

**FAX TRANSMISSION COVER SHEET**

from

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Date: 20. Dezember 2004Subject: Öffentliche Anhörung des Ausschusses für Arbeit, Gesundheit,  
Soziales und Angelegenheiten der Vertriebenen und Flüchtlinge zum Thema:  
"Entwurf eines Gesetzes zur Einrichtung eines flächendeckenden bevölkerungs-  
bezogenen Krebsregisters in Nordrhein-Westfalen"Number of pages (including this page): 10Recipients name: Herrn SchlichtingAddress: Referat I.1-AGS  
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40002 DüsseldorfFax-no.: 0211-884-3002**Comments:**

Sehr geehrter Herr Schlichting,

im Auftrag von Frau Prof. Nippert übersende ich Ihnen ihre Stellungnahme zum  
"Entwurf eines Gesetzes zur Einrichtung eines flächendeckenden  
bevölkerungsbezogenen Krebsregisters in Nordrhein-Westfalen (EKR-NRW)".

Mit freundlichen Grüßen

Karina Bertmaring



Kopie: Frau Marianne Hürten

## I. Nippert

### **Stellungnahme zum "Entwurf eines Gesetzes zur Einrichtung eines flächendeckenden bevölkerungsbezogenen Krebsregisters in Nordrhein-Westfalen (EKR-NRW)"**

Der Entwurf eines Gesetzes der Landesregierung zur Entwicklung eines flächendeckenden bevölkerungsbezogenen Krebsregisters in Nordrhein-Westfalen (EKR-NRW) ist grundsätzlich zu begrüßen.

Ich möchte meine Stellungnahme auf §3, Absatz 4 (Epidemiologische Daten) des Gesetzentwurfes beschränken.

Hieraus geht hervor, dass nicht beabsichtigt ist, Daten für Minderheiten mit unterschiedlicher ethnischer Herkunft zu erheben, sondern nur zwischen der Staatsangehörigkeit "deutsch"/"nicht deutsch" zu unterscheiden.

Zur Zeit leben in NRW etwa 27% aller in Deutschland ansässigen Zuwanderer/-innen. Der Ausländeranteil in NRW beträgt etwa 11%. Viele Zugewanderte haben inzwischen die deutsche Staatsangehörigkeit angenommen. Die Gruppe der Migranten/Migrantinnen ist in ihrem ethnischen Spektrum keinesfalls homogen.

Der Gesetzentwurf vergibt die Chance des epidemiologischen Monitoring der gesundheitlichen Lage (bezogen auf Krebs) dieser Gruppen und für diese Gruppen. Auch unter Forschungsgesichtspunkten ist dies bedauerlich. Populationen mit unterschiedlichem Migrationshintergrund bzw. unterschiedlichen Ethnien können unterschiedliche Risikoprofile aufweisen, an Krebs zu erkranken bzw. zu versterben.

In den USA als Einwanderungsland ist dies erkannt und die Krebsregister erheben entsprechende Daten. Als Beispiel für die praktische Anwendung soll auf das Krebsregister von Kalifornien hingewiesen werden. Begründet wird die Erhebung ethnischer Daten wie folgt: "*Race and ethnicity are two of the most important data items to epidemiologists who investigate cancer* [Hervorhebung von mir]. Differences in incidence rates among different ethnic groups generate hypotheses for

researchers to investigate. The National Cancer Institute has recognized the need to better explain the cancer burden in racial/ethnic minorities and is concerned with research on the full diversity of the U.S. population. The CCR recognizes the importance of these data items and relies on quality data to assist researchers in identifying and reducing disparities due to race and ethnicity." (California Cancer Registry Data Standards and Quality Control Unit: California Cancer Reporting System Standards, Volume One, 7th Edition, July 2003, S. 46).

