

COLLECTING INFORMATION ON RACE, HISPANIC ETHNICITY, AND BIRTHPLACE OF CANCER PATIENTS: POLICIES AND PRACTICES IN CONNECTICUT HOSPITALS

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Objective: Cancer incidence, treatment, and prognosis show important disparities by race, Hispanic ethnicity, and birthplace, but hospital policies and procedures in obtaining this information are poorly documented. This study documented policies and procedures in a state (Connecticut) with a high-quality population-based cancer registry.

Methods: Directors of medical records and/or admissions at all 30 hospitals were surveyed, and hospital records were abstracted for a sample of 220 minority (African-American/Black, Asian, and Hispanic) cancer patients diagnosed in 2000–2001 at three hospitals of various sizes.

Results: At least one staff member at 86% of the 28 responding hospitals reported a hospital policy to ask patients about their race, vs 25% for ethnicity and 57% for birthplace, and patient self-reports were reportedly used to obtain race in 100% of hospitals vs 54% for ethnicity. Race was regarded as “very important” or “important” by staff at 89% of hospitals, vs only 46% for ethnicity and 61% for birthplace, and 68% of hospitals reported using a single item for both race and ethnicity. Results of record abstraction for the 220 minority patients at the three selected hospitals were generally consistent with data from surveys of hospital staff. Ethnicity was rarely recorded on any specific type of document, although preferred language was usually recorded. Disagreement in recorded race or ethnicity on different documents was rare (2%–3%).

Conclusions: Efforts are needed to educate hospital staff on the importance of collecting information on Hispanic ethnicity and birthplace. Similar studies are needed in other states. (*Ethn Dis.* 2005;15:90–96)

Key Words: Patient Demographics, Cancer, Race/Ethnicity

INTRODUCTION

The policies and procedures used by hospitals to ascertain race and Hispanic ethnicity of patients diagnosed with cancer, as reported to population-based cancer registries, appear to be largely undocumented.^{1–3} Hospital clerks may be reluctant to ask patients about their race,⁴ and possibly also their ethnicity and birthplace. A report from the North American Association of Central Cancer Registries (NAACCR) suggested that race and ethnicity are specified on hospital admission face sheets “with decreasing frequency” and that Hispanic ethnicity may be found in physicians’ and nurses’ notes or other places in the chart⁵; however, the frequencies of recording such data and their actual use (along with Spanish surname lists) to determine race or ethnicity were unknown. In a 1993 survey of administrators in 70 northern California hospitals, information was reportedly recorded on admission face sheet and physical examination reports in >50% of hospitals for race but <50% for ethnicity (ie, Spanish origin or surname) and birthplace, while patient self-report was indicated as the source of data on race in 84% vs 44% for ethnicity.⁶ Similar surveys are needed for more recent years and for other states.

The present study surveyed staff at all of Connecticut’s acute-care hospitals, which are required by state regulations to report incident cancers to the statewide registry. According to the 2000 Census, Connecticut had 320,323 Hispanics (9.4% of the state’s 3,405,565 population) of any race, 309,843 (9.1%) African Americans (Blacks) reporting one race, 82,313 (2.4%) Asian Americans reporting one race, and 9,639 American Indians/Alaska Natives

reporting one race. Only 2.2% of the population reported more than one race. While a large number of persons reported American Indian/Alaska Native alone or in combination with one or more other races, reporting and coding of multiple races had not yet commenced for cancer registries at the time of this study. The study used the population-based Connecticut Tumor Registry (CTR), part of the National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) Program of high-quality population-based cancer registries. The SEER data are often used to estimate national cancer rates by racial-ethnic group.^{2,7} The study also abstracted hospital records for samples of minority cancer patients from selected hospitals to assess the kinds of documents used for recording information on race, Hispanic ethnicity, and birthplace, along with consistency of information recorded in the different documents.

