

Meeting: CSTE Data Standardization – Identifiers -Data Element-Specific Team Meeting

Date: May 17, 2024

Attendees: 73

CSTE (3)	PHAs (35)	CDC (30)
Becky Lampkins Gillian Haney Meredith Eddy	<u>DSWG Co-Chairs</u> Laura Erhart AZ Molly Crockett MA	Luis Hernandez GDIT Myrna del Mar González GDIT Shawn Arshad GDIT Angie Agunloye Desiree Mustaquim Erin Miller Hailey Vest Heather Clayton John Gerstle Julie Vanderkolk Katherine DeBord Lauren Korhonen Lizzi Torrone Melissa Pagaoa Meeyoung Park Nicole Gallaway Nicolette Bestul Noreen Kloc Peter Boersma Peter Daly Rachelle Oseni Renee Boehmert Samantha Retzloff Sandy Price Sara Johnston Shaoman Yin Shelby Lyons Sonia Singh
JMC (4) Erin Kough Grace Mallard Sam Spoto Sara Sanford	<u>DEST Members</u> Morrow Toomey AK Melissa Kealey CA Saumya Rajamohan DC Kayleigh Nerhood GA Shawna Stuck GA John Satre IA Luis Vela ID Andria Apostolou IHS Kristin Goldesberry IL Nora Kelly IL Lunden Espinosa IN Heather Elder MA Hollie Sheller MO Aaron Bieringer MN Elizabeth Lando-King MN Hanna Chakoian MN Jesse Ellis MS Kristen Merrell MT Stella Tsai NJ Annaliese Mayette NM	
Unknown Affiliation (1) Anne McIntyre		

	Isaiah Francis NM Benjamin Schram ND Theron Huntamer NV Beth Isaac NYC EJ Klingler NYC Rob Arciuolo NYC Rob Laing OR Michael Eberhart PA Kacee Redden SD Steve Eichner TX Sophia Cantor WA Misty Johnson WI Suzanne Gibbons-Burgener WI	Walter Alarcon Yuritzzy Glez Pena
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**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):

DEST Opportunities for Participation

- DEST sign-ups are ongoing.
- **[Action Requested]** Please sign up for upcoming data elements on the [DEST Sign-Up here](#).
- Upcoming data elements
 - Disability
 - Identifiers (Case/Event Related/Laboratory)
 - Medication/Treatment
 - Laboratory
 - Race/Ethnicity/Tribal Affiliation
 - Social Determinants of Health
 - Reporting Source
- DEST member expectations—members are not expected to write documents, lead meetings, or prepare slides. The goal is to keep members engaged in conversations about content during and between meetings.

- Active participation in polling, document review, discussion, and other input during and between meetings is expected.

DSWG Reminders

- The next general DSWG Call is on June 28 at 1 pm ET

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.

In-Scope vs Out-of-Scope

- Focus on core data for surveillance and transmission to the CDC within selected data classes.
- We will work to identify standard definitions and value sets within that definition of core data.
- This is not a discussion of how to collect this data, frame questions in surveys or interviews, or implement these data standards. This is also not meant to impose limitations on how jurisdictions collect data.

Identifiers Structure

Identifier Data Type

- Within case data, there are a lot of different identifiers connected to a single case. Currently, within MMGs, identifiers are captured as discrete data elements, such as the identifiers from the generic v2 MMG show on this slide. While this approach can clearly describe what is requested, it does not allow for any flexibility or for easily adding new identifiers. For instance, if a new identifier is needed in an emergency response, the addition would require OMB approval and a version update to the MMG, a process that can take months to complete.

Potential Identifier Structure

- We'd like to receive feedback on a proposed approach for more flexibility in capturing identifiers within MMGs. This approach involves capturing identifiers using a repeating group, with data elements that capture the type of identifier, the unique value, and the assigner.
 - Identifier Type would have a defined value set. This could include things like the legacy case identifier on the previous slide, or new identifiers we haven't touched on yet like an outbreak ID, birthing parent's local record ID, or possibly even IDs like WGS ID Number.
 - The second element called "Identifier value" captures the actual ID value
 - The final "Identifier assigner" element is a way to denote who assigned the ID, possibly sent as a text field, a coded field, or as a universal identifier.
- In practice, this could look like the example presented here. The first OBX segment transmits the identifier type of NORS ID (or CDC's National Outbreak Reporting System), the second transmits the identifier value of EIP1234567, and the third indicates that it was assigned by CDC. In some circumstances, the first description may make it clear who is assigning the ID, and thus the third

value for assigner might not need to be specified. In other examples, such as laboratory IDs or case IDs, it could be helpful to include who is assigning the ID. For instance, when transmitting a legacy case identifier there would be a place to specify which system assigned that legacy ID.

