<tr>
<th>Summary Stage</th>
<th>(n)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>IN SITU</td>
<td>5183</td>
<td>5.73</td>
</tr>
<tr>
<td>LOCALIZED</td>
<td>51449</td>
<td>56.87</td>
</tr>
<tr>
<td>REGIONAL EXTENSION</td>
<td>1782</td>
<td>1.97</td>
</tr>
<tr>
<td>REGIONAL NODES</td>
<td>21440</td>
<td>23.70</td>
</tr>
<tr>
<td>REGIONAL NODES AND EXTENSION</td>
<td>3219</td>
<td>3.56</td>
</tr>
<tr>
<td>REGIONAL NOS</td>
<td>56</td>
<td>0.06</td>
</tr>
<tr>
<td>DISTANT</td>
<td>4192</td>
<td>4.63</td>
</tr>
<tr>
<td>UNKNOWN OR UNSTAGEABLE</td>
<td>3152</td>
<td>3.48</td>
</tr>
</tbody>
</table>

Total 90473 100.00

(HIRS 1.0d (DOS) 03/31/94) 09/13/95 09:57:51 Query Time: 0.11 seconds
California 1988-1992 Breast Cases

##### COUNT

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IN SITU</strong></td>
<td>5183</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2540</td>
<td>2643</td>
</tr>
<tr>
<td>Col%</td>
<td>5.73</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>12.71</td>
<td>12.80</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>49.02</td>
<td>50.99</td>
</tr>
<tr>
<td>Tab%</td>
<td>5.73</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>2.81</td>
<td>2.92</td>
</tr>
<tr>
<td><strong>LOCALIZED</strong></td>
<td>51449</td>
<td>9853</td>
<td>9524</td>
<td>10195</td>
<td>10687</td>
<td>11190</td>
</tr>
<tr>
<td>Col%</td>
<td>56.87</td>
<td>58.79</td>
<td>58.70</td>
<td>60.50</td>
<td>53.46</td>
<td>54.19</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>19.15</td>
<td>18.51</td>
<td>19.82</td>
<td>20.77</td>
<td>21.75</td>
</tr>
<tr>
<td>Tab%</td>
<td>56.87</td>
<td>10.89</td>
<td>10.53</td>
<td>11.27</td>
<td>11.81</td>
<td>12.37</td>
</tr>
<tr>
<td><strong>REGIONAL EXTENSION</strong></td>
<td>1782</td>
<td>362</td>
<td>376</td>
<td>334</td>
<td>353</td>
<td>367</td>
</tr>
<tr>
<td>Col%</td>
<td>1.97</td>
<td>2.16</td>
<td>2.32</td>
<td>1.98</td>
<td>1.77</td>
<td>1.73</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>20.31</td>
<td>21.10</td>
<td>18.74</td>
<td>19.81</td>
<td>20.03</td>
</tr>
<tr>
<td>Tab%</td>
<td>1.97</td>
<td>0.40</td>
<td>0.42</td>
<td>0.37</td>
<td>0.39</td>
<td>0.39</td>
</tr>
<tr>
<td><strong>REGIONAL NODES</strong></td>
<td>21440</td>
<td>4319</td>
<td>4113</td>
<td>4230</td>
<td>4337</td>
<td>4441</td>
</tr>
<tr>
<td>Col%</td>
<td>23.70</td>
<td>25.77</td>
<td>25.35</td>
<td>25.10</td>
<td>21.70</td>
<td>21.51</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>20.14</td>
<td>19.18</td>
<td>19.73</td>
<td>20.23</td>
<td>20.71</td>
</tr>
<tr>
<td>Tab%</td>
<td>23.70</td>
<td>4.77</td>
<td>4.55</td>
<td>4.68</td>
<td>4.79</td>
<td>4.91</td>
</tr>
<tr>
<td><strong>REGIONAL NODES AND EXTENSION</strong></td>
<td>3219</td>
<td>662</td>
<td>640</td>
<td>638</td>
<td>634</td>
<td>645</td>
</tr>
<tr>
<td>Col%</td>
<td>3.56</td>
<td>3.95</td>
<td>3.94</td>
<td>3.79</td>
<td>3.17</td>
<td>3.12</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>20.57</td>
<td>19.88</td>
<td>19.82</td>
<td>19.70</td>
<td>20.04</td>
</tr>
<tr>
<td>Tab%</td>
<td>3.56</td>
<td>0.73</td>
<td>0.71</td>
<td>0.71</td>
<td>0.70</td>
<td>0.71</td>
</tr>
<tr>
<td><strong>REGIONAL NOS</strong></td>
<td>56</td>
<td>17</td>
<td>13</td>
<td>8</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Col%</td>
<td>0.06</td>
<td>0.10</td>
<td>0.08</td>
<td>0.05</td>
<td>0.05</td>
<td>0.04</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>30.36</td>
<td>23.21</td>
<td>14.29</td>
<td>17.86</td>
<td>14.29</td>
</tr>
<tr>
<td>Tab%</td>
<td>0.06</td>
<td>0.02</td>
<td>0.01</td>
<td>0.01</td>
<td>0.01</td>
<td>0.01</td>
</tr>
<tr>
<td><strong>DISTANT</strong></td>
<td>4192</td>
<td>863</td>
<td>871</td>
<td>827</td>
<td>814</td>
<td>871</td>
</tr>
<tr>
<td>Col%</td>
<td>4.63</td>
<td>5.15</td>
<td>5.37</td>
<td>4.91</td>
<td>4.07</td>
<td>3.96</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>20.59</td>
<td>20.78</td>
<td>19.73</td>
<td>19.42</td>
<td>19.49</td>
</tr>
<tr>
<td>Tab%</td>
<td>4.63</td>
<td>0.95</td>
<td>0.96</td>
<td>0.91</td>
<td>0.90</td>
<td>0.90</td>
</tr>
<tr>
<td><strong>UNKNOWN OR UNSTAGEABLE</strong></td>
<td>3152</td>
<td>685</td>
<td>687</td>
<td>618</td>
<td>615</td>
<td>547</td>
</tr>
<tr>
<td>Col%</td>
<td>3.48</td>
<td>4.09</td>
<td>4.23</td>
<td>3.67</td>
<td>3.08</td>
<td>2.65</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>21.73</td>
<td>21.80</td>
<td>19.61</td>
<td>19.51</td>
<td>17.35</td>
</tr>
<tr>
<td>Tab%</td>
<td>3.48</td>
<td>0.76</td>
<td>0.76</td>
<td>0.68</td>
<td>0.68</td>
<td>0.60</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>90473</td>
<td>16761</td>
<td>16224</td>
<td>16850</td>
<td>19990</td>
<td>20648</td>
</tr>
<tr>
<td>Col%</td>
<td>100.00</td>
<td>100.00</td>
<td>100.00</td>
<td>100.00</td>
<td>100.00</td>
<td>100.00</td>
</tr>
<tr>
<td>Row%</td>
<td>100.00</td>
<td>18.53</td>
<td>17.93</td>
<td>18.62</td>
<td>22.09</td>
<td>22.82</td>
</tr>
<tr>
<td>Tab%</td>
<td>100.00</td>
<td>18.53</td>
<td>17.93</td>
<td>18.62</td>
<td>22.09</td>
<td>22.82</td>
</tr>
</tbody>
</table>

(HIRS 1.0d (DOS) 03/31/94) 09/13/95 09:58:48 Query Time: 0.48 seconds

22