Disparities Demographic Data Recommendations

Division of Public Health
Department of Health & Human Services
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INTRODUCTION

This document provides recommendations for the collection of a minimum data set of health disparities data, developed as a work product of the Nebraska Department of Health and Human Services (DHHS) Division of Public Health 2013-2016 Strategic Plan. The Division of Public Health is committed to engaging these recommendations to improve the collection of health disparities data in Nebraska to support the effort of achieving health equity in our state.

We would like to invite and encourage our public health partners and community stakeholders to consider opportunities to improve their collection of health disparities data. When data is collected uniformly and can be compared collectively, a richer picture of our state unfolds. As we elevate the effort to achieve health equity in Nebraska, ensuring our capacity to understand the landscape is vital. We honor the intentional efforts by our public health system partners to include all Nebraskans in the vision to become the healthiest state in the nation.

This document provides recommendations for a core group ("minimum data set") of **six factors** that would be relevant to most programs: **race and ethnicity, primary language, gender, age, disability, and geographic location** (urban/rural). While other demographic elements are also applicable to health disparities (e.g., education or military status) these six were considered primary. The key issue underlying selection of these six factors were the concepts of equity and injustice – programs may (or may not) need to tailor their services differently for groups with different values of the factors. This document offers a strong recommendation that *all* programs include these six factors in their data collection systems because the concepts of equity and justice apply to all people and programs. For even those programs that are not directly behavior or health status related (e.g., well water contamination) the information should still be collected for the home, land or facility owner.

Recommended definitions for the **six factors** are summarized in Appendix 1; suggested aggregations are outlined in Appendix 2; and race and ethnicity definitions are offered in Appendix 3.

RACE AND ETHNICITY RECOMMENDATIONS

Race and ethnicity should be self-reported whenever possible. Racial categories "represent a social-political construct for the race or races that respondents consider themselves to be and generally reflect a social definition of race recognized in this country."… "The race categories include both racial and national-origin groups… Race and ethnicity are considered separate and distinct identifies..." (U.S. Office of Management and Budget (OMB), 2001). **Hispanic ethnicity is the only ethnicity question recommended.** Note that while technically "Hispanic" and "Latino" have different meanings, they are often used interchangeably. This document does not offer a strong rationale to recommend one over the other, and the OMB recommends using both terms, "Hispanic or Latino."

a) **Hispanic or Latino Ethnicity:** Ethnicity should always be asked before race, and as yes/no. Placing it first reduces the number of responses of "Hispanic" under race.

☐ Are you of Hispanic or Latino origin?

Other ethnicities, or subcategories of Hispanic (e.g., Mexican, Guatemalan) could be added if the benefit of additional detail outweighs the disadvantages of additional questions and options.

b) **Race**: Six categories of race are recommended by the OMB: White; Black or African American; American Indian or Alaska Native; Asian; Native Hawaiian or other Pacific Islander; and, "Some Other Race (please specify:_____)".

Note 1: It is recommended not to substitute "Native American" for "American Indian" as this term can conceivably be applied to all persons born in the U.S. Native-born Africans should be included in "Black or African-American."

Note 2: The racial designation of people from the Middle East and North Africa is controversial. The Census Bureau currently considers Middle Easterners, and North Africans of Middle Eastern descent, as White. However, there is pressure to create either a racial or ethnicity option for Middle Eastern ancestry. For the time being, however, persons from the Middle East are preferably recorded as White. Distinction between "Middle Eastern origin" and "African" origin for North Africans is, and is likely to remain, problematic.

Note 3: Although most persons in the U.S. who self-report as Hispanic consider themselves to be of White race, this is not universally true. Missing answers for race by respondents who have already selected Hispanic ethnicity should not be presumed to default to White. All reports or other products that include race and ethnicity data should state specifically how groups were defined.

Questionnaires and databases should be constructed so as to allow for the selection of multiple race categories.

☐ What is your race? (please select all that apply)

Additional subcategories of specific races (e.g., Korean, Vietnamese) could be added if the benefits of additional detail outweighs the disadvantages of additional questions and options.

PRIMARY LANGUAGE RECOMMENDATIONS

The standard for primary language is a measure of English proficiency. For statistical, planning, analytical and research purposes, disparities have been associated with English language proficiency rather than the specific language spoken, and thus recommended for collection. The recommended question is based on the American Community Survey, which has been collected by the Census Bureau since 1980. The question applies to participants aged five years and above.

