Meeting: CSTE Data Standardization – Immunization Data History -Data Element-Specific Team Meeting
Date: January 19, 2024
Attendees: 54

CSTE (1)	PHAs (31)	CDC (12)
Becky Lampkins	DSWG Co-Chairs	Abhilasha Saxena | GDIT
	Laura Erhart | AZ	Angie Agunloye | GDIT
JMC (7)	Molly Crockett | MA	Doris McGinness | GDIT
Erin Kough		Luis Hernandez | GDIT
Grace Mallard	DEST Members	Myrna del Mar González | GDIT
Laura Lane	Amy Lai |AZ	Allison Miller
Natalie Raketich	Brittany Martin | CA	Alphonso Rodriguez Lainz
Sam Spoto	Karene Thomas-Watts | CO	Chrissy Miner
Sara Sanford	Andria Apostolou | IHS	Lesliann Helmus
Susan Downer	Nora Kelly | IL	Noreen Kloc
	Jim Sainsbury | IN	Sandy Roush
Unknown Affiliation (2)	Lunden Espinosa | IN	Sara Johnston
Elise Balzer	Monique Birmiel | IN	
Hang Nguyen	Andrea May | KS	**ONC (1)**
	Jason Geslois | KS	Kathleen Tully
	Lamyaa Shaban | MA	
	Mario Beltran | MD	
	Ed Hartwick | MI	
	Mario Beltran | MI	
	Aaron Bieringer | MN	
	Hanna Chakoian | MN	
	Alison Keyser | NE	
	Jordan McBride | NH	
	Molly Yang | NJ	
	Isaiah Francis | NM	

	Emma Stanislawski | NM Amanda van Rest | NV | CDC Foundation Lea Moser | NV Theron Huntamer | NV Vajeera Dorabawila | NY Beth Isaac | NYC Rob Arciuolo | NYC Rob Laing | OR Greg Fowler | SC	

**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*):

Meeting Ground Rules and Updates

- 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.

Data Element-Specific Teams (DEST)

- DEST member expectations – members are not expected to write documents, lead meetings, or prepare slides. The goal is to keep members engaged in conversations around content during and between meetings.
- There is an expectation of active participation in polling, document review, discussion, and other input during and between meetings.
- **[Action Requested]** Please sign up for upcoming data elements on the DEST Sign-Up here.
- After SOGI, Immunization History, and Death wrap up, the next data elements will be
    - Exposure/Risk/Underlying Conditions
    - Signs/Symptoms/Clinical Manifestations

Core Data: In Scope for DSWG

- Focus on core data for surveillance for transmission to CDC within selected data classes.
- We will work to identify standard definitions and value sets within that definition of core data.

Core Data FAQ

- Identification as core does not mean it is required to fill in or send an answer for every core data for every case; it is okay to leave it blank or unknown. Thinking about immunizations, data would not need to be transmitted for conditions where immunizations are not relevant.
- Data, elements, and data classes should be considered core if they are relevant for many conditions.

- A good way of thinking of this is if we were to create a GenV3 MMG, would it make sense to include that data element here as core?

IMMUNIZATION HISTORY

Between Meeting Poll Summary: Immunizations

- Background will not be covered, but a summary of results from the previous meeting and polling will be addressed

Last Meeting…

- At our last meeting we discussed and polled on the data elements within the vaccine history repeating group to determine if they were individually core data elements for transmission to CDC as a part of case-based surveillance.
- Vaccine type, administered date, and manufacturer are considered to be core and easily met the goal of 80% consensus.
- Vaccine Dose number, lot number, and event information source had more than half the group voting for these elements as core, but did not reach the 80% consensus mark, and we will speak more about these today.

Poll Results

- When jurisdictions were asked about the ease of capturing IIS data within a case message to CDC, there were a variety of responses about the process being totally automatic or totally manual or somewhere in between, and whether the automation occurs for only a few conditions or all conditions.
- Then jurisdictions were asked to rank data elements on how easy or difficult it was to capture them in their surveillance system and send in a case notification message.
- Overall, it seems like the data elements in the Repeating Group are easier to capture and send, which makes sense if the information is being directly pulled from fields in the IIS.
- The Interpretive Vaccine Questions have generally higher averages (meaning more difficult to capture), with the easiest elements in that group being if the case was "Ever Vaccinated" and "Date of Last Dose Prior to Illness Onset". We will talk about this group more today.

