Looking for Cases in All the Right (or Wrong) Places

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BACKGROUND

Researchers, public health planners, and physicians rely on the completeness and validity of registry data. NCI's SEER program provides Data Quality Profile (DQP) markers that each SEER registry is contractually obligated to meet. In early 2014, it became apparent that, for the first time in more than 40 years, Utah Cancer Registry (UCR) was not going to meet the Completeness Estimate (CE) portion of the DQP for 2012 cases.

PURPOSE

UCR assessed several strategies to enhance case completeness.

Table 1. Summary of UCR Case-Finding Method and Number of Resulting New 2012 Cancer Cases.

Strategy	New 2012 Cases Found	Continue This Strategy?
1. Clinic Survey	74	Yes
2. Accession Number Verification	28	Yes
3. Non-CTR Hospitals Pathology Review	8	Yes
4. Missing Abstract Pathology Report Review	0	Yes
5. Medical Record Mentioning "History" Review	9	Yes
6. Early 2013 Diagnosis Verification	39	Yes
7. Deleted Cases Review	3	No
8. Non-Reportable Pathology Review	6	No
9. Physician-Reported "History of Cancer" Review	80	Yes
TOTAL NEW CASES FOUND	247	

STRATEGY	METHOD	RESULTS
1. Clinic Survey	Dermatology and urology clinics and physician offices were contacted to request information regarding where they were sending pathology specimens. We then contacted those labs and requested reporting of Utah cases.	Contacts with 65 clinics and physicians and identified 11 pathology labs that were not reporting to UCR.
2. Accession Number Verification	Accession numbers from hospital abstracts were checked to verify all cases had been submitted to UCR.	We found 28 new cases that had been abstracted by hospital registrars but not reported to UCR.
3. Non-CTR Hospitals Pathology Review	Pathology reports from hospitals without a CTR were identified to ensure the hospital was reporting all cases.	Review of 2,400 pathology reports identified 8 new 2012 cases, added facility information for 5 cases, and added diagnosis information for 40 cases.
4. Missing Abstract Pathology Report Review	Pathology records submitted to UCR that did not have a hospital abstract were reviewed.	There were 1,780 open "abstract facility leads" that resulted in new hospital abstracts for 279 cases. Because we had a pathology report for these cases, none of these cases would have been "missed".
5. Medical Record Mentioning "History" Review	Cases that had a mention of a "history of cancer" in the medical records were reviewed to verify previous cancer diagnoses, specifically focusing on prostate, melanoma and hematopoietic cases.	Among 2,424 cases with "history of cancer", most were non-reportable skin cancers; 9 new reportable cases were identified.
6. Early 2013 Diagnosis Verification	Cases with diagnosis dates in early 2013 were reviewed to identify any diagnosed in 2012.	A total of 39 cases initially coded as 2013 were diagnosed in 2012. While these cases were not "missed" and would have been corrected when we worked with our 2013 cases, our review ensured they were reported in a timely manner.
7. Deleted Cases Review	Abstracts initially deleted as non-reportable were re-reviewed to find any actually reportable.	Review of 128 case abstracts identified 3 that were deleted in error.
8. Non-Reportable Pathology Review	Reviewed pathology records found to be non-reportable skin cancers, looking for "evolving melanoma in situ cases".	Review of 22 non-reportable skin pathology reports identified 6 reportable cases of "evolving melanoma in situ."
9. Physician-Reported "History of Cancer" Review	Followed back on all physician-reported "history of cancer" cases.	From 263 letters sent to physicians for "history of cancer" cases, we found 80 new cases. The majority were hematopoietic cases.

Table 2. Invasive cancers diagnosed in Utah 2010-2012: overall and five major sites. After these case-finding efforts, prostate remained the cancer site with the lowest CE (71.5%). Overall CE for Utah in 2012 did not reach 98%.