Preferred version: How well do you speak English? (5 years old or older)

The primary language data standard represents a minimum standard and the question and answer categories should not be changed. Additional questions on language may be added to any data collection system as long as the minimum standard is included.

Optional details: 2 yes/no questions are optional in order to collect the specific language spoken at home.

☐ Do you speak a language other than English at home? (5 years old or older)

☐ What is this language? (5 years old or older)

GENDER RECOMMENDATIONS

Gender should be self-reported as Male or Female. Additional options for transgender and/or sexual orientation must be approved by Division administration.

AGE RECOMMENDATIONS

Recommended methods to determine age vary by whether the information is for a program's client-level records or database, or for a presumably anonymous survey. Directly asking for a person's age is generally not recommended, as the answer is only valid for at most one year and accurate projections can be problematic. Having actual dates allows an age calculation related to whatever time frame is needed.

For *programs*

Preferred version: Date of birth (mm/dd/yyyy).

Acceptable version: Current age in completed years; must be accompanied by the response year.

*Avoid***:** "How old are you?"

For *surveys*

Preferred version: Date of birth (mm/dd/yyyy) or (mm/yyyy). 4-digit years are strongly encouraged.

Acceptable: Year of birth (yyyy) or current age in completed years. Should be recorded along with the survey response year.

Acceptable: Current age based on age range, with the definition based on program's needs, and categories as small as possible. Should be recorded along with the survey response year.

>**Recommended minimum for children:** 0 (<1), 1-4, remaining 5-year groups.

>**Recommended minimum for adults:** No larger than 10-year groups.

DISABILITY RECOMMENDATIONS

The American Community Survey (ACS) definition of disability that focuses on the impact specific conditions may have on basic functioning, rather than listing the specific conditions themselves.

There are three options from which to choose:

a) **Preferred version:** 6 yes/no questions from the ACS. Anyone with one or more positive responses is considered to have a disability. Questions are not "additive" in the sense that answering yes to more than one does not represent "increased disability."

> ☐ Is this person deaf or does he/she have serious difficulty hearing?

> ☐ Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

> ☐ Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

> ☐ Does this person have serious difficulty walking or climbing stairs?

> ☐ Does this person have difficulty dressing or bathing?

> ☐ Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

The ACS questions are phrased so that one respondent can answer for multiple household members. If asking individual respondents, the questions should be phrased as "Are *you* deaf or do *you* have…"

b) **Acceptable version:** 2 yes/no questions from the Behavioral Risk Factor Surveillance System.

Introduction (optional)**:** The following questions are about health problems or impairments you may have:

☐ Are you limited in any way in any activities because of physical, mental, or emotional problems?

☐ Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone? Include occasional use or use in certain circumstances.

c) **Minimum recommended**: 1 yes/no question from the Behavioral Risk Factor Surveillance System.

Introduction (optional)**:** The following question is about health problems or impairments you may have:

☐ Are you limited in any way in any activities because of physical, mental, or emotional problems?

GEOGRAPHIC RECOMMENDATIONS

Because it was not possible to provide a universally applicable definition for this factor, agreeing with the statement "Terms such as rural and urban are often tossed around casually and are imprecise; there is not general agreement as to what "rural" means." (Rural Health Research Center, undated). It is recommended to:

☐ Only utilize the "Frontier" designation when it is specifically appropriate;

☐ Prioritize flexibility over simplicity; and,

➢ Use at least one of two separate categorization methods, one based on county and the other on zip code. *(Requesting additional address information, e.g., street and house number, is at the program's discretion.)*

Few programs will find it practical to analyze and/or report the full number of categories in the recommended county and zip code methods (8 and 33 categories, respectively); users are thus encouraged to combine and/or condense the basic categories in the way that best meets their needs. However, any such aggregation should be explained in the product documentation.

a) **Method 1: County-based designations**: Eight categories of county-level designations based on the 2013 definitions of metropolitan and micropolitan by the U.S. Office of Management and Budget are

recommended. The minimal definition of "urban/rural" can be considered as "Core metropolitan" versus all others. ***Moving individual counties between categories is highly discouraged; if chosen, then the differences and rationale must be easily accessible to users and viewers of the results.***

☐ Core metropolitan (Douglas, Sarpy, Lancaster)

☐ Core metropolitan outlying (Washington, Saunders, Seward, Cass)

☐ Non-core metropolitan (Dakota, Hall)

☐ Non-core metropolitan outlying (Howard, Hamilton, Merrick, Dixon)