DEST for Discussion

Discussion: Immunization

- First we'll address the interpretive group data elements that haven't been touched on yet. Then we'll revisit dose number, lot number and vaccine event information source. At the end, we may revisit any interpretive group elements for more discussion that landed between 50-80%

Interpretive Group

- The Interpretive Group is broken into three sections to keep discussion on track. This interpretive group is not a repeating group of elements as it conveys summary information about someone's vaccination status as a whole rather than information about individual vaccine doses.
- First we will talk about the data elements in yellow. These convey if and how long ago a case was vaccinated for a condition.
- The second group in blue conveys if the case was vaccinated according to ACIP recommendations. Some jurisdictions find these easy to fill in, but others have expressed that they are more complicated to try and apply interpretation of the recommendations.
- The final data element in orange, and all by itself, is Vaccine History Comments, which is a free text field.

Interpretive Group (2)

- Starting with the first group of three, does anyone have any thoughts on whether these three data elements are important as core or not? At the jurisdictional level are there any complications or issues with collecting any of these?
- Alison Keyser: Did the subject ever receive a vaccine for this disease? I think for us in Nebraska, it would be easy for kids. Receiving feedback from health departments, it is much more difficult to get vaccine history from adults than kids and our immunization system is not required to report into. So we do miss vaccines that are administered if the person administering the vaccine doesn't report into our immunization system – it's not (2 likes from people)
- Sam Spoto: So trying for fill this out from information in an IIS might be difficult and thinking about that in terms of what is core… so far, what's been voted as core is the vaccine type or CVX, the admin date and thinking about that type of information – it's really conveying information about a vaccine event. Is it important to have a question like the first one listed, "did the subject ever receive a vaccine against this disease?" You're able to convey "no, they were not vaccinated." Whereas if you know someone's not vaccinated, does a lack of information about vaccine type and admin date convey that they're not vaccinated or that we don't know if they're vaccinated or not? Or that there might not be that information in the IIS. So, does anyone have any thioughts of this being important or unimportant based on that idea?
- Chat:
    - Alphonso: I am sorry if this has been already discussed but what about recording of foreign immunization records? There is an increasing share of foreign-born persons residing in the US and every year millions of foreign citizens migrate legally to the US for work, study, refugee, or other reasons.
    - Emma: The number of doses prior to illness onset is the iffiest one: it's usually based on however many doses that person has in our IIS, and will be limited for adults whose childhood doses predated the IIS...but it's easy to get the information that is already in there
    - Rob: What's the advantage of states providing this interpretive info vs. CDC calculating it from the core data elements?
- Sandy Roush: So for Rob's question, for the vaccine history or the immunization history components, so the interpretive section and they the repeating group section, back in the beginning of the design of each of our VPD MMGs there was and there still is documented quite a bit of diversity between the jurisdictions. A large group in both directions, some who said "we're not going to be able to do completed vaccine date type manufacturer from IIS kind of level of specificity, but we will send our preferences to send interpretive information so any or none or were they vaccinated according to guidance. So Rob, the instructions that are with the guides indicate that it's not intended for jurisdictions to do both, that they can go interpretive or go repeating group specific – whichever is their pleasure. Keep in mind that some of the questions wouldn't be duplicative in each jurisdiction, it would allow jurisdictions in both directions to be able to submit the relevant kind of information.

Interpretive Group (3)

- Next are these two data elements regarding ACIP recommendations (Vaccinated Per ACIP Recommendations, Reason Not Vaccinated Per ACIP Recommendations). Does anyone have any thoughts on whether these two data elements are important as core or not? At the jurisdictional level are there any complications or issues with collecting any of these?
- Reviewed slide "Reason Vaccine Not Given"
- Laura Erhart: we've struggled with being able to fill these out and feel good about filling these out. I think the "vaccinated per ACIP recommendations" works fine…if you're talking about a young kid. But this gets complicated as soon as you start looking at people that are a

little farther away from the vaccine recommendations: “what period of time?”, “How do we do this?”, “Which recommendations apply?”. I know we’ve struggled with, “Are we doing that one appropriately?”, ”Is that information useful?”, “If we’re not all consistent as well as if we’re sending in the vaccine dates, then is that duplicative?”. The “reason not vaccinated”, we’ve struggled to get that information, it’s often not available. There’s some utility in knowing “religious exemptions or philosophical exemptions” but a lot of times we’ve just not been able to have good data on that one.

