Meeting: CSTE Data Standardization –Social Determinants of Health -Data Element-Specific Team (DEST) Meeting
Date: November 15, 2024
Attendees: 73

CSTE (2)	PHAs (38)	CDC (26)
Becky Lampkins	DSWG Co-Chairs	Amanda Deering
Meredith Eddy	Judie Hyun | MD	Andrea Steege
	Laura Erhart | AZ	Angie Agunloye
JMC (4)		Carmen Pugh
Erin Kough	DEST Members	Chirine Chehab
Laura Lane	Alina Paegle | UT	Danielle Sharpe
Natalie Raketich	Christopher Dumas | SD	Hannah Perry
Sam Spoto	Devann Kirkpatrick | TN	Jessica Purser
	EJ klingler | NY City	John Gerstle
Other/Unknown (3)	Elizabeth Jump | San Mateo County	Josh Bagley | GDIT
Andre	Elizabeth Lando-King | MN	Kayode Olupinyo
Yasemin Kaynas	Erin Doyle | NJ	Kerry Souza
Yenling HO	Genie Tang | CA	Lauren Korhonen
	Hanna Chakoian | MN	Luis Hernandez | GDIT
	Isaiah Francis | NM	Marie Haring Sweeney
	Janet O'Connor | SC	Miriam Van Dyke
	Jazmin Diaz | CT	Myrna del Mar González | GDIT
	Jennifer Kwon | LA County	Nicolette Bestul
	Jill Krause | NB	Noreen Kloc
	John Satre | IA	Peter Boersma
	Karene Thomas-Watts | CO	Rachelle Oseni
	Kayleigh Nerhood | GA	Renee Boehmert
	Keely Wrolstad | WI	Robert Orellana
	Lakin Mauch-Kath | ND	Robert Pratt
	Linda Kelemen | SC	Sara Johnston
	Margaret liams | SC	Susan Carlson
	Maribeth Hoyle | OR	
	Mario Beltran | MI	
	Maya Scullin | OH	
	Meccah Jarrah | OR	
	Pyone Yadanar | WA	
	Sam Hawkins | OR	
	Sarah Love | Chicago DPH	

	Sequoia Rent | DE Stephanie Moberg | NM Steve "Ike" Eichner | TX Suzanne Gibbons-Burgener | WI Taylor Bednarz | Maricopa County Theron Huntamer | NV Tina Lopez | San Antonio Trish McLendon | CA	

**SOME INDIVIDUALS DIALED IN; THE NAMES ARE UNKNOWN, AND THEY ARE LEFT OFF OF THE ATTENDANCE*

HIGH-LEVEL MEETING NOTES (*REFER TO MEETING SLIDES FOR MORE DETAIL AS NEEDED*):

Social Determinants of Health (Call 4)

Meeting Ground Rules

- We welcome everyone's opinions and active participation from jurisdictions, CDC programs, CSTE membership, etc.
- As we work through data elements/classes, we strive for 80/20 consensus.
- This DSWG Post-Meeting Input Form is available at any time to provide additional input

Core Data: In-Scope for DSWG

- As a reminder of the scope of our work, we are to identify what data elements should be considered core data elements for transmission to the CDC. This is for routine, cross-condition, case-based surveillance.

Core Data: Out of Scope for DSWG

This data class has seen increased attendance from people who haven't been part of other DSWG calls before, which is great! However, this is a reminder of the things we are not doing on these calls.

- These recommendations that we are writing define what should be transmitted from a jurisdiction to the CDC.
- The wording and value set(s) we voted on here do NOT describe the best way to ask a question during a case interview or define how a data element must be worded within a jurisdictional surveillance system.
- The data elements we are discussing may come from a case interview, eCR, ELR, manual review of medical records, or a conversation with a healthcare provider.
- It's important to think about all the potential ways that case data are collected when we think about these data elements.
- The value sets we come up with on these calls also do not limit what can be collected within a jurisdiction. A jurisdiction may collect more detailed data and map those values into the value sets defined for transmission to the CDC. An easy example of this is that a jurisdiction may collect responses for various flavors of "Unknown," like "Refused to answer" or "Did not ask," but all those responses may just be sent as "Unknown" to CDC.