METHODS

Letters and surveys were mailed starting in January, 2003, to the director of admissions and director of medical records, along with inpatient and outpatient clerks, at each of the state’s 30 acute-care hospitals. Multiple mailings, phone calls, and personal visits to all hospitals were used to encourage and facilitate response. For two hospitals, the vice president directed that only one joint response should be returned, while at several others the director of medical records deferred to the director of admissions (or vice versa), despite multiple attempts to obtain separate surveys from each staff member. The respondents included the director of medical records

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A report from the North American Association of Central Cancer Registries (NAACCR) suggested that race and ethnicity are specified on hospital admission face sheets "with decreasing frequency"

and/or director of admission at 28 (93%) of the state's 30 acute-care hospitals. Nineteen directors of medical records and 19 directors of admissions responded; both responded with separate questionnaires at 11 hospitals and with one (joint) questionnaire at one hospital. Only an admissions staff member responded at the other two hospitals (one with 3.8% and the other with 1.0% of all cancers statewide); data for these two respondents are not tabulated because the respondents may have had limited knowledge of hospital-wide policies and procedures.

Survey questions were based in part on previous surveys done in California,⁶ including questions on hospital policies and practices with regard to collection of race, Hispanic ethnicity, and birthplace, along with details on where and when data were collected (Table 1). The survey also asked if race and Hispanic ethnicity were collected as a single item or as two items; and whether Spanish surnames were determined (and if so, by sound, spelling, or a specific list of Spanish surnames). Specific perceived barriers to collecting information were also queried with a checklist.

For review and abstraction of information from hospital records, three hospitals with relatively large proportions of minority cancer patients were selected: one of the largest hospitals in the state

(about 2000 cancer patients per year), a mid-size hospital (about 950 cancer patients per year), and a smaller hospital (about 694 cancer patients per year) with a relatively high proportion (ie, 71% vs 36% statewide) of cancers having the CTR/SEER data item "Spanish origin or surname" coded as "7," indicating possible Hispanic origin based solely on computerized matching (by the CTR) with a list of Spanish surnames from the 1980 Census.

The three selected hospitals accounted for 19% of all reportable tumors diagnosed statewide in 2000–2001 (including 18% of Asians, 21% of Blacks, and 27% of Hispanics). While not necessarily representative of all hospitals in the state, the three hospitals should provide an initial assessment of actual documents used to record information on race, ethnicity, and birthplace for many minority cancer patients diagnosed while residents of the state. Random samples of 45 non-Hispanic Black patients, 45 Hispanic patients, and all "Asians" diagnosed in 2001 were selected at each of the two larger hospitals. For the third hospital, all Hispanic patients (estimated at 46–48) and all Asians (estimated at 4–8) diagnosed during two years (2000 and 2001) were selected, due to the smaller number of cancer patients. The total original sample was 250 minority patients, excluding American Indians (due to very small numbers). Useful records were located for 220 (88%) of the 250; other records were missing or too limited (ie, brief outpatient visits such as for radiotherapy alone).

Of the 220 minority patients whose hospital medical records were abstracted, 112 (50.9%) had a code (1 through 7) in the SEER-required data item "Spanish surname/origin," which indicated Hispanic or possibly Hispanic ethnicity, from hospital reports or based solely on Spanish surname. The SEER "race" item was coded as White for 108 of the 220 patients, Black for 84, Asian for 25, and other/unknown for 3 (ie,

selected based on Hispanic ethnicity); no patients had a SEER race code for a Pacific Islander group in this sample. Birthplace was unknown for 22.3% of all 220 and 30.4% of the 112 Hispanics. Sex was male for 103 (46.8%) and female for 117 (53.2%). The most common types of cancer were breast (43), prostate (28), lung (21), colorectal (23), and non-Hodgkin's lymphoma (13), with <9 for other specific types. The study's abstraction form for the admission around the time of cancer diagnosis ("index" admission) and for the previous admission (if any) included the presence or absence of information on each item (race, Hispanic ethnicity, birthplace) for up to nine specific types of documents.

RESULTS

The director of medical records and/or admissions at 24 (85.7%) of the 28 responding hospitals reported that their hospital had a policy that all patients should be asked about their race; two hospitals reported no policy, while responses disagreed for two hospitals (Table 1). For birthplace, a policy of asking patients for the information was reported by 57.1% of hospitals, vs only 25.0% for Hispanic ethnicity (with discrepant responses for five and no response for three) (Table 1).

