SYLVESTER COMPREHENSIVE CANCER CENTER
UNIVERSITY OF MIAMI HEALTH SYSTEM
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FCDS Florida Cancer Data System
A Joint Project of the Sylvester Comprehensive Cancer Center and the Florida Department of Health

FLORIDA DEPARTMENT OF HEALTH

Register

A joint project of the Sylvester Comprehensive Cancer Ctr
and the Florida Department of Health

Division of Cancer Prevention and Control **Volume 52 – July 2011**

Notes from the Statistical Unit: Data in Action

Misclassification of Sex in the Central Registry

By Recinda Sherman, MPH, CTR

Breast cancer (BC) among males is rare and little is known about its etiology. BC among males accounts for <1% of all breast cancer cases. The American Cancer Society estimates 1,970 new BC cases and 390 deaths among men in 2010 in the United States. Compared to BC among women, BC among men occurs at an older age (68-71 average age at diagnosis), higher stage (50% stage II or higher at diagnosis compared to 35% for females), lower grade, and a greater proportion ER+ or PR+. Cause-specific, stage-specific survival rates for men with BC are similar to women.

Risk factors for BC among men are radiation to the chest, genetic predisposition, and increased estrogen levels that can result from conditions like obesity, cirrhosis and Klinefelter Syndrome. In the United States, BC has been increasing among men for the past 30 years. While the cause of the increase is uncertain, longer lifespan, increased awareness, and rising obesity levels are likely sources for the rise in rates.

In 2002, researchers at University of Miami noticed the rates of BC among Floridian men were higher than for men nationally. The data indicated that BC incidence rates were increasing at a faster, statistically significant rate in Florida males compared to SEER-9 males. Studying such a high risk population could be important in advancing etiologic knowledge about the disease. However, before drawing research conclusions, potential spuriousness of results, which can occur due to underlying data errors, had to be evaluated.

Therefore, a data quality project was undertaken at FCDS to evaluate the sex coding of BC among males. The first name of male BC patients diagnosed from 1981-2000 were visually reviewed. A total of 904 of approximately 3,800 male cases of BC were identified as likely female based on first name. Letters of follow-up were sent to the hospital registries for confirmation of the reported sex. All but three were confirmed female by the hospitals, and the sex code was corrected in FCDS. This significantly lowered the rates of BC among males in the FCDS data.

Figure 1 illustrates the number of BC cases that were misclassified as men ("false men") by year of diagnosis. It is clear sex misclassification for BC is more problematic with later diagnosis years.

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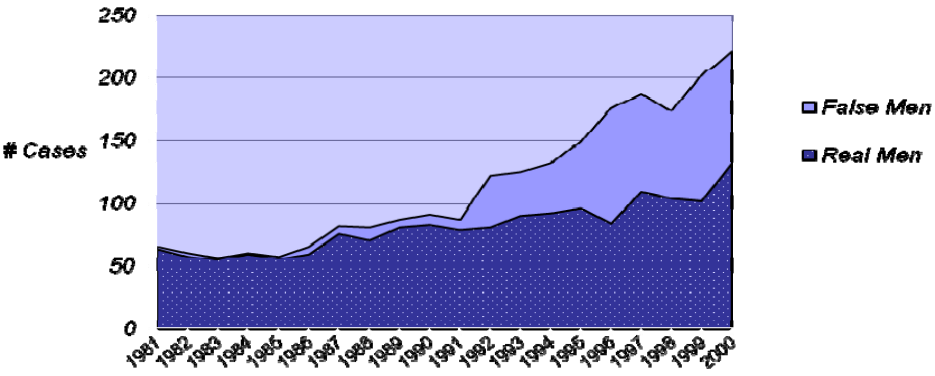
Figure 1. Cases of breast cancer correctly and incorrectly coded as male.



This is likely due to changes in coding. Prior to the 1990s, the ICD-O classification system was similar to the ICD-9 classification with separate codes for female (174) and male (175) breast cancers. Starting with ICD-O-2 in the early 1990s, breast cancer became a single code (C50) regardless of sex. This level of misclassification can significantly inflate BC rates in males but does not alter rates in females.