Sicherlich hat Kalifornien einen höheren Mix von Bevölkerungsgruppen mit unterschiedlichem Migrations- und ethnischen Hintergrund und ein sehr differenziertes Erhebungssystem, das nicht so auf Deutschland übertragen werden muss. Dies sollte aber kein Grund dafür sein, in NRW diesen Aspekt zu ignorieren. Aus gesundheitspolitischer Perspektive besteht Konsens, dass das seit langem erkannte Datendefizit für die Bevölkerungsgruppen mit Migrationshintergrund, die in NRW leben, behoben werden sollte (siehe Landtag Nordrhein-Westfalen (Hrsg.): Zukunft einer frauengerechten Gesundheitsversorgung in NRW. Bericht der Enquetekommission des Landtags Nordrhein-Westfalen, VS Verlag für Sozialwissenschaften, September 2004; Ministerium für Frauen, Jugend, Familie und Gesundheit des Landes Nordrhein-Westfalen (Hrsg.): Gesundheit von Zuwanderern in Nordrhein-Westfalen, August 2000). Es wäre schade, wenn das bevölkerungsreichste Land Deutschlands nicht die Gelegenheit nutzen würde und für alle hier lebenden Bevölkerungsgruppen die Möglichkeit schaffen würde, von den Daten des NRW-Krebsregisters zu profitieren. Die gesetzliche Verankerung eines flächendeckenden Krebsregisters in NRW bietet diese Chance jetzt.

Anlage



**CANCER REPORTING IN  
CALIFORNIA:  
ABSTRACTING AND CODING  
PROCEDURES FOR HOSPITALS**

**CALIFORNIA CANCER REPORTING SYSTEM  
STANDARDS**

**VOLUME ONE**  
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**PREPARED BY**  
California Cancer Registry  
Data Standards and Quality Control Unit

**STATE OF CALIFORNIA  
DEPARTMENT OF HEALTH SERVICES  
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**CANCER SURVEILLANCE SECTION  
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## Patient Identification

### III.2.6 MARITAL STATUS

Studies have shown a correlation between marital status and the incidence and sites of cancer, and that these patterns are different among races. So that further analyses can be carried out to identify high-risk groups, report the patient's marital status at the time of first diagnosis. Use the following codes:

- 1 SINGLE (never married, including only marriage annulled)
- 2 MARRIED (including common law)
- 3 SEPARATED
- 4 DIVORCED
- 5 WIDOWED
- 9 UNKNOWN

### III.2.7 SEX

Enter one of the following codes for the patient's sex:

- 1 MALE
- 2 FEMALE
- 3 HERMAPHRODITE (persons with sex chromosome abnormalities)
- 4 TRANSSEXUAL (persons who have undergone sex-change surgery)
- 9 UNKNOWN

### III.2.8 RELIGION

Enter the code for the patient's religion or creed (see Appendix G for codes), or enter the name of the religion and CNEXT automatically provides the code. CNEXT currently defaults this field to 99. Use code 99 if the religion is not stated.

NOTE: Effective with cases diagnosed January 1, 1998, new codes and definitions were added for religion. Religion codes prior to 1998 were converted. The new codes and definitions are to be used for all cases.

### III.2.9 RACE AND ETHNICITY

Race and ethnicity are two of the most important data items to epidemiologists who investigate cancer. Differences in incidence rates among different ethnic groups generate hypotheses for researchers to investigate. The National Cancer Institute has recognized the need to better explain the cancer burden in racial/ethnic minorities and is concerned with research on the full diversity of the U.S. population. The CCR recognizes the importance of these data items and relies on quality data to assist researchers in identifying and reducing disparities due to race and ethnicity.

### Patient Identification

The CCR requires that race code documentation must be supported by text documentation for those cases where there is conflicting information. Outlined below are examples of when text documentation would be required.