Core Data: FAQ

- When voting for core data, consider that naming something as core does NOT mean that it will be required to be populated for every case to CDC. It is okay to leave a field blank or unknown if the information is not available or not applicable to certain conditions. A data element should be considered core if it's relevant across many conditions, although there is no set number for "many."

CCCD

- The Calculated Case Counting Date was defined by the DSWG in previous work. It is defined as the earliest available of six component dates associated with a case.
    - These dates are listed on the right side of the slide and encompass a range between symptom onset through date the case is entered or recorded by the public health agency.
- The important feature of CCCD is that it is possible to calculate a value for it for all cases, even if all components aren't available for each case. Essentially, it is the earliest available epidemiologically relevant date for a case, which will often be the symptom onset date if that is something that exists or is known, but if it doesn't exist or is not known, there are other dates that can be used instead.

Background: SDOH – Education

Education: Why send it?

- This slide summarized the points that came up last week, in the November 8 SDOH call #3, for why jurisdictions should send educational attainment data to CDC.
- It can be used as a proxy for SDOH information, although since it is a proxy for SDOH, we must understand that on an individual basis, it won't necessarily correlate.
- It can also be used to help the CDC know who to develop communication materials for, which could potentially be a proxy for health literacy.
- For any potential analysis looking to dissect if the burden of disease is disproportionate according to educational attainment, having available denominator information to use is essential.
- Something else that came up last week is for certain scenarios that occur where different people with the same "level of educational attainment" as defined by the ACS survey but have differing job possibilities or earning potential based on further training programs or certifications or maybe more difficult coursework than others in the same category.
- For today's discussion the focus will be on finding a value set that can best be utilized by CDC for the purposes outlined here.

ACS vs. CPS vs NHIS

- Since denominator information is important for being able to use this data element in case notifications, this is a summary of the difference between the data sources that collect this information.
- CDC uses ACS as the gold standard for their denominator information, as its 5-year estimates can be used at the county level (which is not available from CPS or NHIS), the sample size is 3.5 million households per year instead of 100,000 or 35,000, and the ACS includes military and institutionalized populations.

Education: ACS Data Availability

- Census.gov provides access to ACS data, and the slide here shows the level of granularity available for educational attainment.
    - For the population between the ages of 18-24, there are only four groupings available- less than high school graduate, high school graduate or GED, some college or associates degree, and bachelor's degree or higher.
    - For ages 25 and up there are 7 categories- less than 9th grade, 9th-12th grade no diploma, high school graduate or GED, some college no degree, associate's degree, bachelor's degree, and graduate or professional degree.

Education: Certifications

- On the November 8 SDOH call, there was a lot of discussion on trade school or vocational certifications. So here we wanted to show how the ACS handles that.
    - Reading through a lot of technical documentation of the ACS, it's clear that a trade school certificate is not considered by the ACS to be "some college credit" and should not be counted.
    - An evaluation of how people with technical degrees responded to this question showed that it may be quite common for them to be reported in the categories representing some college credit or associate's degree, either because they believe it to be college credit or because they want to represent, they've obtained education beyond high school.
- When we think about this today it is important to note that the main takeaway from the background to is that in the ACS data available for us to use as a denominator, technical schools and certifications are not part of their value set. If we were to create a value for the DSWG recommendation for this category, it would make the denominator data not comparable.
- An assumption here is that, in general, people with a technical certification would respond to this question in similar ways for public health and for the ACS. If we had a separate category for technical or vocational school, trying to combine that category with a high school diploma for analysis would likely skew our data as not everyone in the group would have answered that way if the technical school wasn't a separate option.
- We also had some discussion about dual enrollment last week, and the ACS technical documentation didn't cover that situation at all. This is another instance of where we would assume that in general people responding to public health would respond in a similar way to the ACS.

Discussion: Education

Proposed DE: Highest Level of Education

- This is the value set that started all our discussion last week, the definition is the highest degree or level of school completed by the person at the first epidemiologically relevant date associated with the case (which is the CCCD).

