

Cancer Registry of Greater California  
identifies adolescent cases  
considered lost to follow-up,  
in order to improve follow-up rates

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- Follow-up is a registry activity to monitor the vital status of a patient.
- Through follow-up a patient's contact information, vital status, date of last contact, treatment, and recurrence are updated.
- Lost to follow-up refers to patients diagnosed with cancer, but the registry has not obtained vital status information for one year or longer.
- Patients lost to follow-up can bias results of survival and other studies.
- High rates of patient's lost to follow-up lead to extra resources needed in active follow-up efforts.



**Objective:** Increase the percent of adolescent registry cases receiving current follow up.



# Project Initiation:

- Identify the number of patients age 25 or less, lost to follow-up (5,847).
- Identify software for the project (ACCESS DB).
- Identify Vendors for confidential search (MasterFiles probe 360, TLO).
- Hire of four temporary employees for one month.
- Conduct follow up to hospitals to obtain more recent date of services, especially for patients under the age of 18.

# SELECTION CRITERIA

(May 2014)



- Diagnosed 1988 – 2011.
- Resided in CRGC area.
- Not known to be deceased.
- Age 25 or younger.
- Not followed for current vital status since 2011.

# Work Effort

- Four temporary employees spent 700 hours to search 5,847 records.
- Two Research Associates spent 200 hours on the project.
- One programmer spent 100 hours for the creation and support of the ACCESS database.
- IT Project Manager supervised the project May 2014 – September 2014 (0.25 FTE or 200 hours).

# Search method

- Search SSN, if available.
- Search first and last name with Date of Birth (DOB).
- Search last known address.
- Search address at diagnosis.
- Search relatives, if correct person was not found.

# Lost to Followup

ID:



First Name:

SSN:

Gender:

Last Name:

DOB:

Race:

Middle Name:

Current Age:

Maiden Name:

## Information at Diagnosis

Date DX:  Age @ DX:

## Last Known Contact Information

Date Last Follow Up:

New Followup Date:   Deceased Information Status:

New First Name:  New Last Name:  New SSN:

New Street:

New City:  New State:  New Zip Code:

Comment:



## Issues (1)

- Numerous records with transposed numbers in the SSN and DOBs.
- Misspelled first and last names.
- Incorrect cities and/or zip codes.

## Issues (2)

- Most prisoners did not have inmate numbers recorded, refer to available Inmate locator webpages.

CA: <http://inmatelocator.cdcr.ca.gov/default.aspx>

FEDS: <http://www.bop.gov/inmateloc/>

- Any inmate numbers we were able to determine through searches, using other information, were recorded in the comments.

## Issues (3)

- Biggest challenge was obtaining updated information for patients still under the age of 18.
- Using the last name and address to locate parents' most recent address.

## Issues (4)

- If patient is still less than 18 years of age, they will not be in the vendors database.
- Even if parents' address was found; does not mean the child is still living. For these cases the contact information was updated, but the date of last follow up remained the same.
- If we had a SSN for a child, we looked it up in SSDI to see if deceased. Of the many SSNs entered into SSDI, only one child was found deceased.

# Hospital Response

- Contacted facilities in order to obtain a more recent date of service for patients currently under the age of 18 (718).
- Sent 135 follow up letters and received 80 (59.3%) responses to 347 (48.3%) cases.

## Hospital Response (cont.)

- Of those 347 cases, approximately 127 (36.6%) follow up dates are within the 18 month period. Resulting in a 17.7% improvement for the target group of currently under 18 (718).
- While surprised by the high response rate from the Active Follow Up letters, it did not yield follow up dates that fall within the target date parameter. The majority (220 or 63.4% ) of responses were the date of diagnosis.

Project Cases: 5,847    Updated Info Received: 4,210 (72.0%)

New Follow Up Date            3,555 (60.8%)

New Contact Address            2,603 (44.5%)

New SSN                            1,838 (31.4%)

New Last Name                    948 (16.2%)

New First Name                   174 (0.03%)

**Cases still under age 18            1,196 (20.5%)**

# Passive Follow Up Results Lost to Follow Up



August 3, 2014 (prior)    August 10, 2014(post) Increase

Cases dx 1988 -2011 followed into 2012

Age < 20	87.84%	93.52%	5.68%
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Cases dx 1988 -2011 followed into 2013

Age < 20	68.61%	74.02%	5.41%
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Cases dx 1988 -2011 followed into 2014

Age < 20	67.94%	73.75%	5.81%
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# Table 1: Disposition Count by Age at DX

Source Description	DX 0 To 17	DX 18 To 25	TOTAL
Found on Master Files	1,595	2,083	3,678
Found on National Death Index (NDI)	1	4	5
Hospital Follow up	237	110	347
Needs further Follow up	2	11	13
No Information Found	975	649	1,624
TLO search	42	138	180
<b>TOTAL</b>	<b>2,852</b>	<b>2,995</b>	<b>5,847</b>

# Table 2: Disposition Count by Current Age

Source Description	Age 0 To 17	Age 18 To 24	Age 25 To 34	Age 35 To 44	Over 44
Found on Master Files	583	365	945	1109	676
Found on National Death Index	1	0	1	1	2
Hospital Follow up	184	21	36	86	20
Needs further Follow up	1	1	2	1	8
No Information Found	408	344	360	378	134
TLO search	19	4	22	48	82
Inmate site search	0	1	2	1	1
<b>TOTAL</b>	<b>1,196</b>	<b>736</b>	<b>1,368</b>	<b>1,624</b>	<b>923</b>



# Table 3: New Follow Up Dates by Year

Year of new follow up date	N	%
2012	299	5.1%
2013	907	15.5%
2014	2,349	40.2%
<b>Total</b>	<b>3,555</b>	<b>60.8%</b>

## Suggestions (1)

- *Improve the quality of the contact information*
  - Training on importance of accurate data entry information for adolescent cases.
  - Verify Social Security Number once or twice a year.
  - Use USPO and/or NAACCR GEOCODE websites to ensure addresses we have are complete and actual addresses.

## Suggestions (2)

- *Inmate diagnoses*
  - Provide training to obtain the inmate number when prisoners are diagnosed.
  - Work with CA Department of Corrections and Rehabilitation on prisoners diagnosed while incarcerated.
- *The less than 18 group*
  - We can find parents' address but this does not verify if the child is still living.

## Suggestions (3)

- *Search databases*
  - Using both Master files and TLO in conjunction proved to be the most useful in obtaining the most up to date information.
    - We would find a SSN in Master Files but an outdated address. In TLO, we would find a current address.
  - Explore additional sources to follow up on patients.
- *Children who are diagnosed*
  - Provide training to collect information on the parents of diagnosed children.
    - Ensure SSN is the child's, not the parent's.
  - Create a protocol for what constitutes a follow up for minors.

# Follow Up Percent SEER Submission November 2014, age < 20

Percent



# Passive Follow Up Project Team

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