Incorrect coding can produce invalid research results, but visual review and follow-back is both time consuming and expensive for hospitals and FCDS. FCDS is the nation's second largest cancer registry and relies heavily on automated processes to ensure integrity of the data. Although FCDS utilizes sex-specific automated edits, less than 15% of all cancers are sex-specific. To address this problem, FCDS tested an automated algorithm developed by the New York State Cancer Registry—the NY Sex Edit.

The Sex Edit evaluates names that are highly correlated with gender and flags suspicious name/sex combinations. Many names are gender specific names (e.g., "Elizabeth" and "Charles"), but the use of such names can change over time (e.g., "Rosario" was a typical male name in 1900 but became typically female in 1940 forward). The Edit uses the Social Security Administration database of the most popular male and female names for each decade from 1890-2008. This list of names is matched against the names in the cancer registry and improbable name/sex combinations are flagged.

The Edit was tested against the original 904 cases manually followed back to hospitals in 2003. The Edit correctly identified 81% of the "false males" as female plus one of the three "true male" BC cases as male. The remaining cases were un-assessable—either the name was not gender specific, the date of birth was unknown, or the decade of birth was not included in the Edit. Although the Edit could not determine a probable sex code for 175 of the cases, the Edit did not misclassify the sex of any of the breast cancer cases.

The Edit was also tested against specific sites (breast, colorectal, thyroid and liver cases diagnosed from 1981-2008). The Edit agreed with the coded sex on 68% of the cases for the specific sites tested, 31% could not be evaluated, and 0.5% were flagged as an improbable sex (this is compared to 0.3% of the NY cases). Additionally, there were 145 cases of unknown sex that were flagged with a probable sex. However, 21% of the BC cases in patients codes as male were flagged as improbable (0.2% for BC among females). For thyroid, a site three times more common in women than men, 1.3% of the male thyroid cases were flagged as improbable (0.4% for thyroid cases among females). For colorectal cancer, a site with similar rates for both sexes, the percent of cases flagged with an improbable sex was similar for men (0.5%) and women (0.6%). For liver, a site often diagnosed in persons born outside the United States, 1.1% of the liver cases among females were flagged as improbable (0.3% for liver cases among males).

The liver cancer results were not as anticipated. A limitation of the Edit is that foreign born or first generation males may not be accurately assessed. For instance, Jean, Carmen, Andrea, and Angel are common names for females in much of the United States but are male names among Hispanics and Haitians. However, slightly more females with liver cancer than males had their names flagged as improbable combinations, so further investigation is needed to determine if the Edit is accurately coding sex for these ethnic sub-populations common in Florida. Despite this issue, it is clear the Sex Edit can be used to improve the quality of sex coding in the FCDS data.

Recommendations:

Hospital registrars should consider a second review for accuracy of the sex code for BC in a male patient prior to submission to the central registry.

At the central registry level, the Sex Edit should be implemented. Any BC case in a male patient flagged with an improbable name/sex combination should be changed to female and the reporting hospital notified. Any BC case in a male patient that is flagged as un-assessable should be followed-back to the hospital. For all cancer sites, the probable sex from the Edit should be assigned to any cancer case with a unknown sex and the reporting hospital notified.

References:

1) Johansen Taber KA, Morisy LR, Osbahr AJ III, Dickinson BD. Male breast cancer: Risk factors, diagnosis, and management (Review). *Oncology Reports* 2010 24:1115-1120.
2) Gnerlich JL, Deshpande AD, Jeffe DB, Seelam S, Kimbuende E. Margenthaler JA. Poorer survival outcomes for male breast cancer compared with female breast cancer amy be attributable to in-stage migration *Ann Surg Oncol* 2010 Dec 14 (epub ahead of print).
3) Hodgson NC, Button JH, Franceschi D. Moffat FL, Livingstone AS. Male breast cancer: is the incidence increasing? *Ann Surg Oncol* 2004 Aug:11(8);751-5.

2011 NAACCR Annual Meeting

By Recinda Sherman, MPH, CTR

The 2011 NAACCR Annual meeting was hosted by the Kentucky Cancer Registry, in Louisville, KY, June 18-24. The main conference was flanked by short course trainings on topics like Geocoding, Central Registry Principles, and Multilevel Modeling. This year's conference was horse-racing themed: *Cancer Surveillance: Keeping Pace with Policy, Science, and Technology*.