- Rob Laing: I agree with Laura, this is also easier for clearly defined vaccine-preventable diseases than those w/o schedules or follow-up with the patient is harder to do b/c this is not something we necessarily get from the IIS. So it gets more difficult to consistently populate these fields with reliable data.
- Beth Isaac: I just wanted to clarify, if a jurisdiction is completing their vaccination information in the repeatable blocks to find doses then we could opt out of these questions. If those actual doses are available then the most standardized way of putting these data together would just be the doses and then you have one sole calculation of whether or not they’re vaccinated due to ACIP recommendations.
    - (Sandy in chat: That’s correct Beth)
- Jason Geslois: RE: slide Reasons Vaccine not given, It’s great having all these options but when those are listed as “unknown” or “other” it may hurt data quality from this perspective
- Chrissy Miner: IZ devision, in charge of HL7 implementation guides that EHRs use to submit to IIS. This value set is not in alignment with what’s in the implementation guide for what EHRs can submit. It has a smaller subset of only 4 values (1) Parental Decision, (2) Religious Exemption, (3) Other, and (4) Patient Decision.
- Laura Erhart (chat): Asking about the reason not vaccinated can get tricky in the context of talking to a family with a sick kid, for example.

Reason Vaccine Not Given

- **Shared in reference to previous slide**

Interpretive Group

- Finally, does anyone have any thoughts on whether this last free text data element of Vaccine History Comments is important for sending to CDC?
- Laura Erhart: we don’t transmit comments b/c free text could have anything in it and we don’t want to send those w/o a value set, not recommending we add a value set
- Molly Crockett reiterated what Laura said
- Ed Hartwick (chat): We wouldn’t send comments either
- Chrissy Miner: Similarly, with EHRs to IIS and the implementation guide, we are evaluating taking away the option of sending in vaccine comments. That piece of info may no longer be transmitted if this update is made.

Polling Process

- Now we're going to poll on the data elements within the vaccine history repeating group. The goal is to reach 80% or more agreement on a data element as core or not core while identifying and discussing any major points of dissension.

Core Data FAQ

- When voting for core data elements, consider that naming something as a core data element does NOT mean that it will be required to be sent for every case to CDC. It is okay to leave the field as blank or unknown if the information is not available or not applicable to certain conditions. Naming immunization related data elements as core does not mean there would be data to transmit for conditions where immunizations don't exist. Consider "should these data elements be transmitted in the exact same way for all conditions where immunizations are relevant?"

Poll 1 – Interpretive Group

- Poll Question: Select all of the data elements that should be considered core data elements.
- Options: Did the subject ever receive a vaccine against this disease?, Vaccination Doses Prior to Illness Onset, Date of Last Dose Prior to Illness Onset, None of These
- **See results here**
- "Did the subject ever receive a vaccine against this disease?" passed threshold for "core"

Poll 2 – Interpretive Group

- Poll Question: Select all of the data elements that should be considered core data elements.
- Options: Vaccinated per ACIP Recommendations?, Reason Not Vaccinated per ACIP Recommendations, None
- **See results here**
- Neither data elements passed the threshold for core, decision to conclude discussion about these.

Poll 3 – Interpretive Group

- This final one is a simple Yes/No, for the final data element of Vaccine History Comments. Does anyone have any questions before we launch this poll?
- **See results here**
- No was the majority response.

Remaining VHRG Elements

- Today we will go through these previously discussed repeating group data elements one at a time, I will summarize the thoughts from the poll, allow for additional discussion, and then poll again. Feel free to change your mind from last month. Any data element this week resulting between 50-80% will be included as a core data element "with weak support" from the group, as previously done with some of the hospitalization data elements.