ACS Value Sets

- In the spirit of "how is CDC going to utilize what is sent to them?" the discussion began with two value sets that represent what data are available from the ACS.
    - For the population over 25, there are 7 levels of granularity available and only four for ages 18-24.

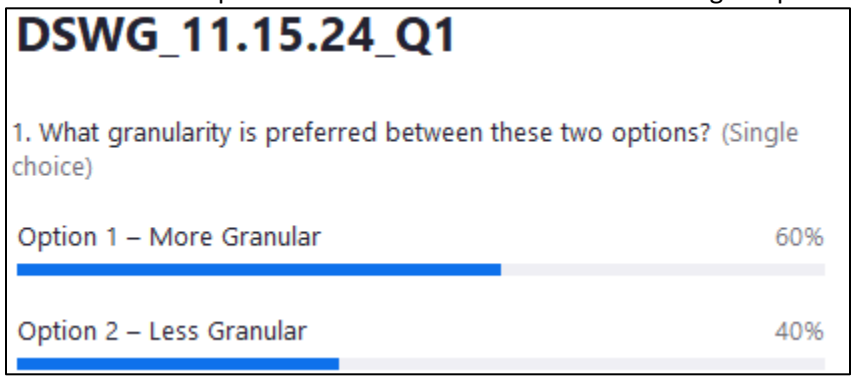
- We used these as a starting point to talk as a group about where granularity is useful in our public health data collection and where it's not.

Poll 1 (n= 35) – Education Value Set

- The first place these two value sets differ is for those with less than a high school diploma.
  - The first option is to have as separate values "less than 9th grade" and "9th-12th grade, no diploma".
  - The second option is just one value of "less than high school graduate."
  - For our public health use case, does anyone have thoughts on if one of these is better than the other?

Discussion for Poll 1

- Steve Eichner observed that 'Less than high school' could be a bit complicated, as different jurisdictions may have varying definitions of high school, whether from a structural or grade-level perspective. In some places, high school might be defined as grades 10–12 or similar rather than the more common 9–12.
- Chris Dumas voiced concerns about changing value sets at 25, as it complicates data aggregation. Consistency in value sets is important throughout the process.
  - Sam Spoto noted that she was not suggesting we change the value set based on age; that's simply how the ACS data are displayed. Regardless, the CDC can use the granular data for individuals over 25 or aggregate it for analysis down to age 18. Today, we're selecting a single value set, not varying it by age.
- EJ Klingler acknowledged a preference for the less granular options for most of these, considering the limitations of surveillance data. Using less granular data would likely improve accuracy and ease when reporting to the CDC.
- John Satre questioned ACS's rationale for these breakdowns.
  - Sam Spoto could not speak to ACS's rationale but noted they collect data at a more granular level. However, this is what's available if you're using an existing denominator.
- Sam Spoto moved the conversation to launching the poll.

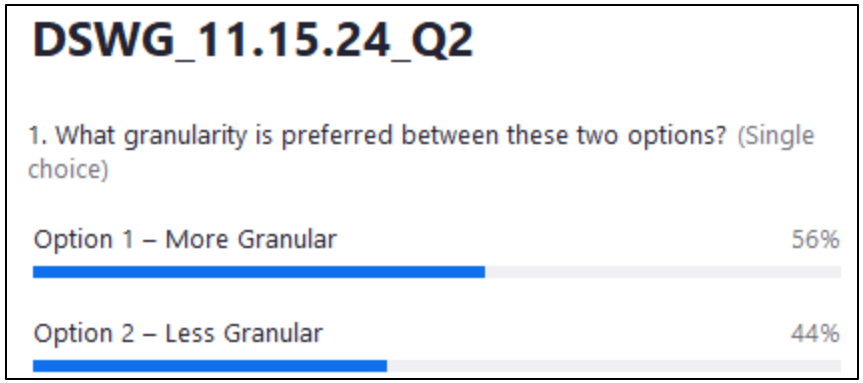


Poll 2 (n= 34) – Education Value Set

- The next discussion is for granularity for college or associate's degrees.
    - Option one separates these as "some college, no degree" (a description could be added here to be clear what is meant by the university) and then associate's degree separately, and
    - Option 2 combines these categories.
    - Does anyone have any thoughts here on what's useful for transmitting to CDC?

