

Winter 2011

# MISSOURI Cancer Registry and Research Center

Newsletter

Newsletter for Registrars including Timeliness Reminders, Calendar of Events and Updates

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*Season's Greetings from all of us to all of you!*

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## MCR Staff Updates

Staff changes are inevitable in any line of work and though MCR has little turnover, we do have several changes to share. We are pleased to announce the hiring of Sarah Arrandale and Fred Raithel as our newest additions to MCR-ARC.

- Sarah will work with Brenda's Data Collection and Processing team.
- Fred Raithel is our latest staff addition and replaces Hope Morris, MCR's office manager, who accepted a position with the University of Missouri system earlier this year.

We also have news about other MCR-ARC staff. Deb Eccleston relocated to Iowa in September. Cate Ellis will be leaving MCR in mid- January. She has accepted a position with a company that provides oncology staffing on an assignment where her RN experience will be valuable. We miss Deb and will certainly miss Cate too!

We will be posting the openings as soon as possible. If you are interested in the opportunity for professional growth with MCR, please watch our website for updated information. Meanwhile, feel free to discuss your interest confidentially with Nancy Cole.



*Sarah Arrandale*



*Fred Raithel*

## Website Works!

MCR's web site has come a long way since we started creating it in 2002. It took two years to develop, get necessary approvals, etc. and on April 14, 2004 the MCR website was finally launched. Our original goals were:

- cost containment (reduced expenditures for printing and mailing manuals, etc.);
- improved customer service (quick, convenient access to abstracting resources) ; and
- greater visibility/credibility (mostly for non-hospital facilities who questioned our "authority" to require them to submit cancer cases to MCR).

We have successfully met those goals and have achieved other successes we had not yet envisioned. Just to mention a few – it is a portal for the CDC's Web Plus internet-based reporting system, it can provide training/educational services via recorded presentations, and it can provide data through the Instant Atlas program. Having basic cancer reporting information on the website has also allowed our QA staff to direct their energies to callers with QA questions. In the first six months of this year there were 6,636 visits from 40 countries – that's about 35 hits a day! We think that is amazing. Our thanks and appreciation to our webmaster, Shari El-Shoubasi, for her great work!

## Upcoming Live Meeting Topics

If you haven't participated in one of our teleconferences, we encourage you to do so. And remember, recordings for most of the sessions will be posted on our website so you may access them at your convenience. We have planned more great topics for the next few months. In January, Nancy Cole and Iris Zachary will present "Data Security: Is Your Personal Data Next?" In February, Nancy Rold will present "By Request: Ambiguous Terminology and Lymph Node Coding Rules." Please submit any suggestions for topics to Deb Smith, MCR's education coordinator. Nothing is too minor to be addressed. Thanks for your participation.

## QA CORNER

### Race and Ethnicity (by Nancy Rold)

You might remember in our Spring newsletter our article about a new Joint Commission requirement that hospitals collect race and ethnicity data. The other day, when I went for an annual exam, the registration person said “We have a new requirement to ask and record the following:

- What language do you prefer to use here?
- What is your race?
- Is that Hispanic or non-Hispanic?”

I asked whether she had to get the info from me, or could she assume and fill it out. She said she was required to ask for my answer. So it sounds like hospitals are collecting that information (some perhaps for the first time directly from the patient). If your registry is not seeing this information recorded in your records, you might ask to have it made visible to you.

These requirements were put in place as part of the Joint Commission’s new “Patient-Centered Communication Standards.” By improving communications, the Commission hopes to improve health outcomes and quality of care regardless of race, ethnicity, language, disability or sexual orientation.

For more information: <http://health-information.advanceweb.com/Editorial/Content/Editorial.aspx?CC=233858>  
[http://www.jointcommission.org/Advancing\\_Effective\\_Communication/](http://www.jointcommission.org/Advancing_Effective_Communication/)

### Follow-Up Resources

Hospital registrars in CoC-approved facilities (who are required by CoC to do lifetime follow-up of patients) reported to us recently that the Ancestry.com site where they used to access the Social Security Death Index, no longer provides free searches by SSN.

As I mentioned in a past newsletter, registrars who report data to MCR can access the SSDI info via a free NPCR website. A User ID and password is needed which, at your request, MCR can provide to you in a separate email. Please have one person from your facility contact Nancy Rold if this would be of use in your registry.

When this news broke, several Missouri registrars volunteered suggestions of two other sites that they have used (below). We have such a supportive community! As always with electronic information, you should research a site to be sure it meets your facilities needs or policies. No MCR endorsement is implied.

