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About this Issue

Katheryne Vance, BA, CTR

In the midst of the annual seasonal preparations and anticipations, the time has come to say "goodbye and best wishes" to Cynthia Creech as she embarks on a well deserved and well earned retirement. I first met Cynthia when I was preparing for my first ACoS cancer program survey when she visited the hospital where I was working for a pre-survey. At the time, she was one of four full time cancer program consultants for the ACoS. She became a mentor from the moment I met her and as time went by we became colleagues, co-workers, and friends. Cynthia is the consummate Cancer Registrar!

This issue is Cynthia's opportunity to give us her thoughts and memories in the article Dear Friends. Always the advocate of high quality data, Cynthia teamed up with Rosemary Cress from the CCR's Cancer Surveillance and Research Unit to discuss the importance of the data item Conclusive Diagnosis. This article reminds us how important this data item is to researchers. This article also prompted the CCR to survey facilities on how reporting facilities notify patients that cancer is a reportable disease. You are invited to take a moment and complete the survery mentioned in Patient Notification Survey; please complete this survey by Friday, January 20, 2012.

The CCR wishes you and yours blessings of the holiday season and a healthy and prosperous New Year.

Dear Friends

Cynthia Creech, CTR California Cancer Registry

Dear Friends

Not everyone gets to write a final message to the community they have worked with for so many years, so I count myself fortunate. Katheryne offered me this opportunity to reflect on my thoughts about our profession. First of all, I didn't decide to become a cancer registrar. After all, how many people back in 1966 knew what a cancer registrar was? For that matter, how many know today?

I wasn't looking for a career when I first became a cancer registrar (then cancer registry secretary) back in 1966. I was looking for a day-shift job since I had been working evenings in the lab for several years. But since the work sounded interesting and I was ready for a change, I decided to give it a try. And change it was, and it hasn't stopped changing since.

Not much later, I realized that my work had become a career, and the next thing I knew I was involved in working with colleagues for a state association, a national association, certification of cancer registrars, and many other activities in addition to my job. Along the way, I have met many registrars, developed networks and friendships, and sadly, lost a few friends, some to this disease that we all hope will be cured, or become fully controllable someday soon. Then we all (or should I say, you all) will find other important work to do. It is clear that we still have a way to go before that happens, so I think jobs are secure!

One reason I've seen a lot of change is that I have worked in a variety of settings over the years. I was a hospital registrar, a trainer, a consultant, a field representative, back to hospitals, worked in a couple of regional registries and finally a central registry. I also worked in a variety of hospitals—community, academic and an NCI-designated Comprehensive Cancer Program. This variety has served me well over the years and I highly recommend it. New jobs keep you fresh, and broaden your perspective.

The changes that we have been experiencing, especially in the past couple of years, are exciting, and I will miss that excitement. Maybe I won't miss the aggravation of the last minute changes, the delayed edits, and similar hiccups, but these new data items are instilling new life into our registries, making them more valuable to the people we serve. It is in our best interest to embrace them and make them work.

I would like to commend all of you who do this important work. I know I am leaving it in good hands. As I move to Iowa to spend time with my family, I wish you all the very best, and charge you all with giving it your very best.

Cynthia Creech, CTR

Conclusive Diagnosis

Rosemary Cress, Dr.P.H. and Cynthia Creech, CTR California Cancer Registry

Recently I received a call from a gentleman who had been contacted to participate in a study of quality of life among cancer survivors. He was distressed because his physician had told him he did not have cancer. The man explained that although his physician had originally suspected prostate cancer, further review of the slides from his biopsy revealed no malignancy.

This scenario is not uncommon. Often a patient undergoes a diagnostic work-up because there is a suspicion of cancer (ambiguous terminology), and only later is there a clear and definitive statement of either cancer or a non-malignancy. The "conclusive diagnosis" data item, implemented with multiple primaries and histologies (MP/H) rules for cases diagnosed 1/1/2007, was designed to capture this questionable information. The conclusive diagnosis field indicates whether or not a definitive diagnosis was made for a patient originally accessioned based on ambiguous terminology. Cases accessioned based on ambiguous terminology (Code 1) should be excluded from case selection in research studies, particularly patient contact studies.

Upon review of the above patient's information in the CCR database, and based on the information in the

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pathology report stating "suspicious for cancer," the hospital registrar had correctly abstracted and reported the case. However, the conclusive diagnosis field had not been coded correctly, and even if it had, it is likely that the research group would not have known to exclude this case from patient contact studies. Both registrars and researchers need to be aware of this data item so that patients are not contacted and distressed unnecessarily.

Further description of this data item including coding instructions can be found in Volume 1. V.1.7.2 http://www.ccrcal.org/DSQC_Pubs/V1_2011_Online_Manual/Part_V_Tumo

Patient Notification Survey

The California Cancer Registry is conducting a survey of how reporting facilities notify patients that cancer is a reportable disease. The purpose of the survey is to assess what methods reporting facilities are using to disseminate cancer reporting information to their patients.

When cancer patients are informed of their diagnosis, it is important that they are also informed of the cancer reportability requirement and the possibility that they may be contacted as part of ongoing investigations into the causes of cancer. Any miscommunication during this process can lead to further undue stress for the patient and their family.

The California Cancer Registry Standards document, Volume I, Appendix J, provides suggested verbiage for reporting facilities and physicians in notifying patients that cancer and other specific benign and borderline tumors are reportable.

Please click on the link below to complete the brief survey. All responses are anonymous, unless otherwise indicated. Please complete the survey by January 20, 2012.

<u>Click to view the Patient Notification Survey</u>

Educational Opportunities

April 11, 2012, NCRW Educational Meeting, CPIC, Fremont. Contact: Kathleen Davidson-Allen at Kathleen.Davidson-Allen@cpic.org

April 11, 2012, NCRW Educational Meeting, Desert Sierra CSP, Loma Linda. Contact: Becky Cassady at <u>rcassady@ahs.llumc.edu</u>

May 16, 2012, Save the Date! The 22nd Annual USC CSP Educational Symposium is tentatively scheduled for, May 16, 2012. Contact: Michelle King at <u>mking@usc.edu</u>

Quick Links

<u>California Cancer Registry</u> <u>California Department Public Health</u> <u>Public Health Institute</u>

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