The conference began on Tuesday with a dynamic, live performance of the official state dance of Kentucky—clogging. This was followed by a less lively but pertinent plenary panel discussing national policies influencing, and influenced by, cancer surveillance. The second plenary panel gave an overview of current cancer research with a focus on genetics. The third plenary panel on Wednesday discussed technological advances in electronic data exchange and challenges for central cancer registries. The final plenary on Thursday was a germane and interactive conversation about the future of cancer registries—how to maintain relevancy with multiple stakeholders while confronting limited funding. This closing session was named "*The Finish Line"*, and the discussion underscored the reality that our finish line is constantly being shifted farther away in this field.

But the conference wasn't all work—there was a 6am NAACCR supported 5K Run/Walk from Kentucky to Indiana and many of us were able to visit the Louisville Slugger Factory and Churchill Downs. Wednesday night, however, was a wee too thrilling when we were evacuated from our hotel rooms due to a tornado—luckily, the damage was minimal and no one was hurt.

Florida was well represented with five oral presentations: "*Taming the Text: Incorporation eMaRC Plus into Florida Central Registry Pathology Laboratory Processing"* presented by Dr. Jill MacKinnon; "*Cancer Trends Among Persons of African Descent in Florida"* presented by Dr. Monique Hernandez; "*Tumor Size and Depth for Breast cancer and Melanoma in CINA Deluxe*" and "*Tumor Size and Depth for Breast cancer and Melanoma in CINA Deluxe*" both presented by Brad Wohler; and "*Sex Misclassification in Central Cancer Registries*" presented by Recinda Sherman. Also, Florida was one of seven states whose data was used in a special HPV concurrent section, and a number of us were co-authors on a poster, "*National Health Interview Survey (NHIS)-Florida Cancer Data System (FCDS) Data Linkage Project: Update*" by Laura McClure, which received a 3rd place prize.

Below are the abstracts presented by FCDS:

Taming the Text: Incorporating eMaRC Plus into Florida Central Registry Pathology Laboratory Processing

Jill MacKinnon; Mark Rudolph; Alba Maya; Michael Thiry; Gary Levin

Background: Florida has been successful in receiving electronic pathology reports (over 1 million electronic pathology records from approximately 600 laboratories annually) but not as successful in operationalizing the 'unmatched' cases. After matching the incoming records against Florida's cancer incident master file, approximately 45% do not match and contained a 'cancer keyword'. Visual review of over 450,000 pathology records is not operationally feasible, therefore, Florida would follow-back on a small sample.

Methods: In August 2010, FCDS began working with CDC's eMaRC Plus software in conjunction with the FCDS pathology software. After overcoming several technical issues, all 2008 pathology records were processed through eMaRC Plus for reportability status and coding.

Results: After consolidating the pathology reports at the patient level,

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eMaRC Plus coded the FCDS pathology records as follows: 31,000 unmatched 'reportable' cases; 5,700 unmatched 'non-reportable' cases; and 600 unmatched cases that did not contain a cancer term.
Visual review of these cases found there was 100% concordance with eMaRC's coding of no cancer terms; 97% concordance with eMaRC's coding of non-reportable and 70% concordance with eMaRC's coding of reportable cases (with 44% concordance of autocoded primary sites). The site distribution of the unmatched, reportable cases was 50% prostate, 30% reportable skin, 3% bladder, 2.5% cervix and 1.5% breast.
Conclusions: While not perfect, integrating eMaRC Plus software into the FCDS routine operations should enhance Florida's ability to more fully operationalize pathology reports. There are still several technical issues to overcome. Additionally, the personnel necessary to follow back on approximately 30,000 records is not inconsequential.

Cancer Trends among Persons of African Descent in Florida – A Florida Cancer Data System (FCDS) Publication

Monique N Hernandez, Lora E Fleming , Jill A MacKinnon, David J Lee, *Florida Cancer Data System (FCDS), Sylvester Cancer Center, University of Miami, Miami, FL; Florida Dept of Health, Tallahassee, FL.*