Discussion for Poll 2

- Steve Eichner noted that other certifications, such as those issued by a community college, can blur the line with an associate's degree. Some of this comes down to labeling—whether it's an associate's degree in criminal justice or a professional certification in the same field. The course requirements may be identical, but one is labeled as a degree, and the other is not. Further, those two are closely related and not necessarily mutually exclusive. For example, a nursing program might offer both a professional certificate and an associate's degree, counting for both categories.
- Suzanne Gibbons-Burgener felt that it's an implied hierarchy, some college no degree would be considered less education than an associate's degree.
- Sam Spoto acknowledged input in the chat for Option 1, which covers what's available for those under 25. The question hasn't been asked, and no information is available for it. However, Option 2 is available for those under 25. If you're analyzing that age group with more granular data, you'd just combine these two options. As for how associate's degrees are translated for foreign-born individuals, that's a great question, and any input here would be helpful.
    - Angie Agunloye replied that, typically, the concept of an associate degree doesn't exist in many countries. She is working on finding guidance, but the Census provides advice on selecting equivalent levels for certain post-secondary qualifications. As Sam mentioned, the questionnaire is much more detailed than the aggregated data. We must navigate those responses into broader categories to minimize disparities caused by international differences.
- Sam Spoto guided the conversation to remind the group that we're considering how the CDC might use and share this data for smaller states and areas. The more granular the data, the less likely it may be shared or used effectively, as smaller sample sizes could result in many 'NAs' due to stratification. Additionally, some individuals may have been educated outside the U.S., especially those who emigrated as adults, where education systems differ. As Jessica pointed out, a 2-year degree or certificate may be classified differently.
- Sara Johnston acknowledged that what was presented today clarified how ACS data is available, but she felt the previous presentation focused on how ACS data is collected, and there are some differences in that. She wanted to point that out and consider how it may impact things. Right now, ACS is publishing data in a combined format, even though the data was collected in a more granular way. She wondered if this difference could affect how people think about how we should collect data so that we have the flexibility to analyze it in the future.
- Sam Spoto moved to launch the poll to understand the group’s thoughts.

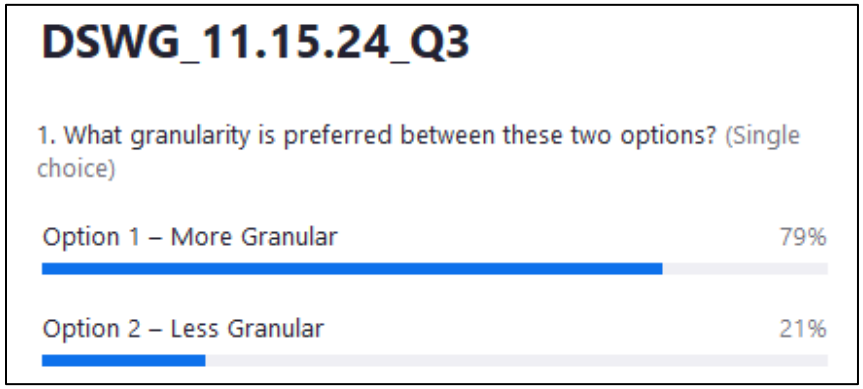


Poll 3 (n= 33) – Education Value Set

- The last difference between the two value sets is at the higher end.
    - Option one separates a bachelor's degree from a graduate or professional degree, and
    - Option 2 is just a bachelor's degree or higher.
    - It was asked if anyone has any thoughts on what distinction is useful for public health. When we think about our use? Cases of a proxy of social determinants of health, or as a measure of maybe how communications are going to be created for certain conditions.