Site	2010	2011	2012	2012 Completeness*
Overall	9,311	9,491	9,779	96.1%
Prostate	1,751	1,709	1,298	75.1%
Breast	1,294	1,402	1,425	102.8%
Melanoma	768	794	828	98.8%
Colorectal	693	733	696	97.6%
Lung	580	652	679	107.4%

*Completeness estimates (CE) are based on cancer counts and population from 2002-2011.
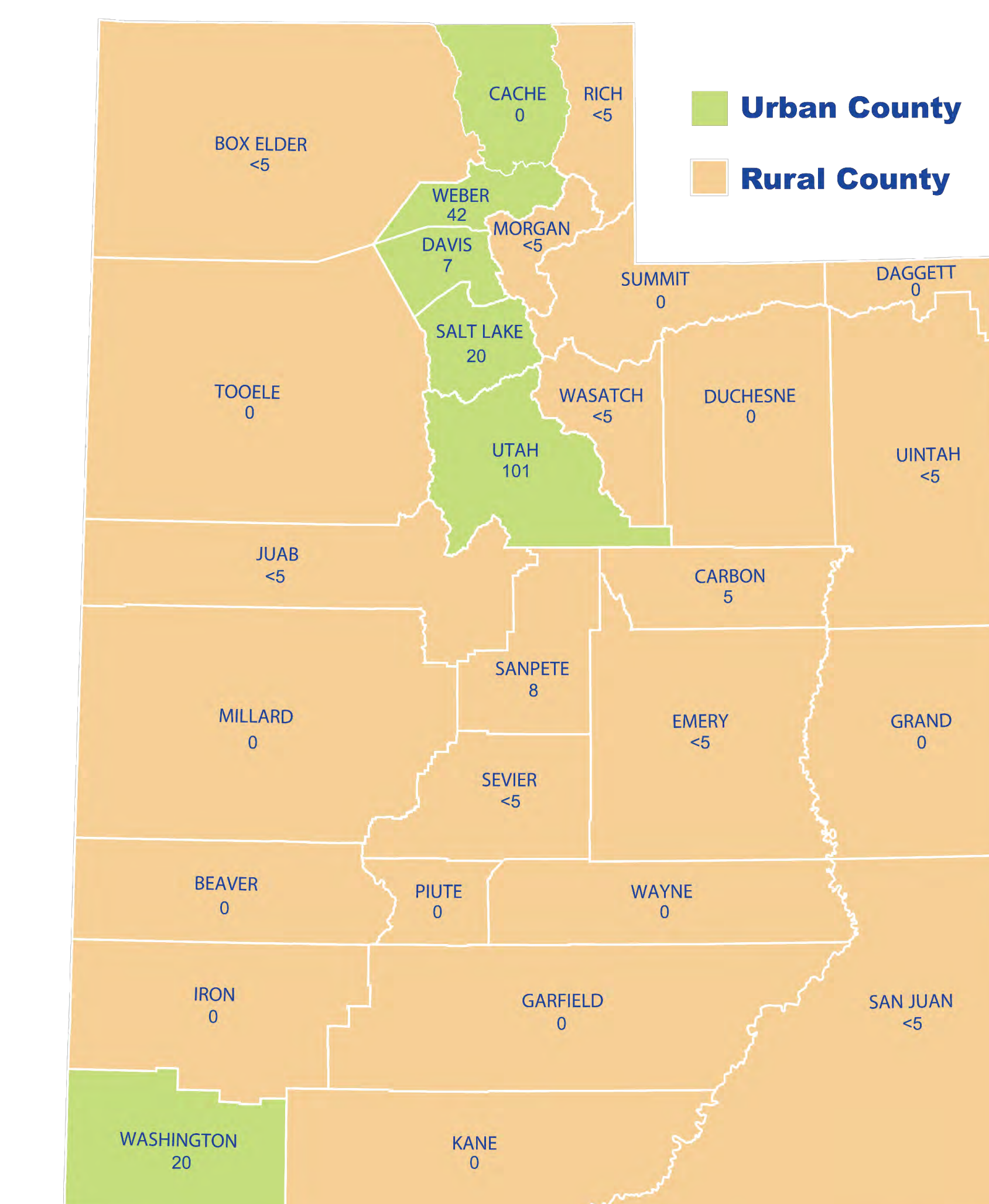

Figure 1. New Cases Reported by Newly Found Pathology Labs, Diagnosed 2009-2014

DISCUSSION

Through additional case-finding efforts, we found 247 new cases for 2012, representing less than 2% of our total case load. Surveying dermatology and urology clinics resulted in the bulk of newly identified cases with the greatest long-term reward in new pathology labs discovered. Some steps in our plan required significant staff time with poor return on investment and are not recommended. The more effective steps will become part of UCR's surveillance procedures.

Even with the additional case-finding efforts, UCR was unable to meet the CE goal. Our decline in prostate cancer cases is different from trends in other cancers and appears to represent a true shift in incidence, rather than unreported cases. We believe future calculations of CE should consider changes in screening recommendations and practice patterns, especially for prostate cancer.