Background: In the US, persons of African Descent account for 13.5% of the population. In 2008, there were 3.1 million (16%) persons of African Descent among Florida's rapidly growing population. FCDS has created a Monograph focusing on the cancer experience of Persons of African Descent in Florida.
Methods: The data were all cancer cases diagnosed among Florida residents between 1988-2007. Primary cancer site and histology data were categorized according to SEER site groups. The top 10 cancers among all Florida residents for 2007 were selected. Cancer incidence trends between 1988-2007 were conducted using joinpoint regression model.
Results: Cancer rankings among Whites and persons of African Descent were similar for the top four cancers. Proportionally, males of African Descent had lower urinary bladder rates, and higher proportions of prostate, stomach and liver cancers. Females of African Descent had higher proportions of cancer of the breast, and lower proportions of lung cancer than their White counterparts. Although Whites and Persons of African Descent had decreasing trends since the early 1990s in overall cancer rates, the decrease was greatest for males of African Descent. While racial disparities in distant stage incidence persisted to the end of the study, with higher rates among persons of African Descent for cancers of the breast, colon and rectum, bladder, liver, stomach and cervix, these gaps reduced significantly, with some disparities disappearing altogether.
Implications: Cancer disparities between persons of African Descent and Whites in Florida remain an issue. In particular, persons of African Descent continue to have higher proportions of prostate, breast, and cervical cancers. However, declining trends in advanced stage cancers are tightening the racial gap.

Tumor Size and Depth for Breast Cancer and Melanoma in CINA Deluxe

B Wohler[2], X Wu[1], P Andrews[1], B Huang[3], B Qiao[4], M Hsieh[1], U Ajani[6], A Jemal[5], Q Yu[7],
[1]Louisiana Tumor Registry, New Orleans, LA; [2]Florida Cancer Data System, Miami, FL; [3]Kentucky Cancer Registry, Lexington, KY; [4]New York State Cancer Registry, Albany, NY; [5]American Cancer Society, Atlanta, GA; [6]Cancer Prevention and Control CDC, Atlanta, GA; [7]LSU Health Sciences Center, New Orleans, LA

Background: The NAACCR Data Assessment Work Group was created in 2010 to assess the quality and completeness of specific variables contained in CINA Deluxe and to provide recommendations to researchers as to how the data can be used. This presentation will focus on data quality regarding tumor size for breast cancer and tumor depth for melanoma.
Methods: Data were extracted from the 1995-2007 CINA Deluxe Data with analysis restricted to 2004 - 2007. Tumor size and depth were stratified by age, race, reporting source, diagnostic confirmation, positive lymph nodes, morphology type, rural-urban residence, and diagnosis year. Melanoma tumor depth is collected in CS Site-Specific Factor 1, which is not a NAACCR required variable for the study years; some registries do submit it and this variable was analyzed as available.
Results: Distribution of breast cancer size varied widely across the registries: 13% - 26% for tumors measuring 0 – 1 cm; 27% – 37% for 2 - 3 cm tumors; 17% – 23 % for 4 – 5 cm tumors and 16 – 26% for tumors > 5 cm. The widest range was for unknown tumor size, 2 – 17% across registries. The majority of melanoma cancer (43% – 66% across registries) was reported with depths between 0 and 1 mm; 1 – 2 mm depths ranged from 10% to 15% across registries; 2 – 4 mm depths, 5% – 10%; and > 4 mm, 2 – 7%. The percent of unknown depth varied substantially by registry (7% – 32%).
Discussion: Tumor size is important for assessing the adequacy of adjuvant chemotherapy for breast cancer patients. Large variations in tumor size distribution may indicate data quality issues. Tumor depth is an important prognostic factor for early-stage melanoma. Variations were smaller than those of breast tumor size, indicating that registries may have better quality of data on melanoma depth. NAACCR should consider requesting all site specific factors for all schemas as available.

Data Quality of Surgery and Radiation for Four Major Cancer Sites in CINA Deluxe

B Wohler[2], B Qiao[4], M Schymura[4], X Wu[1], P Andrews[1], M Hsieh[1], B Huang[3], Q Yu[7], U Ajani[6], A Jemal[5]
[1]Louisiana Tumor Registry, New Orleans, LA; [2]Florida Cancer Data System, Miami, FL; [3]Kentucky Cancer Registry, Lexington, KY; [4]New York State Cancer Registry, Albany, NY;

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[5]American Cancer Society, Atlanta, GA; [6]Cancer Prevention and Control CDC, Atlanta, GA; [7]LSU Health Sciences Center, New Orleans, LA

Background: The NAACCR Data Assessment Work Group was created in 2010 to assess the quality and completeness of specific variables contained in CINA Deluxe and to provide recommendations to researchers as to how the data can be used. This presentation will examine the quality of surgery and radiation data for four major cancer sites – female breast, prostate, lung and colorectal.