Irrespective of stated hospital policy, use of the patient's own verbal or written report as a source for information was specified by at least one respondent at all 28 of the 28 responding hospitals for race and for 78.6% of hospitals for birthplace but only 53.6% for Hispanic ethnicity. A large proportion of hospitals reported using a relative's report for race and birthplace, vs a smaller proportion for Hispanic ethnicity. Using a patient's physical characteristics (such as skin color) was reported for 32.1% of hospitals for race vs only 7.1% for Hispanic ethnicity. In contrast, use of a patient's language was reported for 25% of hospitals

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Table 1. Responses (% of hospitals) from directors of medical records and/or admissions at 28 Connecticut hospitals to questions on hospital policies and practices regarding the collection of data on race, Hispanic ethnicity, and birthplace

Question	Race %	Hispanic Ethnicity %	Birthplace %
Questions with Only One Response			
Hospital rule or policy on asking patients			
No rule or policy	7.1	42.9	25.0
Yes, to ask	85.7	25.0	57.1
Yes, not to ask	0.0	3.6	7.1
Discrepant responses	7.1*	17.9*	10.7*
Unknown, missing	0.0	10.7	0.0
Total (28 hospitals)	100%	100%	100%
Importance of information			
Very important	50.0	32.1	39.3
Important	39.3	14.3	25.0
Not so important	7.1	25.0	10.7
Unimportant	0.0	7.1	17.9
Discrepancy	3.6†	7.1†	7.1†
Don't collect; don't know	0.0	14.3	0.0
Total	100%	100%	100%
Questions with More than One Possible Response			
Source(s) of information	% (%)‡	% (%)‡	% (%)‡
Patient self-report	96.4 (100.0)	35.7 (53.6)	71.4 (78.6)
Patient's family	67.9 (75.0)	25.0 (35.7)	57.1 (60.7)
Patient's friend	28.6 (39.3)	3.6 (7.1)	28.6 (39.3)
Patient's physical appearance	21.4 (32.1)	3.6 (7.1)	0.0 (0.0)
Patient's language	14.3 (25.0)	10.7 (25.0)	0.0 (0.0)
Patient's birthplace	10.7 (21.4)	7.1 (10.7)	NA
Patient surname	46.4 (57.1)	10.7 (17.9)	28.6 (35.7)
Existing medical record			
Same hospital	64.3 (82.1)	25.0 (39.3)	42.9 (60.7)
Another hospital	46.4 (57.1)	10.7 (17.9)	28.6 (35.7)
When collected			
Inpatient admission	89.3 (96.4)	32.1 (46.4)	64.3 (75.0)
Outpatient admission	85.7 (96.4)	28.6 (46.4)	53.6 (64.3)
Radiotherapy	21.4 (32.1)	3.6 (14.3)	10.7 (17.9)
Physical exam	7.1 (17.9)	7.1 (17.9)	3.6 (10.7)
Location in record			
Face sheet	82.1 (82.1)	21.4 (35.7)	39.3 (57.1)
Physical exam/history	17.9 (39.3)	7.1 (17.9)	3.6 (10.7)
Discharge summary	10.7 (28.6)	7.1 (10.7)	3.6 (10.7)
Nurse's notes	10.7 (17.9)	3.6 (10.7)	3.6 (7.1)
Radiotherapy report	0.0 (7.1)	0.0 (3.6)	0.0 (0.0)

NA: Not applicable.

* Both staff (director of medical records and director of admissions) responded and responses did not agree.

† Discrepancies all involved "very important" vs "important."

‡ Percentage includes report by at least one of the two respondents for hospitals for which two staff responded (see text).

for both race and ethnicity. Use of birthplace in assigning race or ethnicity was uncommon. Use of information already in the hospital record was reported for 82% of hospitals for race, 39% for ethnicity, and 61% for birthplace, with lower figures for use of information from other hospitals. Admission reports (on face sheets) were reportedly the

most common place for recording of race and ethnicity, albeit less common for birthplace, while other locations or times for recording (radiotherapy, physical examination, and nurse's notes) were infrequently involved. Race and birthplace were regarded as either very important or important more often than Hispanic ethnicity, and consistency in

rating was high among the 11 hospitals with two respondents (Table 1).