- This approach allows for IDs to be formatted consistently and included in one central spot. It also allows for IDs to be more easily added to MMGs, which is important in times of emergency response. The addition of a value to a value set takes days and doesn't require jurisdictions to go through a formal onboarding process, whereas adding a new data element to an existing MMG can take months.
- This approach would exclude local record ID and patient ID, as those are already required to be included in every message in their own specified HL7 fields.
- We'd like to hear now from you all:
 - If jurisdictions would like to send IDs in a repeating group like this, or is it preferred to map to discrete data elements?
 - Would this structure be beneficial for routine IDs used across conditions, or only ad-hoc IDs?
 - Other general comments?
- Discussion
 - John Satre: We currently receive IDs in the standard HL7 2.5.1 message. Typically, they're contained in one field in one segment. So, any reason why you've thought of going this route?
 - Sam: The IDs we're talking about for this potential new structure would not be the first 2 in the last slide that are sent in those PID 3 or OBR 3 fields. The way messages are currently sent to NNDSS there are other IDs in the current generic V2 and the other IDs that we're going to talk about today that would not have specific place within an HL7 message. They're just sent as their own OBX segments currently.
 - John: This is in the context of case notification right? (Sam: yes) Okay
 - Suzanne: First, I'm thinking that this repeating option, we've used this in some of our other elements and it has allowed for some level of flexibility because each disease or condition that may be reported may have more or less of these identifiers potentially. And I can see the use, sometimes we call it cluster ID and sometimes we call it outbreak ID if it rises to that level. I know it's been difficult to pass along, even between our state laboratory and public health. That's been a challenge in itself. So if we can come up with a way that we basically reserve a section of the message for whichever ones are relevant for the particular condition, this seems the cleanest way to go. I'm interested in hearing from other places if this would be challenging to standardize across their conditions. I'm in favor of this route as long as we're very clear what is the definition of the particular ID that's being requested. Probably on that Identifier type we would have to provide more guidance on what meets the identifier type.
 - Sam: We are going to talk about defining some core identifiers as things that should be prepared to be collected and sent across conditions that could apply to many conditions. But then this structure does also allow for a particular condition if there's an ID that's really only applicable to that one, adding additional values into that identifier type value set for those conditions.

- Gillian: When you're talking about repeating structure, so you're thinking one identifier data element that would be listed with a corresponding Specimen ID, Case ID, Event ID that would then be repeatable?
 - Sam: The first value would be a coded value and have value set associated with it, and then in a message you could send a segment with identifier type like we have here, sent as the NORS ID, the value is EIP and then the assigner is CDC with the repeating group structure. You could then send another set of 3 OBX segments where the first one is a different identifier type, a different identifier value and a different assigner.
 - Gillian: got it
- Gillian: So I understand that you could have multiple IDs within a certain OBX segment, but how would you have a 1 to many relationship, and would we need to create a one to many relationship when sending data to CDC?
 - Laura: Are you thinking one record multiple identifiers?
 - Gillian: Specifically having one person, multiple event IDs or multiple specimens associated with a single event.
 - Laura: I also think we could have guidance from CDC, presumably about what kind of identifiers we'd want here, and so as everyone's been discussing that there's multiple things brought up, I don't know if all of those would go into the structure or not. But I think this could be used in contrast to the previous slide that had four identifiers within the current gen V2, and each of them have their own column to be able to send data. This could give us the flexibility for any given case there could be multiple identifiers, and they could be different identifier types for different conditions, different cases, however many variations you need. So maybe for one record you don't have anything that goes in here, maybe for a different record you have a NORS ID as well as a local outbreak identifier and both of those could be in here within their own repeating group. We could potentially add in whatever other identifiers it's about.
- Suzanne: We're talking core transmissions, we're not talking enhanced surveillance and providing all the data so I really see the programs identifying at CDC what's critical for any given disease. Generally we don't send multiple lab results, if any, in the Gen V2. So it's some basic stuff. That's why we always have an event or certain dates that we have decided are part of the core. So in this situation we recognize that in a core message there could be some variability. So this is clean way to customize it to a particular disease, whether a cluster is relevant. So do we reserve in the message this spot that would only hold a cluster ID or do we have flexible placeholder for it is what we're deciding.
 - Sam: yes with the first part we're discussing here, structure. We are going to talk about some specific IDs as core after this that might go as a minimum value set for that identifier type field – the handful of things that we should be prepared to transmit across conditions. But that could be added too for specific conditions that have certain IDs associated with them. I see a lot in the chat about lab IDs. We're not going to talk about lab IDs today. As you know there are a set of IDs associated with a laboratory result that might be attached to a case and those would stay part of a laboratory result, not part of this type of structure. This is really just for identifiers associate at the case level, not at a lab level b/c Julian's correct, one case might have multiple labs associated with it. Next month we will talk about potential ways to link labs and case information for labs sent to CDC, and maybe this has a role there, but we're not going to talk about that today.
- Chat