Vaccine Dose Number

- For Vaccine Dose Number, only two poll respondents indicated dose number should be core, highlighting that this concept is important to understanding if someone has received all the doses to confer full immunity. There were 8 Nos and 2 Maybes. Many people mentioned the data were difficult to ascertain and interpret or that they've had issues with the calculations being incorrect and the data not being trustworthy. Two responses touched on opposite ideas of the same topic, where one mentioned that EHRs must send the dose number to the IIS so not all IIS systems are able to handle calculating it on their own, and another response said it can be calculated differently by different IIS forecaster engines. A few responses mentioned that it can just be calculated by CDC.

- Does anyone have anything they'd like to add to this summary of the responses for why dose number should or should not be considered a core data element for transmission in case notifications to CDC?
- Noreen Kloc: As sandy presented there could be an option that either jurisdictions fill in the interpretive or they send the raw data but if we don't have the dose number we still can't calculate whether or not the full vaccine has been administered. So we would need this as part of the calculation and I wondered if any of the jurisdictions that felt they could not send this if they could give more information on why it's not possible.
- Beth Isaac: I wanted to understand your question a bit more. As I understand it, if jurisdictions are only completing the interpretive section and don't have the actual dose information, and they would not be completing this field. But if they are completing this field, then they should also be including the dates of the doses, so therefore that could be calculated.
- Noreen Kloc: There are two options, but if jurisdictions are choosing to the raw data, then I feel dose number would be important to calculate whether the vaccine has been administered per ACIP. So I feel it's an essential piece of information and especially being in a repeating group. If it's not part of core then it would be really hard to have one data element as an outlier within the condition specific guide.
- Chrissy Miner (chat): Just wanted to clarify that dose number is not something EHRs send to IIS.
- Rob adds to what Beth said: would require some actual assessment of dates anyway, so us (jurisdictions) putting in dose number may not be as useful as a more standardized approach to analyzing the dates that are received.
- Noreen Klock: so you would view submitted vaccine date and all of the dates in the repeating block would be the way to go

Vaccine Lot Number

- For Lot Number the responses were more evenly split. Seven poll respondents indicated dose number should be core, highlighting that this concept is important to understand if there is a problem with a specific lot of vaccine or if cases are being identified in relation to a recall, or could be used as part of a QA check for the CVX and MVX information. These Yes responses did still note limitations with data quality and availability.
- There were 5 Nos with people also mentioning the data were not consistently reported. Different themes about necessity also arose, such as it's not needed in most case investigations or not related to an individual's vaccination status, and it's only needed in circumstances of special studies or investigation of outbreaks.
- Does anyone have anything they'd like to add to this summary of the responses for why lot number should or should not be considered a core data element for transmission in case notifications to CDC?
- Sandy Roush: NCIRD surveillance office in the MMG has prioritized lot number as 2, which is great to have but not a high priority in particular b/c not all repeating group data comes directly from an IIS, comes from an extract of chart itself or school record. The use of lot number would be if there seemed to be a problem but not for general passive national surveillance vaccine history. The program and the current MMG does not rate it as highest priority – if that's equivalent to being "core."

Vaccine Event Information Source Value Set

- A list of concept codes and concept names is provided. These are used to communicate where the information about the vaccine event being reported came from