<http://www.genealogybank.com/gbnk/ssdi/>

<https://www.dobsearch.com/death-records/search-ssn.php>

### Data Reporting: Deadline & Format Reminders

November was a crazy month at MCR with many of us working overtime to prepare our annual Call for Data to NPCR and NAACCR which included cases diagnosed through 2009. We are thankful for the high quality of reporting by facilities across Missouri. Now we will focus on our deadline for reporting 2010 cases to NPCR by March 1. We appreciate all that you are doing to **send any remaining 2010 cases to us by the end of January** so that we have time to consolidate, QA and edit our dataset with another “flurry” of MCR activity during February. We’re hoping to avoid blizzards! Of course, 2011 cases are gladly accepted as well. Remember that we can accept 2010 cases in either NAACCR v12.0 or 12.1, but that you need to upgrade to v12.1 to abstract and send us 2011 cases.

## The Medical Record Disease Index and Its Importance to Low-Volume Facility Reporters

One purpose of the Medical Record Disease Index (MRDI) is to have a complete visual listing of each patient who has been to your facility with a reportable cancer code. This list is the most efficient way to do case finding. You can use this list to keep track of which patients you submitted as well as ones you did not submit and why.

Another purpose of the MRDI is that it helps simplify the case finding audits which ensure complete reporting for each facility as well as identify any problem areas in coding or case finding. In the past low-volume facility audits were a separate process from data submission and required extra effort on your part. We request specific fields because not only does it help us to determine which cases may need to be reported but it also allows consistency in our facility audits. We ask you to provide the name of the patient, date of birth, social security number, service code, admission date, discharge date, medical record number, ICD-9 codes (mainly the final diagnosis code), procedure codes and CPT codes. It is very important that the requested fields are provided, including the Social Security Number.

### Abstracting Tip

**Grade Path System and Value:**  
Please refer to FORDS 2010 pages 114-115 when coding Grade Path System and Grade Path Value.

**Hot tip: When correctly coded, these fields will be blank for most primary sites in a general case-mix registry.**

We realize each software system has different capabilities. You may require the help of your IT/IS staff to assist in setting up the report. Once you have run your report, you can then import that file into an excel spreadsheet where you can easily keep a record of which charts you have submitted. If you include notes explaining why a patient's chart was not submitted, this will also serve as a useful record during an audit and might eliminate the need to access the complete chart.

A complete explanation about creating an MRDI may be found on our website (<http://mcr.umh.edu>). Please contact Angela Martin ([martina@health.missouri.edu](mailto:martina@health.missouri.edu) or 573-882-4537 ) if you have questions.

### Low Volume Facility Reporting Schedule

Reporting Period	Cases Diagnosed	Due Date
Quarterly	Apr/May/June 2011	January 15, 2012
	Jul/Aug/Sept 2011	April 15, 2012
	Oct/Nov/Dec 2011	July 15, 2012
	Jan/Feb/Mar 2012	October 15, 2012
	Apr/May/June 2012	January 15, 2013

### Data Security Starts With You!

- Are you familiar with NCRA's code of ethics pertaining to data security?  
*"The patient has a right to feel confident that all identifiable information about him possessed by the cancer registry will be kept confidential unless he waives the privilege, or release of the information is compelled by statute, regulations, or other legal means."*
- Do you know the difference between privacy, confidentiality and security? *Privacy* is each individual's right to hold information about themselves free from the knowledge of others. *Confidentiality* is the assurance that such information will not be disclosed except as allowed by law. *Security* is the mechanisms by which confidentiality policies are implemented.