- Hanna Chakoian: Agreed, Suzanne!
- Melissa Pagaoa: The national jurisdiction that is associated with the identifier value should also be included in these data elements
- Laura Erhart: I believe there would be guidance about what kinds of identifier types we would want PHAs to send using this structure (rather than up to each jurisdiction to figure out what we want to include)
- EJ Klingler: And since the difficulty in coding grandchild vs child and questions was brought up before, the value and assigner would only be children, right?
- Misty Johnson: But I think the Outbreak ID will go somewhere else, not here.
- Gillian Haney: but I could see sending multiple labs in the future associated with a case notification.
- Misty Johnson: Maybe I'm wrong, but I don't think lab IDs would go in this repeating group...it would remain with the lab repeating group...
 - Peter Boersma: Agree. Something like specimen ID that could refer to many lab results would be best kept within lab repeating group where it is clear which result it is referring to

Polling process

- Each poll question today will have it's own slide, and today the answer choices are really going to vary by question. For the polls where we are asking if something is core or not, the goal is to reach 80% or more agreement, and ideally have additional discussion when not quite there.
- Data elements that receive at least 80% agreement are considered resolved with “strong support”. If for any questions we can't reach the target agreement of 80%, but still more than half the group is in agreement, these points have been included in previous recommendations as having "weak support".

Poll 1 – Identifier Structure

- I think we're going to take feedback today and tweak the new structure, particularly thinking about the assigner field, and come back to this topic on the next call, but we wanted to get a pulse check today about how the group is feeling about this potential new structure. Does anyone have any questions before we open this poll?
- Discussion
 - EJ Klingler: (hard to hear)
 - Sam: She was talking about how we previously had conversations about difficulty coding grandchild versus child questions and she's right with this structure here, both of these second questions would just be dependent on identifier type and not necessarily the value.
 - John Satre: Is the second segment, the Identifier value itself, is that a typo for OBX 5 or is that supposed to be in CWE format within a triplet format. (Sam – yes that is a typo)
 - Chat:

- Melissa Pagaoa: For conditions that link maternal cases to infant cases, is this how the potential identifier structure could be used: Identifier Type: Maternal Identifier Value: Maternal Case ID (123456) Identifier Assigner: National Reporting Jurisdiction for Maternal Case (Pennsylvania)
- Poll Question: What would your preference be for the structure of sending identifier values? (Excluding local subject ID and local record ID)
- Options: Discrete Data Elements | Repeating Group

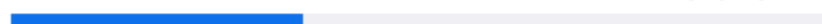
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Poll | 1 question | 28 of 65 (43%) participated

1. What would your preference be for the structure of sending identifier values? (Excluding local subject ID and local record ID.)
(Single Choice)

28/28 (100%) answered

Discrete data elements (10/28) 36%



Repeating group (18/28) 64%



Potential Core Identifiers

- Next we're going to move on to talking about specific identifier data elements.

What does it mean for an identifier to be core?