☐ Micropolitan (Scotts Bluff, Lincoln, Dawson, Buffalo, Adams, Madison, Dodge, Platte, Gage)

☐ Micropolitan outlying (Banner, McPherson, Logan, Gosper, Kearney, Clay, Pierce, Stanton)

☐ Non-metro/micro with large town (Dawes, Box Butte, Cheyenne, Cherry, Keith, Custer, Red Willow, Phelps, Holt, York, Jefferson, Richardson, Nemaha, Otoe, Saline, Butler, Colfax, Cuming, Wayne)

☐ Non-metro/micro with no large towns (Sioux, Kimball, Morrill, Sheridan, Garden, Deuel, Grant, Arthur, Perkins, Chase, Dundy, Hooker, Thomas, Hayes, Hitchcock, Frontier, Furnas, Harlan, Keya Paha, Brown, Blaine, Rock, Loup, Boyd, Garfield, Wheeler, Valley, Sherman, Franklin, Greeley, Webster, Nuckolls, Nance, Boone, Antelope, Polk, Fillmore, Thayer, Pawnee, Johnson, Knox, Cedar, Thurston, Burt)

b) **Method 2: Zip code or census-tract-based designations**: Because any given county will include areas that are a mix of "urban" and "rural" characteristics, programs that need more precise delineation are recommended to use the Rural-Urban Commuting Area (RUCA) designations based on zip codes or census tracts. "...the RUCA taxonomy is based on the size of cities and towns and their functional relationships as measured by work commuting flows… There are 33 separate codes to allow … (users) to aggregate these codes according to their needs." (Rural Health Research Center, undated). The 2013 update of the RUCA database is available at http://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes.aspx. Several basic categorization schemes are provided on the RUCA website (http://depts.washington.edu/uwruca/ruca-uses.php). For instance, "Categorization A" aggregates the RUCA 33 codes into 4 groupings:

☐ Urban focused

☐ Large Rural City/Town (Micropolitan) focused

☐ Small Rural Town focused

☐ Isolated Small Rural Town focused

REFERENCES

Rural Health Research Center. Undated. What is rural? Available at http://depts.washington.edu/uwruca/ruca-rural.php. Accessed 3/2/2015.

U.S. Census Bureau. 2001. Questions and Answers for Census 2000 Data on Race. Available at http://web.archive.org/web/20100304131211/http://www.census.gov/Press-Release/www/2001/raceqandas.html. Accessed 3/2/2015.

COMMENTS

APPENDIX 1: RECOMMENDED <u>DATA COLLECTION</u> FORMATS

Race/Ethnicity
1. Are you Hispanic or Latino? (1) Yes   (2) No

2. What is your race? (please select all that apply)
   a) White
   b) Black or African American
   c) American Indian or Alaska Native
   d) Asian;
   e) Native Hawaiian or other Pacific Islander
   f) Some Other Race (Please specify:_____)

Primary Language
1. How well do you speak English? (5 years old or older)
   a) Very well
   b) Well
   c) Not well
   d) Not at all

Optional details to add if collection of specific language spoken at home is desired:

2. Do you speak a language other than English at home? (5 years old or older)   (1) Yes   (2) No
3. What is this language? (5 years old or older)
   a) Spanish
   b) Other Language (Identify:_____)

Gender
What is your gender?   1. Male   2. Female

Age
Option1: (Preferred): What is your birthdate? ____/____/_____ (mm/dd/yyyy)

Option 2: What is your birthdate? ____/_____ (mm/ yyyy)

Option 3: Current age in completed years. <u>Should only be used for surveys</u>; year of survey must be recorded.

Option 4: Selection of age range categories based on program's needs. Must be recorded along with survey year.

Disability

<u>Option 1:</u>

1. Are you deaf or do you have serious difficulty hearing?   (1) Yes   (2) No

2. Are you blind or do you have serious difficulty seeing even when wearing glasses?
   (1)Yes   (2) No

3. Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? (1) Yes   (2) No

4. Does this person have serious difficulty walking or climbing stairs? (1) Yes   (2) No

5. Does this person have difficulty dressing or bathing? (1) Yes   (2) No

6. Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? (1) Yes   (2) No

<u>Option 2:</u>

1. Are you limited in any way in any activities because of physical, mental, or emotional problems?

2. Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone? Include occasional use or use in certain circumstances.

<u>Option 3:</u>

1. Are you limited in any way in any activities because of physical, mental, or emotional problems?

Geographic location

1. Which county (state) do you live in?
   (If state is recorded, use full word as 2-letter abbreviations are often misused.)