For other survey items (not shown in Table 1), many (19 or 67.9%) of the 28 hospitals responding reported using a single question for race and ethnicity, and only three (10.7%) used two separate questions, while responses disagreed for three and were reported as not ap-

Table 2. Presence of information on race, ethnicity, and birthplace in specific documents for 220 minority patients sampled from three Connecticut hospitals

Document	Document Found in Record		% Among Patients with Document*					
			Race		Ethnicity		Birthplace	
	No.	%†	No.	%*	No.	%*	No.	%*
Inpatient admission	116	52.5	78	67.2	30	25.9	54	46.6
Outpatient admission	86	39.0	56	65.1	25	28.7	52	60.5
Discharge summary	105	47.5	42	40.0	12	11.4	3	2.9
Physical exam	204	92.3	85	41.7	19	9.3	16	7.8
Oncology nurse notes	195	88.2	10	5.1	3	1.5	2	1.0
Radiotherapy report	75	33.0	52	69.3	16	21.3	21	28.0
On any document‡	—	—	218	99.1	76	34.5	141	64.1

* Proportion of patients with the document who had the information (other than unknown or missing) on the sociodemographic item.

† Proportion of patients for whom the specific document was found in the hospital record.

‡ Proportion of patients who had the information (other than unknown or missing) on at least one document.

plicable or unknown for three. Only six hospitals (21.4%) reported using the sound or spelling of surnames in assigning ethnicity, and none reportedly used a specific list of Spanish surnames. For perceived barriers to collecting data, only the sensitivity of questions (14 or 50% of hospitals for race and 11 or 39.3% for Hispanic ethnicity) was frequently reported. "Hospital policies prohibit or discourage" was reported as a barrier by two hospitals for race and four for Hispanic ethnicity, which is consistent with the low frequency of reporting that hospital policy was not to ask about race and Hispanic ethnicity (as shown in Table 1).

Of the hospitals used in sampling hospital records, staff at all three reported a policy of asking patients about race and birthplace, but none about ethnicity; all reported using admission forms for recording race and birthplace but none for ethnicity. The hospital records for the sample of 220 patients reviewed at these hospitals showed that inpatient or outpatient admission documents were very likely to include information on race and birthplace but much less likely for ethnicity (Table 2). Oncology nurse's notes rarely included any of the items studied. Compared to admission documents, radiotherapy reports were similar in completeness for race and ethnicity but were less frequently found in the record.

For the subgroup of 112 patients coded as Hispanic in the CTR, 71 (63.4%) had Hispanic ethnicity mentioned on one or more documents for the index admission (data not shown). This proportion was 93.6% (44/47) in the first hospital and 68.8% (22/32) in the second hospital but only 15.2% (5/33) in the third, which was selected in part because of a relatively high proportion of patients coded as Hispanic in the CTR solely on the basis of matching of patient surname.

Within the index admission, discrepancies in recorded race were infrequent among records that had information coded on two or more different documents (Table 3). Reporting of race as Hispanic (or a similar term) on one document but "White," "Black," or other specific race in another document was not counted as discrepant, because Hispanics can be of any race (as in the US Census) and some Hispanics identify their race as Hispanic (or similar term) in Censuses. Among the 121 patients with an admission to the same hospital prior to the index admission all but 20 had race recorded on both admissions, and discrepancies in race were infrequent (1.7%). More precise information such as "Vietnamese" vs "Asian" was sometimes found in only one of two or more documents (Table 3). Among the subgroup of 112 patients recorded as Hispanic/Spanish surname in the

CTR (data not shown), no disagreements were found for the 70 patients with a previous admission (42 of whom had ethnicity recorded for both admissions) or for the 37 with information on ethnicity in two or more documents in the record for the index admission.

Use of patient's self-report vs clerk's observation for obtaining race and ethnicity was unclear to the abstractors for most of the types of documents examined. For oncology nurse reports, however, information was often self-reported by patients, but race, ethnicity, and birthplace were seldom recorded. Information on preferred or primary language was recorded for all but 17.7% of the 220 patients, most often in nurse's notes and/or physical examination reports. Of the 220 patients, 124 (56.4%) preferred English and 40 (18.2) Spanish; 3 (1.4%) were English-Spanish bilingual, one preferred Portuguese, seven spoke another language, one patient was mute, four had inconsistent information on preferred language, one was diagnosed in infancy, and the remainder had missing information (data not shown). Of the subgroup of 112 Hispanics, 39 (34.8%) preferred Spanish.