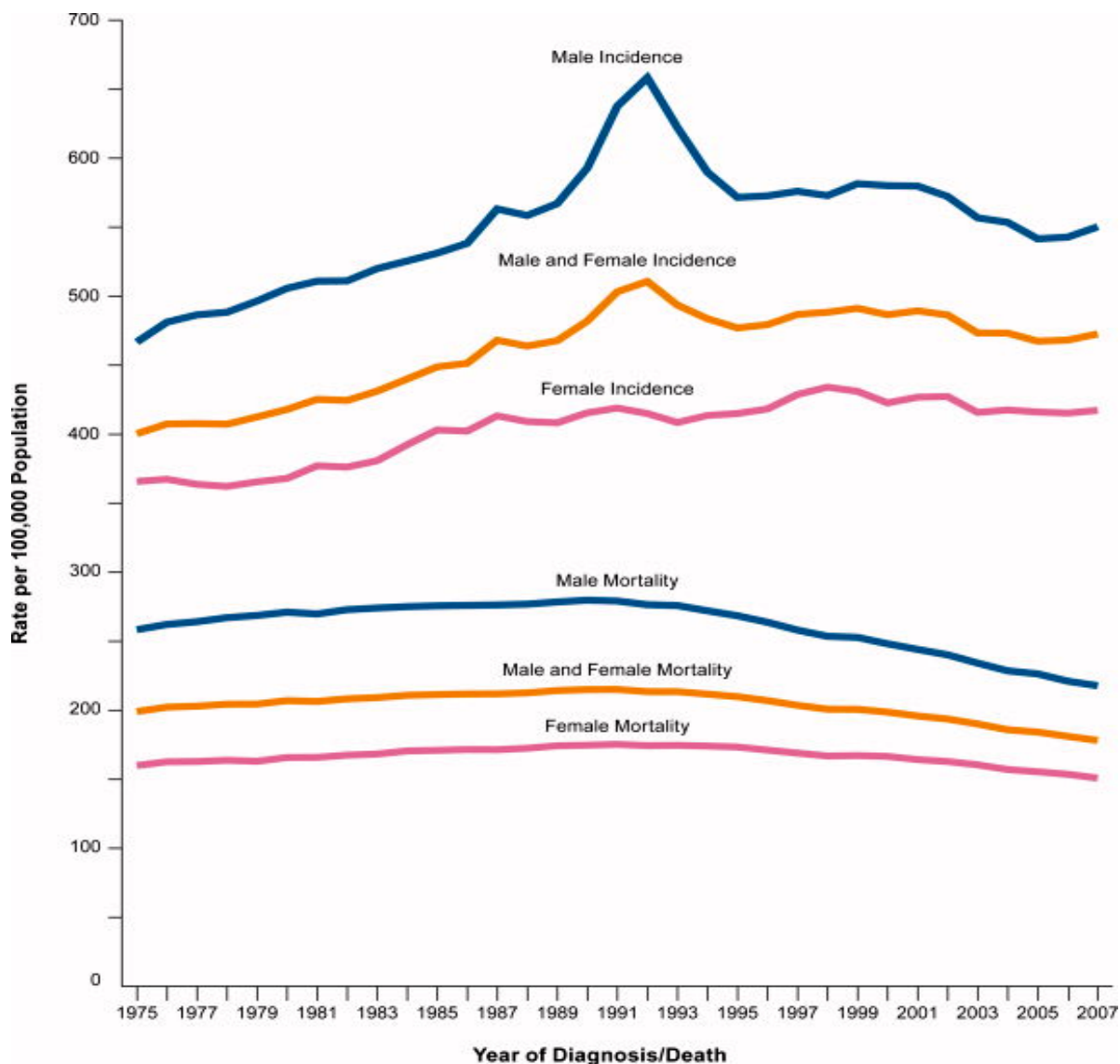
## ACS Report: Cancer Death Rates Continue to Drop

<http://www.cancer.org/Cancer/news/News/annualreport-u.s-cancer-death-rates-decline-but-disparities-remain>

“Cancer Statistics, 2011”

Newly-published data from the American Cancer Society indicate US cancer death rates continue to decrease, however, this is not true for less educated segments of the population. This disparity is clearly seen in cases of lung cancer, “for which the death rate was 5 times higher in the least educated than for the most educated.” The authors indicate almost 900,000 cancer deaths have been avoided since death rates began to decrease in the early 1990s.

Annual Age-Adjusted Cancer Incidence and Death Rates\* by Sex, United States, 1975-2007



\*Rates are age adjusted to the 2000 US standard population. Incidence rates are adjusted for delays in reporting. Sources: Incidence: Surveillance, Epidemiology, and End Results (SEER) program (available at: [www.seer.cancer.gov](http://www.seer.cancer.gov)). Delay-adjusted incidence database: SEER Incidence Delay-Adjusted Rates, 9 Registries, 1975-2007. Bethesda, MD: National Cancer Institute, Division of Cancer Control and Population Sciences, Surveillance Research Program, Statistical Research and Applications Branch; released April 2010, based on the November 2009 SEER data submission. Mortality: US Mortality Data, 1975 to 2007, National Center for Health Statistics, Centers for Disease Control and Prevention.