*NOTE: These examples are not intended to demonstrate all possible scenarios.*

#### Scenarios Demonstrating Conflicting Race Information:

- |  |  |
|--|--|
| A. Name: June Hashimoto<br>Race: White<br>Birthplace: Unknown<br>Marital Status: Single          | B. Name: Bob Nguyen<br>Race: White<br>Birthplace: Mexico                                   |
| C. Name: Robert Jackson<br>Race: Mexican<br>Birthplace: California                               | D. Name: Moon Smith<br>Race: Japanese<br>Birthplace: California<br>Marital Status: Married |
| E. Name: Maria Tran<br>Race: White<br>Birthplace: Spain<br>Marital Status: Separated             | F. Name: Carlos Johnson<br>Race: Black<br>Ethnicity: Hispanic<br>Birthplace: California    |
| G. Name: Arlene Thompson<br>Race: Filipino<br>Birthplace: California<br>Marital Status: Divorced |  |

A text statement indicating patient's race, i.e., "Pt is Japanese", is required for conflicting types of cases. This information must be entered in either the physical exam or remarks text fields.

Cases with conflicting information that lack supporting text documentation will be returned as queries and counted as discrepancies.

While race code documentation is only required when there is conflicting information, CCR recognizes the importance of race code documentation and strongly recommends that registrars continue to document race in the physical exam or remarks fields. Remember to search beyond the facesheet for the most definitive race and/or ethnicity information.

### Patient Identification

Race and ethnicity are defined by specific physical, heredity and cultural traditions, not by birthplace or place of residence. Beginning with cases diagnosed January 1, 2000, four race fields were added to the data set in addition to the existing race field. These fields have been added so that patients who belong to more than one racial category can be coded with multiple races, consistent with the 2000 Census. The codes for all five fields are identical with the exception of Code 88 - No further race documented. Code 88 is not to be used for coding the first race field. Code 99 is to be used for coding the second through fifth race field if the first race field is unknown. If information about the patient's race or races is not given on the face sheet of the medical record, the physical examination, history, or other sections may provide race information. For cases diagnosed prior to January 1, 2000, only the first race field is to be completed and patients of mixed parentage are to be classified according to the race or ethnicity of the mother. For cases diagnosed January 1, 2000 and later, this no longer applies. Enter each race given. No "primary" race is designated, and multiple races may be listed in any order, consistent with the 2000 Census. When any of the race fields are coded as Other Asian - Code 96, Pacific Islander, NOS - Code 97, or Other - Code 98" and a more specific race is given which is not included in the list of race codes, this more specific race must be entered in the Remarks field. (When a patient is described as Asian or Oriental and the birthplace is recorded as a specific Asian country, use the birthplace if possible to assign a more specific code.) If there is no information on race in the medical record, a statement documenting that there is no information must be entered in the Remarks Field.

#### III.2.9.1 Codes For Race Fields. Enter the most appropriate code for a patient's race(s) or ethnicity:

- 01 WHITE
- 02 BLACK
- 03 AMERICAN INDIAN, ALEUTIAN, OR ESKIMO
- 04 CHINESE
- 05 JAPANESE
- 06 FILIPINO
- 07 HAWAIIAN
- 08 KOREAN
- 09 ASIAN INDIAN, PAKISTANI, SRI LANKAN (CEYLONESE), NEPALESE, SIKKIMESE, BHUTANESE, BANGLADESHI
- 10 VIETNAMESE
- 11 LAOTIAN
- 12 HMONG
- 13 KAMPUCHEAN (CAMBODIAN)
- 14 THAI
- 20 MICRONESIAN, NOS
- 21 CEAMORRO
- 22 GUAMANIAN, NOS
- 25 POLYNESIAN, NOS
- 26 TAHITIAN
- 27 SAMOAN
- 28 TONGAN
- 30 MELANESIAN, NOS



Patient Identification

- 31 FIJI ISLANDER
- 32 NEW GUINEAN
- 88 NO FURTHER RACE DOCUMENTED (Do not use for coding the first race field.)
- 96 OTHER ASIAN, INCLUDING BURMESE, INDONESIAN, ASIAN, NOS AND ORIENTAL, NOS
- 97 PACIFIC ISLANDER, NOS
- 98 OTHER
- 99 UNKNOWN

Example

A person of Chinese ancestry born in Thailand and living in Hawaii at the time of diagnosis is to be reported as Chinese (code 04) instead of Thai (code 14) or Hawaiian (code 07).