DISCUSSION

The high proportion (86%) of the 28 responding hospitals reporting a pol-

Table 3. Comparison of recording of race among documents for the index admission, and between two admissions at the same hospital, for 220 minority cancer patients in three Connecticut hospitals

Within the Index Admission*		
Information only on one document	85	38.6
Information on two or more documents	135	61.4
Disagreement	4	(3.0)†
No disagreement	109	(80.7)†
Hispanic used as race	15	(11.1)†
More precise information on another document	4	(3.0)†
Index vs Previous Admission		
No previous admission	99	45.0
Previous admission	121	55.0
Information not recorded	20	(16.5)‡
No disagreement	87	(71.9)‡
Hispanic used as race	12	(9.9)‡
Disagreement	2	(1.7)‡
More precise information in the previous admission	6	(5.0)‡

* Admission closest to the time of cancer diagnosis.

† Proportion among patients with two or more documents.

‡ Proportion among patients with a previous admission.

icity of asking patients about race and the considerably lower proportions for Hispanic ethnicity (25.0%) and birthplace (57.1%) in Connecticut hospitals (Table 1) differ somewhat from the results of a survey in northern California in 1993 that showed that 5% of responding hospitals never collected race vs 55% for Hispanic ethnicity and 31.7% for birthplace, based on reports from a single hospital staff member (ie, administrator) at 60 of all 70 hospitals.⁶ The lower proportion of hospitals reportedly asking about ethnicity in Connecticut than in California may reflect the smaller Hispanic population and less awareness of Hispanic patients in Connecticut.

Self-reported race and ethnicity are generally regarded as desirable for most purposes. Consistent with the responses of hospital staff to the questions on hospital policy, at least one respondent at all responding hospitals reported that patient self-reports were used for race, vs 79% for birthplace and 53.6% for Hispanic ethnicity. For northern California hospitals in 1993, the figures were 84.2% for race, 61% for birthplace, and 43.8% for ethnicity.⁶ Such frequent use of self-reported race in Connecticut hospitals was unexpected in view of anecdotal information that

hospital clerks in Connecticut hospitals often recorded race based on observation (without asking patients). A report from the statewide cancer registry in Florida stated that Hispanic ethnic identification was based on self-identification “as originally abstracted from the medical record at each hospital,” but no details were provided.⁸

A patient’s physical appearance was reported as a source for assigning race by 32.1% of hospitals (Table 1), which is lower than the 52.1% figure for northern California hospitals.⁶ This finding may be related to the much higher frequencies of minority patients (especially Asians and Pacific Islanders) in California than in Connecticut. The figures for use of physical appearance for assigning ethnicity were low both in California (7.1%)⁶ and in Connecticut (7.1%, Table 1). Conceivably, some patients may be reluctant to report their race, and hospital staff may then resort to other sources. This possibility would be consistent with some staff reporting that a barrier to obtaining race was that it was a “sensitive” item. Rather common reported use of patient’s family or relative for assigning ethnicity and (especially) race, and uncommon use of patient’s birthplace and language for as-

signing race and ethnicity (Table 1) were consistent with findings from northern California hospitals.⁶ The explanation for the use of family members needs further exploration; perhaps mainly infants, young children, severely ill, or non-responsive patients are involved.

Noteworthy was the large proportion of hospitals not using separate data fields for race and Hispanic ethnicity, despite the requirement of the American College of Surgeons’ Commission on Cancer⁹ and the SEER Program.¹⁰ Recommendations for changing hospital procedures should include use of separate items for race and ethnicity at those hospitals using only one item.

Disagreement in responses between two respondents at the same hospital, for the 11 hospitals involved, indicate the need for additional studies involving meeting with hospital staff to resolve discrepancies. Directors of medical records may be most familiar with hospital-wide policies and procedures, but this requires examination. However, none of the respondents reported using a specific list of Spanish surnames to assist in classifying patients as Hispanic. The central (statewide) cancer registry routinely does surname matching by us-

Hospital staff should be targeted for interventions to increase use of patient self-reports of ethnicity.

ing the 1980 Census list of Spanish surnames, which improves the accuracy of estimated cancer incidence rates for Hispanics.¹¹ Portuguese and Filipinos, not considered Hispanic by most (but not all) authorities, with Spanish surnames are not a major issue in Connecticut vs other areas.¹²