Methods: Data were extracted from the 1995-2007 CINA Deluxe Data set. First, the availability of surgery and radiation data by registry and diagnosis year was examined. Then, more specific analyses were conducted using data from 2004 to 2007. Percentages of unknown surgery and radiation were used as indicators of data quality, and were examined by registry, age, gender, race, stage, laterality, reporting source, diagnostic confirmation, rural-urban, and diagnosis year. Data quality based on SEER 17 was analyzed for comparison purposes.

Results: The availability of surgery and radiation data in the CINA Deluxe dataset varied by diagnosis year and registry. In general, surgery data showed better quality than radiation data. Data quality varied considerably among registries, and was also affected by type of reporting source, diagnostic confirmation, and rural-urban. There were no major changes in data quality between 2004 and 2007. Percentages of unknown surgery and radiation in CINA were higher than in SEER17 data. Further analyses will focus on specificity of treatment information.

Discussion: The percent of unknowns is higher in CINA compared to SEER. Data quality varied widely by registry, and was also affected by other factors. Researchers must take these factors into account when they use the surgery and radiation data.

Sex Misclassification in Central Cancer Registries

R Sherman[1], J Button [1], L Soloway[2], F Boscoe [2]

[1]Florida Cancer Data Systems, Miami, FL; [2]New York State Cancer Registry, Albany, NY

Background: Site-sex edits are a standard tool to improve quality of the sex code in cancer registries. But the percentage of sex-specific cancers is low (20% of invasive cases). Visual review and follow-back to improve the quality of the sex coding is labor intensive and typically only performed as a special project on subsets of data. The New York State Cancer Registry (NYSCR) created an edit for identifying potential sex misclassification for cancer registries. The edit uses the most popular male and female first names based on decade of birth to flag potentially miscoded cases. This edit was tested by the Florida Cancer Registry (FCDS).

Methods: Breast (100x more female than male cases), thyroid (3x more female than male cases), liver (more minorities), and colorectal cases diagnosed in Florida from 1981-2008 were evaluated using the NY edit. Most, 68%, of the 953,074 cases agreed with the edit's probable sex, 31% could not be evaluated, and 0.5% disagreed. Additionally, 145 cases were unknown in the registry but the edit identified a probable sex. Results varied by site: 21% of the male breast cases were flagged by the edit as probably female; and 1.3% of the male thyroid cases. Results varied by year and race/ethnicity. The NYSCR edit may be appropriate for automated correction of sex in specific instances.

Results: Results for FCDS breast cases were compared to a 2003 FL QC project. Male breast cancer cases were reviewed visually by first name and 904 were identified as probably female. Hospitals were asked to verify male sex. All but 3 cases were subsequently changed to female. The NYSCR edit identified 729 (81%) of the cases correctly as females and 1 case correctly as male. For the 2 other male cases (and the remaining cases), the NYSCR edit was unable to assign a probable sex.

Implications: Sex misclassification is likely artificially inflating male breast cancer rates in FL. For male breast cancers, it may be appropriate to change to female cases the NYSCR edit flags as female.

Cancer Awareness

OCTOBER 2011
BREAST CANCER AWARENESS MONTH

NOVEMBER 2011
LUNG & PANCREATIC CANCER AWARENESS

"Source: 2011 National Health Observances, National Health Information Center, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services, Washington, DC."

COMPLETENESS REPORT—2011 CASES

Month	Complete	Expected
Jul 2011	1%	8%
Aug 2011	2%	17%

Congratulations to Florida's Newest CTRs

Elizabeth Andrade
Jennifer S. Bruns
Vicki M. Hawhee
Celia M. Mathews
Delyis Sequeira

CALENDAR OF EVENTS

CALENDAR OF EVENTS

NAACCR CANCER REGISTRY & SURVEILLANCE WEBINAR SERIES 2011-2012

Time: 9:00 am—12:00 pm
Locations: Baptist Regional Cancer Center (Jacksonville, FL)
Boca Raton Community Hospital (Boca Raton, FL)
Gulf Coast Medical Center (Panama City, FL)
H. Lee Moffitt Cancer Center (Tampa, FL)
M.D. Anderson Cancer Center (Orlando, FL)
Shands University of Florida (Gainesville, FL)
Florida Cancer Data System (Miami, FL) *New
Contact: Steve Peace at 305-243-4600 or speace@med.miami.edu
To Register: http://fcds.med.miami.edu