Vaccine Event Information Source

- Again we have a more even split. Five poll respondents indicated vaccine event information source should be core as it's important to understand the reliability or credibility of the data. Once again these Yes responses did still note limitations, as not all IIS collect this information and not all EHRs transmit it with a consistent value set.
- There were 6 Nos with people also mentioning those same limitations. Again themes about necessity arose, like jurisdictions should only be transmitting vaccine information they have already deemed is reliable, this information is not tied to public health interventions or outcomes so it should not be core, or that the dose information isn't accepted or rejected based on this field.
- This is the data element that scored highest in our polls last month, and was one NCIRD considered important for core. Does anyone have anything they'd like to add to this summary of the responses for why vaccine event information source should or should not be considered a core data element for transmission in case notifications to CDC?
- Rob Arciuolo: Sometimes data sources are multiple, how would you apply that in this question? The bulk of info comes from IIS, lot and manufacturer is filled in manually. Does this apply to all of the questions in the block or just specific to vaccine date?
- Sam Spoto: So where did this information come from, if you're filling in different elements within this repeating block from different sources, how do you answer this question?
- Aaron Bieringer: requests to go back a slide to values. As IIS we are instructed to report out historical information markers on all vaccination info we send out. So if you're trying to use this as an indication between administered and historical and you're using the IIS as a source of data, you should be getting all some flavor of historical and then you lose the possibility of administer. I don't know if anyone wants to take that into consideration, but if everyone in the chain is doing what they're supposed to be doing, you'll just be getting different version of historical.
- Sandy Roush: I wanted to point out that quite often it is a goal that the repeating group can be ingested from IIS, but it is not true for all jurisdictions. And so, remembering that vaccine event information may also be entered but during the investigatory effort (came from parent, came from school record, etc.) I agree that not all IIS collect this information and I would encourage a group not to be concerned that this would be a reason not to call this core b/c quite a bit of this info comes from the epi in the county who can gather it elsewhere. The application of this information is indeed to give the epis/investigators a sense of whether data lines up in the investigation. The validity and strength of confirmation is the main point of inclusion for this information and was actually a part of including it int the current guides as part of the highest priority data element list and copied directly over from IIS component.
- Emma (chat): The reliability of a person's vaccination history could become relevant to a public health outcome. For example, there's a significant difference in whether a person's MMR history is based on parent recall, a handwritten vaccine card in another language, or was entered directly into our IIS at the time of administration.
- Beth Isaac: This conversation is just making me think that I wonder if there have ever been any conversations about uniformity around which doses get reported to CDC in terms of the source. In NYC we only take and report out doses that we have documentation of. I think that what you've been saying in terms of being a marker of how much we trust these data is important but it's complicated to collect.
- Sandy Roush: I agree that the guidance from NCIRD is absolutely just to report and rely on only the appropriately documented. Unfortunately that doesn't happen completely uniformly across the country. But yeah, the guidance is very strongly stated that the only appropriate vaccine history is something that is documented appropriately good, when deciding whether to give a vaccine or not.

Poll 4 – VHRG Redo

- Poll Question: Select all of the data elements that should be considered core data elements.
- Options: Vaccine Dose Number, Vaccine Lot Number, Vaccine Event Information Source, None of These
- **See results here**
- Vaccine event Information source met threshold for core while other two did not reach 50% and will not be included.

Re-Poll?

- Reviews color association of data elements for interpretive group with results. Question to Laura about discussion, another call, polling.
- Laura: not sure another meeting is worth it, can address via a follow-up poll.
- Sam Spoto: I'm not sure we'd have enough engagement in a follow up poll to be valuable, we could include in the document noting weak support.
- Laura Erhart: I like that approach

Impromptu Poll 5?

- N/A

Potential data elements related to immunization

- Here is a reminder of the list of immunizations related data elements compiled from MMGs and other standards. In this case we have actually in depth discussed most of them and those have been crossed out. I did add on here dose validity and provider organization type that someone had brought up in the poll. Next we're going to do one final poll on if any of these shown here, or anything you might know of from your jurisdiction that's not on this list should be further discussed as a potential core data element.
- Reviewed in between poll information

Poll 6 – Additional Immunization Elements

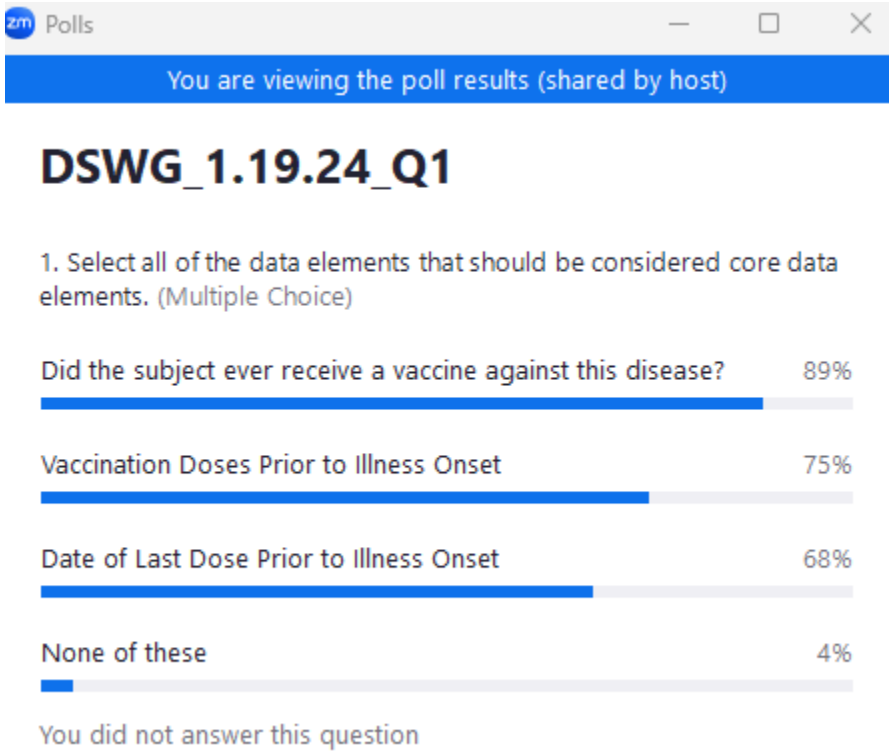
- **Poll Question: Are there any other immunization related variables that need to be further discussed as recommendations for core data for surveillance?**
- **Options: Yes, No**
- Results were a resounding "No"