Although almost all hospital staff responding regarded race as important or very important information, this was not true for ethnicity and birthplace (Table 1). Central cancer registries should emphasize to hospital staff the importance of ethnicity and birthplace. Cancer rates, risk factors, prognostic factors, and outcomes differ not only by Hispanic ethnicity but also between foreign-born and US-mainland-born persons. For example, tumor size and stage of breast cancer differed by birthplace among Hispanic women in California and New Mexico SEER areas, but birthplace was missing for about one third of patients.¹³

Limitations of the hospital record abstraction study involve the small numbers of minority patients and use of only patients diagnosed with cancer, although it is unlikely that findings would differ for non-cancer patients. Abstraction was limited to three hospitals, but the finding of relatively common use of inpatient/outpatient admission forms to record race and (albeit less frequently) Hispanic ethnicity (Table 2) was consistent with reports from surveys of staff at all responding hospitals (Table 1). Although use of specific types of documents may vary regionally in the United States,⁵ the types of documents used (Tables 1 and 2) were similar to those reported in a survey of hospital staff in

northern California (record abstraction was not included).⁶

Another limitation of this study, conducted in Connecticut, is the small number of patients sampled who had race coded, by using the SEER Program's coding scheme, to an Asian group. In a few hospital records the documents differed in specificity of terminology (ie, "Asian" vs a specific subgroup such as "Vietnamese"). Studies of methods used and consistency in recording of race-ethnicity in hospital records are needed in population-based registries located in geographic areas with larger numbers of Asians and Pacific Islanders. Subgroups of Asians and Pacific Islanders differ in their cancer patterns. For example, ethnic-specific cancer incidence rates among Asian-American women in Los Angeles County show that Japanese Americans have experienced a rapid rise in breast cancer incidence rates, and that rates in women of Japanese and Filipino ancestry are twice as high as those for women of Chinese and Korean ancestry, but that the methods used by hospitals to record information on ethnicity (eg, self-reported vs observation by hospital clerks) were unknown.¹⁴

The much lower frequency of documentation of Hispanic ethnicity than race in hospital records for the sample of 220 minority at three selected hospitals (Table 2) is consistent with reports by responding staff at all hospitals (Table 1) and at the subgroup of three hospitals sampled. Documentation of ethnicity varied by hospital. The third (ie, smallest) hospital selected had a high proportion of patients coded as "Spanish surname or origin" solely on the basis of a Spanish surname, and examination of hospital records for a small sample of Hispanic patients at this hospital confirmed an unusually low proportion with documentation of ethnicity.

Hospital staff should be targeted for interventions to increase use of patient self-reports of ethnicity. Greater use of

physical examination reports and nurse's reports to record self-reported ethnicity (and birthplace) should be advocated, especially in view of evidence from this study that preferred language is often obtained from these sources.

Despite the apparently high degree of consistency in recorded race and ethnicity among documents for the index admission and between admissions (Table 3), hospital staff may have consulted information already recorded in the record at the same hospital or (less often) from another hospital (Table 1). Therefore, the items may not have been recorded independently in the different documents, although the occurrences of more precise information (eg, specific Asian group) in one document than another (Table 3) could suggest independent recording.

Collection of race, ethnicity, and "primary" language has been recommended for all patients in healthcare programs such as Medicare and Medicaid.¹⁵⁻¹⁷ Collection of birthplace has not been mentioned, although primary/preferred language is closely associated with birthplace because original language is largely lost after the first or migrant generation.¹⁸ While cancer registries have limitations for completeness and accuracy of information, hospital discharge databases are often more limited because birthplace and complete surname may not be included as variables.¹⁹ Increasing recognition of the need to address disparities in healthcare access and quality by race and ethnicity, and also by immigration status and language, may result in increasing attention to completeness and accuracy of these items in various healthcare facilities and databases.^{16,17} Continuous surveillance of hospital policies and practices regarding collection of these data items will be needed in Connecticut and other states, as the populations of minorities and immigrants continue to expand.

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Design and concept of study: Polednak

Acquisition of data: Polednak

Data analysis and interpretation: Polednak

Manuscript draft: Polednak

Statistical expertise: Polednak

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