Discussion for poll 3

- *No discussion was needed ahead of the poll*



Poll 4 (n= 40) – Trade/Vocational School Certificates

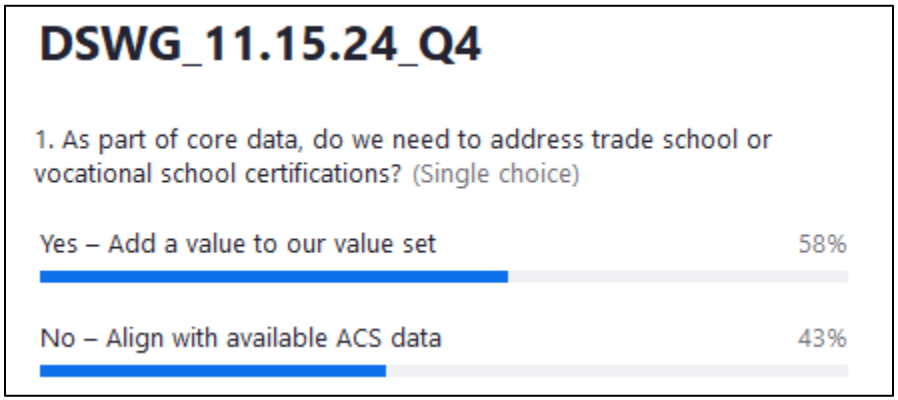
- At the beginning of the call, we shared how ACS handles trade or vocational certifications.
- There was also a lot of discussion about this topic last week.

- Here, we want to make sure to weigh the pros and cons of capturing something that we think is important and missing from current standards, but also make sure we collect data that can be analyzed in a meaningful way. We heard a lot from jurisdictions last week about how this category is distinct from a high school diploma
- What are the thoughts about the potential for analysis of this data element and if doing something different from the ACS here would be beneficial or not, as well as the potential analysis for this data element and using it in case notifications?

  Discussion for poll 4
  - Steve Eichner noted that, in general, it's better to focus on certification, trade, or location rather than the school-level component. The key is not which institution is providing the certification but the certification itself. There's a difference between looking at whether an individual has received a certification for a particular skill set and the institution that granted them that certification.
    - Suzanne Gibbons-Burgener commented that she felt Steve's comments are trying to distinguish between those who attend trade schools or vocational programs at institutions like community colleges and those who gain experiential learning and then sit for certification.
    - Steve Eichner clarified that it's differentiating between vocational programs offered by community colleges or universities rather than separate vocational schools.
  - John Satre was trying to interpret the options on the screen. He likes the ACS value set but didn't agree with the age break, as it doesn't seem meaningful. Someone under 25 may attain other levels of education, but they haven't yet, so the age break feels unnecessary. He wondered about the intent of this.
    - Sam Spoto responded that this isn't about an age break; it's about how the ACS displays data. We're choosing one value set that focuses on trade or vocational certifications that aren't considered associate's degrees or college education. The issue is that people with these certifications often respond either with a high school diploma or an associate's degree, depending on the individual. This creates inconsistencies in the data. The question is whether we need a separate value for these individuals, which would make us unaligned with the ACS data, or if we should align with the ACS's categories. The key question is whether there's a public health reason to separate this distinct level of schooling.
  - Chris Dumas noted that he believes things have changed significantly since the ACS first developed its value set. There's a growing focus on post-high school training, which doesn't always mean college or university. It often includes community college and other forms of training. As a society, we're increasingly realigning job requirements based on post-high school education. It's crucial to capture this distinction, as failing to do so perpetuates stigma against those with only a high school diploma. We have a responsibility not to reinforce this stigma.
  - Suzanne Gibbons-Burgener considered how the structure of education and related questions could help better understand occupation and industry, which they had expanded upon. While unsure if the ACS asked about this, she emphasized the importance of understanding the environments people work in, which was seen as crucial for public health. They noted that education often prepares people for work, which is linked to income, and that these elements are interconnected. They also reflected on those working in agriculture and the types of education they may receive without attending a university or college. The speaker supported setting a

standard and being proactive in including this additional education, even if it didn't align with the ACS at the time. They believed this could prompt the ACS to reconsider their questions in the future.