2. What is the 5-digit zip code of your home address? _____

APPENDIX 2: SUGGESTED <u>DATA REPORTING</u> CATEGORIES

Race/Ethnicity

<u>Combined:</u>

Non-Hispanic White

Non-Hispanic Black or African American

Non-Hispanic American Indian or Alaska Native

Non-Hispanic Asian or Native Hawaiian or other Pacific Islander

Multiracial (For reporting purposes only, should not be included as an option for the respondent.)

Hispanic (Regardless of reported race(s))

<u>Separate:</u>

White

Black or African American

American Indian or Alaska Native

Asian or Native Hawaiian or other Pacific Islander

Multiracial (For reporting purposes only, should not be included as an option for the respondent.)

Hispanic

Non-Hispanic

Disability

Any versus none

County-based geographic location

Reporting Option 1

Urban-large:

- Core metropolitan (Douglas, Sarpy, Lancaster)
- Core metropolitan outlying (Washington, Saunders, Seward, Cass)

Urban-small:

- Non-core metropolitan (Dakota, Hall)
- Non-core metropolitan outlying (Howard, Hamilton, Merrick, Dixon)
- Micropolitan (Scotts Bluff, Lincoln, Dawson, Buffalo, Adams, Madison, Dodge, Platte, Gage)

Non-urban ("Rural"):

- Micropolitan outlying (Banner, McPherson, Logan, Gosper, Kearney, Clay, Pierce, Stanton)
- Non-metro/micro with large town (Dawes, Box Butte, Cheyenne, Cherry, Keith, Custer, Red Willow, Phelps, Holt, York, Jefferson, Richardson, Nemaha, Otoe, Saline, Butler, Colfax, Cuming, Wayne)
- Non-metro/micro with no large towns (Sioux, Kimball, Morrill, Sheridan, Garden, Deuel, Grant, Arthur, Perkins, Chase, Dundy, Hooker, Thomas, Hayes, Hitchcock, Frontier, Furnas, Harlan, Keya Paha, Brown, Blaine, Rock, Loup, Boyd, Garfield, Wheeler, Valley, Sherman, Franklin, Greeley, Webster,

Nuckolls, Nance, Boone, Antelope, Polk, Fillmore, Thayer, Pawnee, Johnson, Knox, Cedar, Thurston, Burt)

Reporting Option 2
Metropolitan:
- Core metropolitan (Douglas, Sarpy, Lancaster),
- Core metropolitan outlying (Washington, Saunders, Seward, Cass),
- Non-core metropolitan (Dakota, Hall)
- Non-core metropolitan outlying (Howard, Hamilton, Merrick, Dixon)

Micropolitan:
- Micropolitan (Scotts Bluff, Lincoln, Dawson, Buffalo, Adams, Madison, Dodge, Platte, Gage)

Non-urban ("Rural"):
- Micropolitan outlying (Banner, McPherson, Logan, Gosper, Kearney, Clay, Pierce, Stanton)
- Non-metro/micro with large town (Dawes, Box Butte, Cheyenne, Cherry, Keith, Custer, Red Willow, Phelps, Holt, York, Jefferson, Richardson, Nemaha, Otoe, Saline, Butler, Colfax, Cuming, Wayne)
- Non-metro/micro with no large towns (Sioux, Kimball, Morrill, Sheridan, Garden, Deuel, Grant, Arthur, Perkins, Chase, Dundy, Hooker, Thomas, Hayes, Hitchcock, Frontier, Furnas, Harlan, Keya Paha, Brown, Blaine, Rock, Loup, Boyd, Garfield, Wheeler, Valley, Sherman, Franklin, Greeley, Webster, Nuckolls, Nance, Boone, Antelope, Polk, Fillmore, Thayer, Pawnee, Johnson, Knox, Cedar, Thurston, Burt)

Reporting Option 3
Urban:
- Core metropolitan (Douglas, Sarpy, Lancaster)