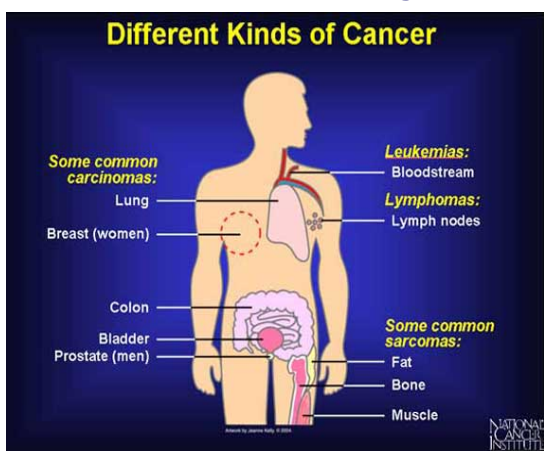
## NCI Offers New Workbook: Making Data Talk

This newly-released publication is designed to help public health practitioners, scientists, health educators, clinicians, researchers, students, and statisticians understand the critical roles data play in communication. It may also be helpful to cancer registrars in communicating cancer data within their institutions.

The workbook is based on the book Making Data Talk: Communicating Public Health Data to the Public, Policy Makers, and the Press. Making Data Talk: A Workbook is available as a print or electronic version. Visit NCI's website to [order a copy](#) or [download](#) the workbook.



## Online Education and Training on Cancer.gov



NCI has re-organized its education and training home page, which includes an "Understanding Cancer Series" which may be of interest to new and "seasoned" cancer registrars alike. It includes a helpful introduction to cancer and more advanced topics such as angiogenesis, gene testing and molecular diagnostics.

There are topics of interest for health care providers, public health program planners, researchers and for cancer registrars.

<http://www.cancer.gov/cancertopics/cancerlibrary/health-professional-training-tools/page4>

## Cancer Coach App Available for Androids and I-phones



How many times have you heard someone say "I wish I could remember exactly what the doctor said"? With this new free mobile tool, breast and colon cancer patients can actually record conversations, take notes, use the calendar to track appointments, etc. The app was developed in partnership with Breast Cancer.org and Fight Colorectal cancer and is provided by Genomic Health, Inc.



### Abstracting Tip

**First Contact:** As clarified in FORDS 2010 the date of first contact is the date that the case became analytic or non-analytic. Thus it will generally match the date of diagnosis (if at your facility) or date of first treatment at your facility depending on class of case.

## Web Plus Offers New Report Feature for Hospital Registries

The newest Web Plus upgrade included a data quality indicator (DQI) report that is generated after each version 12.1 file is uploaded. When the user goes to "Previous Uploads" there is a new link next to the edit report link. (MCR staff can view the reports as well.)

The report will be helpful in monitoring quality and timeliness and may identify potential reporting problem areas or areas in need of improvement. For this report, accepted abstracts are separated into "Analytic" and "Non-Analytic" categories (based on class of case) since non-analytic cases generally contain less specific information and information of lesser quality than analytic reports.

The report indicates missing/unknown values for 16 data elements such as sex, age, class of case, etc. In addition the report indicates non-specific values for primary site (C809 or C76\_), morphology (8000-8005, 8010 or 8800) and diagnostic confirmation (5-8).

The other portion of the report shows the distribution of submitted cases based on diagnosis date and by discharge date for those registries that collect that data element.

We welcome feedback about this report and will share comments with the CDC's Registry Plus development team.