- Sara Johnston appreciated the last two comments and thanked those who brought them forward. She also thanked Sam for the analysis of how the ACS had evaluated the use of the fields, noting its importance for public health applications. While acknowledging that education level is not directly linked to illness, she emphasized the need to align with denominator data for proper statistical inferences about disease occurrence in the population. She supported the idea of promoting inclusion in the ACS and agreed that if the ACS made changes in the future, they could also make those changes. However, she believed it was important to align with the current process when using this data for public health purposes as a factor in the context of the population being studied.
- Sam moved to launching the poll for participant input.



Background: SDOH – Insurance

Health Insurance Coverage

- Different types of health insurance are often linked to various socio-economic factors, making insurance coverage a useful proxy for SDOH. Analyzing these connections can help reveal how insurance coverage interacts with factors like employment status, income, and geographic location, shedding light on health equity dynamics.
- The U.S. Census Bureau's surveys are national resources for tracking population-level trends in health insurance coverage and these include the ACS & CPS, and the Survey of Income and Program Participation, which provides longitudinal data on income, employment, government program participation, and health insurance status over time.
- In 2019, the NHIS began including health insurance coverage as part of its annual core in the Sample Adult and Sample Child questionnaires.
- References:
  - Health Insurance
  - Health Insurance Coverage in the United States: 2023

American Community Survey (ACS) & Health Insurance

- The ACS Health Insurance Survey Question is "Are you CURRENTLY covered by any of the following types of health insurance or health coverage plans? Mark "Yes" or "No" for EACH type of coverage."
- The valid responses include categories of insurance that capture if someone is insured through their employment, privately, or through various federal insurance mechanisms like Medicare, Medicaid, Military, or IHS.
- Reference:
    - ACS-1(GQ)(INFO)(2022) English

Case Notifications to CDC Message Mapping Guides (MMGs)

- The RIBD MMG is the only condition-specific MMG that includes an Insurance data element.
- This data element is a repeating element, meaning it takes a "select all that apply" approach and has a value set with the values: Incarcerated, Indian Health Service, Managed Care (Private), Managed Care Unspecified, Medicaid, Medicare, Military/VA insurance, Other, Private Health Insurance, Uninsured, and Unknown.

Discussion: Insurance

Proposed DE: Insurance Coverage Type

- The potential data element here is "Insurance Coverage" and is defined as a "Person's type of health insurance coverage". The value set can be compared with those defined by the Census Bureau surveys and includes options for private insurance, Medicare, Medicaid, Military (VA/Tricare), Indian Health Service, Correctional Facility Health Care Service, Uninsured, Other, and Unknown.
- For reference
    - Private insurance: Private health insurance is coverage by a health plan provided through an employer or union, purchased by an individual from a private health insurance company
    - Medicare: is a federal health insurance program for individuals who are 65 years or older, certain younger people with disabilities, and people with End-Stage Renal Disease. It has multiple parts (A, B, C, &D)
    - Medicaid: is a state and federal program that provides health coverage to eligible low-income individuals and families. Other forms of public health insurance may include the Children's Health Insurance Program (CHIP) and other state-specific public health programs for low-income residents
    - Military health insurance (such as TRICARE or CHAMPVA): refers to coverage provided to active-duty service members, veterans, and their families through programs like TRICARE and CHAMPVA
    - Indian Health Service: provides healthcare services to American Indians and Alaska Natives through a network of hospitals, clinics, and health stations operated by the IHS or tribes
    - Correction Facility Health Care Service: Refers to health care services provided by a correction facility while incarcerated or detained. Note: Someone who is incarcerated or detained can still bill Medicaid for certain services or may have their Medicaid coverage temporarily suspended. They might still be required to pay a co-pay to receive services