Next steps

- We'll send out the draft Immunization History Core Data Elements document for review.
- There are two upcoming new DEST meetings:
    - Exposure/Risk/Underlying Conditions, 2/9 1-2 pm ET
    - Signs/Symptoms/Clinical Manifestation, 2/16 1-2 pm ET
- The next full DSWG meeting is scheduled for February 23, 2024.
- Sign up for upcoming data element-specific teams in the interest form here
- Additional input is always welcomed between meetings from DSWG members on the form located here.

Polling Results

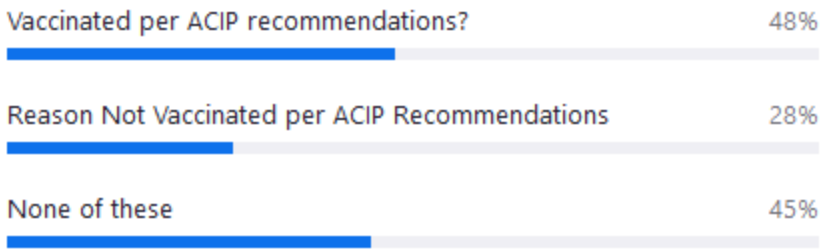
Poll 1 (n = 28)



Poll 2 (n = 29)

DSWG_1.19.24_Q2

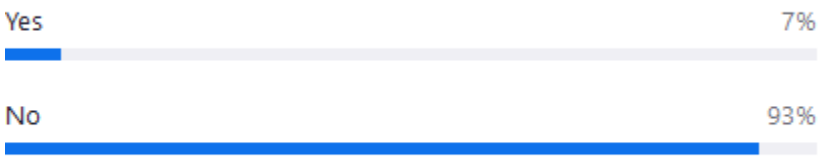
1. Select all of the data elements that should be considered core data elements. (Multiple Choice)



You did not answer this question

Poll 3 (n = 29)

1. Is Vaccine History Comments a core data element? (Single Choice)

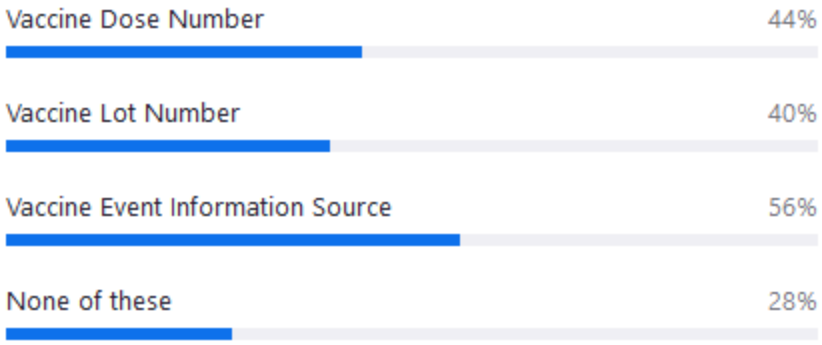


You did not answer this question

Poll 4 (n = 29)

DSWG_1.19.24_Q4

1. Select all of the data elements that should be considered core data elements for cross-condition transmission to CDC. (Multiple Choice)



You did not answer this question

Poll 6 (n= 19)

1 = Yes, 18=No