Any State Cancer Registry Data Quality Indicators Report			
<b>Report From Bundle:</b> v12.1UploadWithErrors.txt			
<b>Internal File Name:</b> F0000001.bun			
<b>Bundle Received From Hospital:</b> Test Facility 1 (1111111111)			
<b>Total Abstracts in the Bundle:</b> 4			
<b>Date Report Created:</b> 9/12/2011			
<b>Edit Set Name:</b> Central: Vs12.1 State Example - Incoming Abstracts			
<b>Total Abstracts with Errors in the Bundle:</b> 3 (75%)			
Data Quality of Accepted Reports			
Missing/Unknown Values	Analytic* (N=4)	Non-Analytic (N=0)	National Standard
Sex [220]	0 (0%)	0 (0%)	<=2%
Age [230]	0 (0%)	0 (0%)	<=2%
County at Diagnosis [90]	0 (0%)	0 (0%)	<=2%
Race [160]	0 (0%)	0 (0%)	<=3%
Ethnicity [190]	0 (0%)	0 (0%)	
Zip code [100]	0 (0%)	0 (0%)	
Street Address (incl. PO Box) [2330]	0 (0%)	0 (0%)	
Month of Diagnosis [390], pos 1-2	0 (0%)	0 (0%)	
Laterality [410]	0 (0%)	0 (0%)	
Behavior [523]	0 (0%)	0 (0%)	
Grade [440]	1 (25%)	0 (0%)	
Derived SEER Sum Stg 2000 [3020]	2 (50%)	0 (0%)	
Diagnostic Confirmation [490]	0 (0%)	0 (0%)	
Class of Case [610]	0 (0%)	0 (0%)	
Primary Site Title [2580]	1 (25%)	0 (0%)	
Histology Title [2590]	1 (25%)	0 (0%)	
Unspecific Values:			
Primary Site [400]: C809 or C76_	1 (25%)	0 (0%)	
Morphology [522]: 8000-8005, 8010 or 8800	0 (0%)	0 (0%)	
Diagnostic Confirmation [490]: 5-8	0 (0%)	0 (0%)	
Date Distribution of Accepted Reports			
Diagnosis Dates**			
< 2006	0 (0%)	0 (0%)	
2007	0 (0%)	0 (0%)	
2008	0 (0%)	0 (0%)	
2009	0 (0%)	0 (0%)	
2010	3 (75%)	0 (0%)	
2011	1 (25%)	0 (0%)	
Discharge Dates			
< 2006	0 (0%)	0 (0%)	
2007	0 (0%)	0 (0%)	
2008	0 (0%)	0 (0%)	
2009	0 (0%)	0 (0%)	
2010	0 (0%)	0 (0%)	
2011	0 (0%)	0 (0%)	
*Analytic Reports are those that have been submitted with class of case 00-22. Non-Analytic Reports are those that have been submitted with blank or unknown (99) class of case, or with class of case 30-49.			
**Diagnosis Year is the year of initial diagnosis by a recognized medical practitioner. It does NOT correspond to either accession year or submission year.			

### Abstracting Tip

**Date Flags:** When it is unknown whether or not the patient received treatment, date flags should be coded 10 (unknown) rather than 11 (not given), and treatment fields also should be coded as unknown. "Unknown" and "Not done" are not interchangeable terms! Refer to FORDS "First Course of Treatment" pp. 209 – 294 for more information.

### Abstracting Tip

Surgical procedures which aspirate, biopsy or remove REGIONAL lymph nodes in an effort to diagnose or stage is recorded in the surgery field "Scope of Regional Lymph Node Surgery", **not** in the "biopsy" field Diagnostic/Staging Procedure. (Learn more about this at our February Live Meeting)

## 2011 – 2012 Quarterly Calendar

## Awareness Months

**January – Cervical Health  
Awareness****December**

December 15  
Monthly Hospital Reporting Deadline (>500)  
For cases diagnosed on or before May 2011

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**January**

January 5  
NAACCR Webinar—Collecting Cancer Data: Pancreas

January 11  
Live Meeting — Data Security: Is Your Personal Data Next?  
presenters: Nancy Cole and Iris Zachary

January 15  
Monthly Hospital Reporting Deadline (>500)  
For cases diagnosed on or before June 2011  
  
Monthly or Quarterly Hospital Reporting Deadline (300-500) -  
For cases diagnosed on or before Jan/Feb/March 2011

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**February**

February 2  
NAACCR Webinar—Collecting Cancer Data: Lung

February 8  
Live Meeting—By Request: Ambiguous Terminology and Lymph Node  
Coding Rules     presenter: Nancy Rold

February 15  
Monthly Hospital Reporting Deadline (>500)  
For cases diagnosed on or before July 2011





*From MCR-ARC staff and management*

*The Missouri Cancer Registry and Research Center (MCR-ARC), under the direction of Dr. Jeannette Jackson-Thompson, collects and maintains a population-based database of all Missourians diagnosed with cancer. As registry data plays a vital role in the fight against cancer, we would like to say thanks to all Missouri facilities that report cancer cases.*

### Contact Us

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PO Box 718  
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Main office: 573-882-7775  
Hospital reporting: 1-800-392-2829  
Non-hospital reporting: 1-866-240-8809  
Fax: 573-884-9655  
Website: <http://mcr.umh.edu>

### MCR Administration

- Jeannette Jackson-Thompson, MSPH, PhD  
Operations Director
- Nancy Cole, BS, CTR  
Operations Manager
- Mary Jane King, BS  
Surveillance, Special Projects & Data Utilization Mgr.

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