Non-urban ("Rural"):
- Core metropolitan outlying (Washington, Saunders, Seward, Cass)
- Non-core metropolitan (Dakota, Hall)
- Non-core metropolitan outlying (Howard, Hamilton, Merrick, Dixon)
- Micropolitan (Scotts Bluff, Lincoln, Dawson, Buffalo, Adams, Madison, Dodge, Platte, Gage)
- Micropolitan outlying (Banner, McPherson, Logan, Gosper, Kearney, Clay, Pierce, Stanton)
- Non-metro/micro with large town (Dawes, Box Butte, Cheyenne, Cherry, Keith, Custer, Red Willow, Phelps, Holt, York, Jefferson, Richardson, Nemaha, Otoe, Saline, Butler, Colfax, Cuming, Wayne)
- Non-metro/micro with no large towns (Sioux, Kimball, Morrill, Sheridan, Garden, Deuel, Grant, Arthur, Perkins, Chase, Dundy, Hooker, Thomas, Hayes, Hitchcock, Frontier, Furnas, Harlan, Keya Paha, Brown, Blaine, Rock, Loup, Boyd, Garfield, Wheeler, Valley, Sherman, Franklin, Greeley, Webster, Nuckolls, Nance, Boone, Antelope, Polk, Fillmore, Thayer, Pawnee, Johnson, Knox, Cedar, Thurston, Burt)

APPENDIX 3: RACE AND ETHNICITY DEFINITIONS

Race and ethnicity, as defined by the United States Census Bureau and the Federal Office of Management and Budget (OMB), are self-identification data items in which residents choose the race or races with which they most closely identify, and indicate whether or not they are of Hispanic or Latino origin (ethnicity).

The racial classifications used by the Census Bureau adhere to the October 30, 1997, Federal Register Notice entitled "Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity" issued by the Office of Management and Budget (OMB) . The OMB requires five minimum categories (White, Black or African American, American Indian and Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander) for race. The race categories are described below with a sixth category, "Some other race," added with OMB approval. In addition to the five race groups, the OMB also states that respondents should be offered the option of selecting one or more races. The following definitions are provided by the OMB and the U.S. Census Bureau to identify race.

White. A person having origins in any of the original peoples of Europe, the Middle East, or North Africa. It includes people who indicate their race as "White" or report entries such as "Irish," "German," "Italian," "Lebanese," "Near Easterner," "Arab," or "Polish."

Black or African American. A person having origins in any of the Black racial groups of Africa. It includes people who indicate their race as "Black," "African American," or "Negro," or provide written entries such as "African American," "Afro American," "Kenyan," "Nigerian," or "Haitian."

American Indian and Alaska Native. A person having origins in any of the original peoples of North and South America (including Central America) and who maintain tribal affiliation or community attachment.

Asian. A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam. It includes "Asian Indian," "Chinese," "Filipino," "Korean," "Japanese," "Vietnamese," and "Other Asian."

Native Hawaiian or Other Pacific Islander. A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. It includes people who indicate their race as "Native Hawaiian," "Guamanian" or "Chamorro," "Samoan," and "Other Pacific Islander."

Some other race. Includes all other responses not included in the "White," "Black or African American," "American Indian and Alaska Native," "Asian," and "Native Hawaiian or Other Pacific Islander" race categories described above. Respondents providing write-in entries such as multi-racial, mixed, inter-racial, or a Hispanic/Latino group (for example, "Mexican," "Puerto Rican" or "Cuban") in the "Some other race" write-in space are included in this category. Estimates for years after 2000 reflect an allocation of this category among other categories.

Two or more races. People may have chosen to provide two or more races either by checking two or more race response check boxes, by providing multiple write-in responses, or by some combination of check boxes and write-in responses.

Race and ethnicity were considered separate and distinct identities, with Hispanic origin asked as a separate question. Thus, in addition to their race or races, all respondents are categorized by membership in one of two ethnicities: Hispanic or Latino, and non- Hispanic or Latino. Percentages for the various race categories add up to 100%, and should not be combined with the Hispanic percentage.

Hispanic or Latino. A person having origins in any of the original peoples of Cuba, Mexico, Puerto Rico, South or Central America or other Spanish culture or origin regardless of race. People who identify their origin as "Spanish", "Hispanic" or "Latino" may be of any race.

Non-Hispanic White. Individuals who responded "No, not Spanish/Hispanic/ Latino" and reported "White" as their only entry in the race question.

These definitions are from the Revisions to the Standards for Classification of Federal Data on Race and Ethnicity by the Office of Management and Budget (October 30, 1997). More information can be found on the Federal Register Notice: (https://www.whitehouse.gov/omb/fedreg_1997standards).

The following Census 2010 document also discusses race and ethnicity definitions in addition to population trends for each racial and ethnic group: http://www.census.gov/prod/cen2010/briefs/c2010br-02.pdf.