Following are some of the ethnic groups included in the White category:

Afghan	Czechoslovakian	Lebanese	Spanish
Albanian	Dominican**	Mexican*	Syrian
Algerian	Egyptian	Moroccan	Tunisian
Arabian	Greek	Palestinian	Turkish
Armenian	Gypsy	Polish	Yugoslavian
Australian	Hungarian	Portuguese	
Austrian	Iranian	Puerto Rican**	
Bulgarian	Iraqi	Rumanian	
Caucasian	Israeli	Russian	
Central American*	Italian	Saudi Arabian	
Cuban**	Jordanian	Slavic	
Cypriot	Latino	South American*	

\* Unless specified as Indian (code 03).

\*\* Unless specified as Black (code 02).

## Patient Identification

**III.2.9.2 Spanish/Hispanic\* Origin.** The Spanish/Hispanic Origin field is for identifying patients of Spanish or Hispanic origin or descent. The field corresponds to a question asked in the U.S. census of population. Included are people whose native tongue is Spanish, who are nationals of a Spanish-speaking Latin American country or Spain, and/or who identify with Spanish or Hispanic culture (such as Chicanos living in the American Southwest). Coding is independent of the Race field, since persons of Hispanic origin might be described as white, black, or some other race in the medical record. Spanish origin is not the same as birth in a Spanish-language country. Birthplace might provide guidance in determining the correct code, but do not rely on it exclusively. Information about birthplace is entered separately (see Section III.2.12). In the Spanish/Hispanic Origin field, enter one of the following codes:

- 0 NON-SPANISH, NON-HISPANIC
- 1 MEXICAN (including Chicano, NOS)
- 2 PUERTO RICAN
- 3 CUBAN
- 4 SOUTH OR CENTRAL AMERICAN (except Brazilian)
- 5 OTHER SPECIFIED SPANISH ORIGIN (includes European)
- 6 SPANISH, NOS; HISPANIC, NOS; LATINO, NOS (There is evidence other than surname or maiden name that the person is Hispanic, but he/she cannot be assigned to any category of 1-5.)
- 7 SPANISH SURNAME ONLY (only evidence of person's Hispanic origin is surname or maiden name, and there is no contrary evidence that the person is not Hispanic.)\*\*
- 9 UNKNOWN WHETHER SPANISH OR NOT

The primary source for coding is an ethnic identifier stated in the medical record. If the record describes the patient as Mexican, Puerto Rican, or another specific ethnicity or origin included in codes 1 to 5, enter the appropriate code whether or not the patient's surname or maiden name is Spanish. If the patient has a Spanish surname, but the record contains information that he or she is not of Hispanic origin, use code 0, Non-Spanish. (American Indians and Filipinos frequently have Spanish surnames but are not considered to be of Spanish origin in the sense meant here.) Enter code 0 for Portuguese and Brazilians, because they are not Spanish. If the record does not state an origin that can be assigned to codes 1-5 and there is evidence other than surname that the person is Hispanic, use code 6, Spanish, NOS. If the record does not state an origin that can be assigned to codes 0-6, base the code on the patient's name, and use code 7, Spanish Surname Only. Use code 7, Spanish Surname Only, for a woman with a Spanish maiden name or a male patient with a Spanish Surname. If a woman's maiden name is not Spanish, use code 0, Non-Spanish, Non-Hispanic. But if her maiden name is not known or not applicable and she has a Spanish Surname, use code 7. If race is not known (Race code 99), use code 9, Unknown Whether Spanish or Not. Code 7, Spanish Surname Only (or code 6, Spanish, NOS, if diagnosed prior to January 1, 1994) may