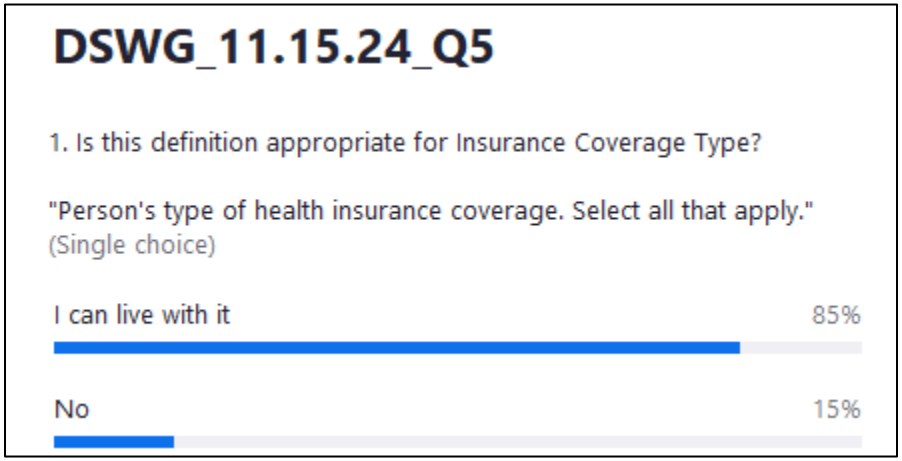
- Uninsured: refers to individuals who did not have any form of health insurance
- Other: includes any other form of health insurance that does not fit into the main categories listed above. It may include coverage through state-specific health programs, student health insurance plans, or temporary insurance options that don't fall under traditional private or public plans
- Unknown: Refers to individuals with insurance status that is not provided or cannot be verified.

- Does anyone have any thoughts on this definition or value set for insurance coverage or its utility to collect and transmit to CDC in case notifications?

  Discussion
  - Christopher Dumas reflected on a previous question about whether insurance was purchased through an employer. He noted that many people who buy insurance through the exchange end up with the same coverage as if they had purchased it directly from an insurance company. However, he pointed out that this distinction might confuse many constituents.
  - Sam Spoto called out a comment in the chat asking about the purpose of collecting this data and requested CDC input for how it could be used.
    - Marie Haring Sweeny emphasized that people without health insurance have less access to healthcare. At NIOSH, they wanted to know whether a person had health insurance, regardless of the type. She noted that this information helps identify disparities and provides insight into access to healthcare, health status, and other related factors, making it a very important variable.
    - Sam Spoto noted a comment in the chat from a local health department perspective: understanding insurance status helps identify disparities and who gets tested and for what. She also referenced Suzanne's suggestion that the core variable could simply be "Yes, No, Unknown," which could be another option to consider.
  - Steve Eichner highlighted the confusion between Medicare and Medicaid among respondents, noting inconsistent reporting in that area. He also emphasized the importance of clarifying the question prompt regarding "private insurance" by providing guidance on how the question is asked. For instance, specifying whether insurance is through employment, a spouse's employment, or purchased in the marketplace could help clarify responses. He also raised the example of a self-insured business, questioning how respondents should classify that as private insurance, other, or unknown. He noted that a relevant question for Medicaid is whether an individual is receiving SSI, as there is a correlation, though not a direct one. He also acknowledged that some individuals can be dual-enrolled in both Medicare and Medicaid.
  - Marie Haring Sweeny expressed that she wouldn't combine Medicare and Medicaid, as Medicare is primarily for individuals over 65, and there may also be differences in the quality and type of healthcare provided by each. She also had a question about what "healthcare service" referred to, as she wasn't sure about its meaning.
    - Steve Eichner clarified that individuals determined to be disabled by the Social Security Administration's disability determination services are eligible for Medicare after a 24-month waiting period, meaning Medicare is not exclusive to those over 65. He noted that while Medicare is typically targeted at older individuals, there is no specific age constraint, and people with disabilities are also eligible to participate.

- Suzanne Gibbons-Burgener explained that while the value set is useful, the focus at the state and local level differs. Public health typically collects insurance information in specific contexts, such as when providing services or facilitating access, not routinely for case investigations. For example, in Wisconsin, the state asks about insurance during tuberculosis investigations, primarily to determine eligibility for services like a special TB program. The goal isn't to analyze coverage but to determine access to care, as insured individuals are more likely to be diagnosed and reported to public health. She expressed curiosity about other diseases and wondered where collecting this information might be useful.
- Sara Love shared that the question about insurance is asked during investigations of potential rabies exposures, like how it's used for tuberculosis. Recently, they've discussed the challenge of not having the data to support campaigns or initiatives aimed at improving access to care. While it is known that insured individuals are more likely to be tested and reported to public health, the lack of data prevents making a strong case for wider testing or care access in underserved regions. She emphasized that at the local health department level, the data could help drive larger conversations and address disparities, but the absence of this information limits their efforts.
- Sam Spoto noted that there was a lot happening in the chat, and with limited time left, she acknowledged Steve's question about whether healthcare services in correctional facilities are considered insurance or should be more generally described as a healthcare provider. She suggested that this could be explored further after the call. Then, the conversation was moved to launch the final polls.