Date	Topic
11/03/11	Collecting Cancer Data: Ovary
12/01/11	Collecting Cancer Data: Thyroid and Adrenal Gland
01/05/12	Collecting Cancer Data: Pancreas

FCDS 2011 EDUCATIONAL WEBCAST SERIES

Time: 9:00 am—11:00 am
Dial-in Number: 888-296-1938
Participant Code: 619968
To Register: http://fcds.med.miami.edu/inc/whatsnew.shtml

Date	Topic
10/20/11	Myeloid Neoplasms (CML/AML/MDS) - MPH Rules/CSv02.03/Site Specific Factors and Treatment
11/17/11	Lung Cancer - 2011 MPH Rules/CSv02.03/Site Specific Factors and Treatment
12/15/11	Genitourinary (Kidney, Bladder, Prostate) - MPH Rules/CSv02.03/SSFs and Treatment
1/19/12	Brain and CNS Tumors - MPH Rules/CSv02.03/Site Specific Factors and Treatment
2/16/12	Head and Neck Cancers - MPH Rules/CSv02.03/Site Specific Factors and Treatment

Calling All Florida CTRs Interested in Collaborative Stage Data Collection and Quality Control Activities at FCDS:

FCDS recognizes the added value when using Florida peer-to-peer CTRs to conduct re-abstracting field audits and other FCDS QC activities. CTRs who abstract on a daily basis are our best resource for providing peer-to-peer feedback on data quality and recommendations to improve our data, statewide. At this time FCDS is in need of several highly skilled abstractors willing to participate in the next FCDS Re-Abstracting Field Audit. This audit will take place in mid-winter (December-February), will include 80 or more facilities, and will focus on Collaborative Stage Core Data Elements and Site Specific Factor Coding for Cases Diagnosed in 2010. The actual data collection will take place during a 6-week window as yet defined but at some time during the in-the-field study window of December-February. FCDS needs registrars from across the state to visit hospitals either in person or via remote access to "re-abstract" key data elements; patient demographics, primary site, histology and collaborative stage data items. No treatment data will be collected. Thank you for your support and interest. Please contact Steven Peace, CTR directly at speace@med.miami.edu with your resume and letter of interest.

New Dermatology Reporting Module

The Florida Department of Health and Florida Cancer Data System are pleased to announce the release of a new cancer reporting module tailored specifically for the Dermatology community.

To assist dermatologist's to meet their legislatively mandated obligation to report skin cancers, this new module has been developed to make reporting easier. The new module simplifies the process of reporting specific types of newly diagnosed and treated skin cancers and has been developed so that anyone from a dermatologist's office, with minimal training from FCDS, can complete the reporting process.

On May 11, 2011, FCDS held a webinar for all licensed dermatologists in the state. The webinar, which has been recorded and is available on our website at http://fcds.med.miami.edu/inc/physicians.shtml covered a number of topics including:

- Cancer Reporting in Florida
- How to Register a Physician in the IDEA system
- How to obtain a new IDEA userid and password
- A review of our new Dermatology Data Acquisition Manual
- An introduction to skin cancers
- How to input a cancer abstract using the new module

For more information about Dermatology Reporting in Florida and the new reporting module, you can access our new Dermatology Data Acquisition Manual on our website at: http://fcds.med.miami.edu/inc/physicians.shtml

The rollout of this new module has been very successful. Since inception, 515 dermatologists from around the state have registered and started using the new system. Those 515 physicians have submitted over 3,000 newly reportable skin cancers.

FCDS will be starting a new compliance program this month to contact any dermatologist office in the state that has not yet registered in our new system. Our goal is to have every dermatology office in the state reporting. We will be working very closely with the department of health to insure compliance.

We would like to thank those dermatologists that have registered and are using our new system and look forward to having all dermatologists in the state participate.

Register

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The FCRA/FCDS Task Force is actively working on many issues that all registrars are facing. If you have any questions, issues or suggestions that you would like the task force to review, please email them to *taskforce@fcra.org*.

The task force meets the first Thursday of every month. We will respond back to your inquiries as quickly as possible.