

Utah Cancer Registry Recurrence Experience

Sandra Reay, ODS
Quality Improvement Specialist/Training Coordinator
Utah Cancer Registry



Utah Cancer Registry Recurrence Project Purpose

- National Cancer Institute funded R01 grant (R01CA260891-04)
 - Overarching objective: establish a scalable approach to accurately identify recurrence using cancer registry data and administrative data streams.

Collaboration with Cancer Surveillance System at Fred Hutchinson Cancer Center

Recurrence Project Design

Data sources for identifying recurrences

Available within the Utah Cancer Registry	• Abstracts • CoC Recurrence variables • Pathology reports • Death certificates
Accessible to Utah Cancer Registry ODS-C (with IRB approval for research use)	• Electronic medical record (EMR) from 3 health care systems (manual chart review)
Administrative data linked to the Utah Cancer Registry through Utah Population Database (UPDB) (external data sources)	• All Payer Claims Database (APCD) • Electronic medical record (EMR) data from 2 large health care systems • Statewide Healthcare Facilities Data (SHFD; Inpatient, Ambulatory Surgery and Emergency Dept) • Medicare • Medicaid

Eligibility criteria for Utah Cohort

- 1) Utah residents age ≥ 18 years at cancer diagnosis
- 2) Diagnosed from 2017 – 2022
- 3) First primary cancer of AJCC stage II-III breast or prostate

Exclusion: Prostate cancer patients who are under active surveillance only. Since they did not receive treatment, they would never be disease-free.

About 6,000 records included for chart review

Documents to review for this project

- Abstraction Manual
- Procedures for Abstraction
- Physician guidance document
- QC Procedures
- Flag Complex Records Procedure – for monthly group discussions

Basic steps for chart review

1. Log in to chart review data collection tool
2. Select the cases to be reviewed
3. Review cancer registry records in SEER*DMS
4. Review hospital EMRs for all information available
5. Monthly QC checks

Chart review data elements

- First course therapy (3): status of completion, date, sources of info
- Disease-free status (6): ever disease free, date, sources of info
- Recurrence (13): details on next slide
- Disease progression/residual disease (11): status, date, sources
- Subsequent treatment of the original primary (6)
- Subsequent primary (3)
- Date of last physician/health care contact (1)

Recurrence

- Source(s) of information in the medical record
 - Location evidence of recurrence would be documented (if applicable)
 - Imaging
 - Medical notes,
 - PSA (prostate only)
 - Pathology report
 - Additional cancer treatment
- First date where there is evidence of recurrence
 - After documented disease-free period
 - Date should correspond with one of the sources of recurrence information
- Type of recurrence
 - in situ, local, regional, distant, unknown

Recurrence, Progression, or Residual Disease
Imaging
Q8010. Recurrence status * must provide value
Medical Notes
Q8015. Recurrence status * must provide value
PSA
Q8020. Recurrence status * must provide value
Pathology, Including Biopsy
Q8024. Recurrence status * must provide value
Treatment
Q8029. Recurrence status * must provide value

Examples

Examples

Patient #1 – Patient w/breast cancer diagnosis. Completed first course therapy including surgery (lumpectomy w/close margins and positive lymph nodes), chemotherapy, radiation. Most recent MD note states “patient doing well”.

Examples

Patient #2 – Prostate bx showed adenocarcinoma. PSA @ time of diagnosis was 6.7. Treated with combination of external beam and brachytherapy. PSA 6 months after tx dropped to 2.79. Pt then moved out of state & no further information available.

Examples

Patient #3 – Breast cancer dx & surgery at a facility we were unable to get approval for EMR access. Abstract and pathology submitted by that facility showed positive nodal involvement. Systemic treatment at stand alone oncology clinic with only information available to central registry being claims data. After completion of first course therapy pt transferred care to another provider at a different stand-alone oncology clinic. No access to that clinic's records.

Preliminary Findings

Preliminary results

Table 1. Recurrence identified in records reviewed as of March 2, 2026

	Breast cancer		Prostate cancer	
	N	%	N	%
Total	953		507	
Recurrence, all time				
No	859	90.1	430	84.8
Yes	94	9.9	77	15.2
Recurrence, 5 years				
No	881	92.4	450	88.8
Yes	72	7.6	57	11.2

Preliminary results

Table 2. Five-year breast cancer recurrence identified by age and stage, as of March 2, 2026

	Five years recurrence for breast cancer	
	N	%
Total Recurrence	72	7.6%
Age at Diagnosis		
20–39	7	10.8%
40–49	14	9.3%
50–59	12	5.9%
60–69	16	6.0%
70–79	16	8.0%
80–101	7	10.4%
AJCC		
I	18	3.6%
II	38	11.0%
III	16	15.5%

Lessons Learned

Lessons learned

- Identifying recurrence is tricky!
- Central registry has access to incomplete clinical information.
- An ODS cannot do this on their own with existing knowledge/training
- QA/QC checks: double abstractions necessary to arrive at reasonable agreement between abstractors coding recurrence
 - Agreement on finding recurrence is complicated!
- Decided to reduce the number of data items because of the time spent per record and complexity of the task

Lessons learned: Physician collaborators

- Vital to have collaboration with clinicians
 - Guidance on interpreting the notes in the records (rules)
 - Example: PSA documented but recurrence status not mentioned. What does that PSA level indicate?
 - Physician documentation is not always clear-cut
 - Example: Patient has completed radiation. PSA has leveled out. Continues to do well.
 - Physician documentation doesn't meet ODS standard setter rules
 - Example: Patient with history of right breast cancer. Now has a recurrent cancer in left breast.

Research Team

MPIs



Mia Hashibe, PhD
University of California,
Los Angeles



**Jennifer A. Doherty,
MS, PhD**
Executive Director, Utah
Cancer Registry



**Stephen M. Schwartz,
PhD, MPH**
Fred Hutchinson Cancer
Center



Lynn Henry, MD, PhD
University of Michigan



Esther Chang, PhD
University of Utah



Ruth Etzioni, PhD
Fred Hutchinson Cancer
Center



Manish Kohli, MD, PhD
Huntsman Cancer
Institute



Lucas Liu, PhD
Fred Hutchinson Cancer
Center

UCR Recurrence Project Team



Carrie Bateman BS
Registry Manager



Kacey Wigren ODS
Operations Supervisor



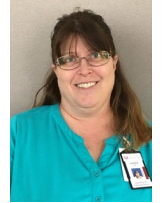
Marjorie Carter MSPH
Research Manager



Valerie Yoder BS
Database Analyst Sr.



Cameron Howlett BS
Database Report Writer



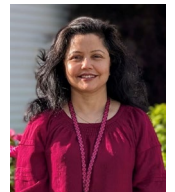
Sandra Reay ODS
Certified Cancer Registrar,
QIS



Kay McCandless ODS
Field Abstractor



Ying Qi ODS
Certified Cancer Registrar, QIS



Nicky Salahuddin ODS
Field Abstractor

Acknowledgements

- Co-author Marjorie Carter
- Utah Cancer Registry is supported by
 - Surveillance, Epidemiology and End Results program (SEER)
 - University of Utah
 - National Program of Cancer Registries (NPCR)
 - Huntsman Cancer Institute







THANK YOU

Sandra.reay@utah.edu