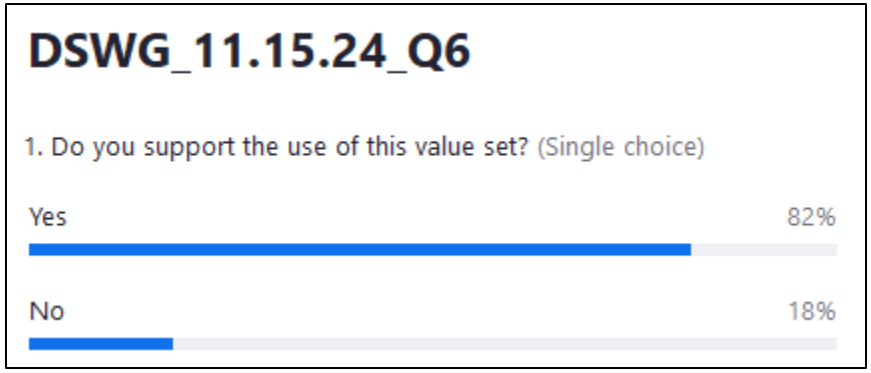
Poll 5 (n=34)- Insurance



Poll 6 (n= 33)- Insurance

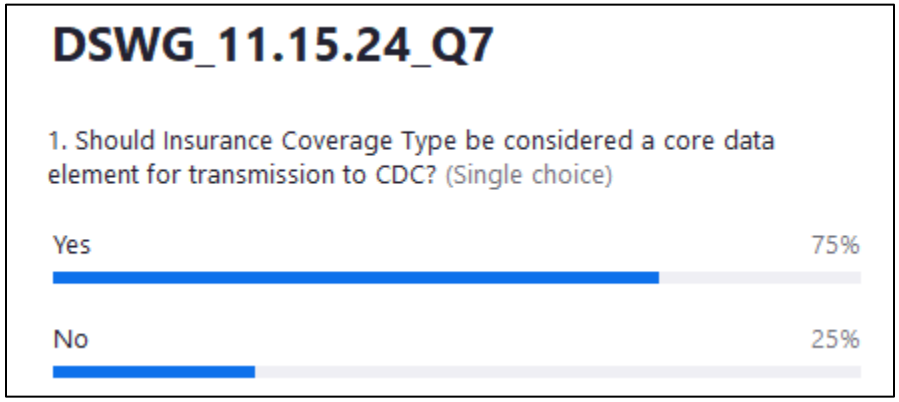
Discussion for Poll 6

- Steve Eichner pointed out that one missing piece in the value set was "other governmental programs." He highlighted the need to distinguish between different types of governmental programs beyond Medicare, Medicaid, military, and Indian Health Services, such as state programs or CHIP, which was also not included in the listed value set.
    - Sam Spoto mentioned that the team would work on the value set and include a poll with questions in the upcoming draft. The final question was whether this data should be considered core for transmission to the CDC.



Poll 7 (n= 36)- Insurance

- Finally, should this be a core data element across conditions for transmission to the CDC? This would mean there's a place to send this for all conditions to NNDSS, but it does not need to be filled in.



Next Steps

- This was the final call for the SDOH DEST. While income was not addressed as a core data element, it remains a topic the DSWG could revisit in the future.
- Look for a draft document for SDOH to come out shortly, incorporating tweaks to the value set based on the conversation, along with a poll to gather opinions on those changes.
- Currently, there are no more scheduled data element-specific team meetings.
- The next large DSWG call will be on December 13, 2024.