- First I'd like us to all be on the same page about what it means when we call an identifier a core data element. A core identifier should be something that would be capable of being transmitted across conditions when needed. For instance, it's very clear that each case requires a unique ID to be identified as a unique case, so this value will always be present. However, something like an "outbreak ID" would rarely be present, but if core then a jurisdiction should be capable of capturing/sending that field across conditions. When we define an identifier as core, we are saying that jurisdictions and CDC will be prepared to transmit and receive that identifier across conditions when applicable. We can think about what we're defining as a minimum value set, or minimum set of identifiers, for what jurisdictions are prepared to send.

- There may be additional identifiers that are needed on a condition-specific basis, and our minimum set of identifiers would not prevent the potential repeating group structure from including those identifiers. The conversation today though is going to focus on what should be consistently implemented across many conditions.
- First I am going to give a description of potential existing and novel core data elements for identifiers, and then I will put them all up together on one slide for discussion.

Current Identifiers

- Coming back to these identifiers currently in the genv2 MMG. The top two identifiers in bolded red are used to identify the person as a unique individual, and the case as a unique case investigation being reported. These identifiers are well established in set HL7 fields, essential to transmission of case information, and would not be part of a potential repeating group. These are out of scope of what we're talking about today.
- The third value of "State case identifier" is not routinely used in case investigations. It is only populated in 1.5% of cases currently, and the most common use there is as a repurposed field for states using the genv2 MMG to report COVID cases. This is not an identifier that we're proposing as core.
- The fourth value of "legacy case identifier" is also rarely used, but important for instances when system transitions are taking place. If a case was originally reported using a different ID value from a previous system, this field allows the linkage of the old case data with the new case ID.
- Discussion
 - Gillian: You said that the 2 in red there are outside of the scope for discussion today?
 - Sam: yes
 - Gillian: Okay, from my perspective the data element descriptions need to be better b/c I think there's a difference between a person and a case event, and it's not clear what is being discussed, referenced in those descriptions
 - Sam: So we should talk about them as core and maybe updating the descriptions for them
 - Gillian: yes, that would be my recommendation
 - Sam: we are not prepared to tackle that today but we can include it in next month's meeting.

CDC-assigned Case ID

- Jurisdictions create case IDs as a way to uniquely identify and track cases occurring within their jurisdiction. These IDs are currently sent to CDC in the "local record ID" field and are used by CDC as a key field to uniquely identify cases.
- However, early on in an emergent outbreak, CDC may assign case IDs, especially before routine data transmissions are established from jurisdictional surveillance systems. For instance, at the beginning of the mpox response, CDC call center staff initially manually assigned unique case identification numbers for each suspect case as it was reported to them, and then this process was automated as case volume grew and the data were managed in DCIPHER. These IDs were used by CDC to uniquely identify cases. They were

provided to jurisdictions and were requested in subsequent case notifications to allow CDC to link updated information to the initially reported case. However, the generic v2 MMG does not currently have a specific field for this information.

CDC-assigned Case ID, 2

- As we're talking about potential identifiers that should be core, a proposal is to add a core identifier that could be used for a CDC-assigned ID assigned in situations like an emergency response or other non-routine situation when it would be helpful to capture this. This would almost always not be present for case notifications to CDC, but including it as core would mean that both jurisdictions and CDC should be prepared to transmit and receive this field across conditions if a situation arises where it's necessary.

National Outbreak ID

- Within the generic v2 MMG, there is the data element "case outbreak name" which is "A state-assigned name for an identified outbreak." This is a priority 1 data element and is also included in the list of minimum data elements necessary for a response, indicating its importance to CDC.
- Some condition-specific MMGs, use an additional data element to capture a national outbreak ID. For instance, FDD, RIBD, and Legionellosis MMGs contain a data element for the CDC NORS Outbreak ID. This helps identify cases associated with an outbreak that involves multiple states.
- For potential inclusion as core data elements in a minimum value set for identifiers, there are two proposed outbreak identifiers. One specifies it is an outbreak ID assigned by a state. This is in replacement of the "case outbreak name" element. We specified "outbreak ID" in the DE name, rather than "outbreak name" to exclude information that could be considered sensitive. For instance, in case an outbreak name is long or contains a school or restaurant name, we do not want that to be a barrier to sending a field that links a case to a jurisdictional outbreak.
- Similarly, the second proposed data element is the NORS ID, which would be populated if the case is associated with an outbreak reported in CDC's National Outbreak Reporting System.

Minimum Set of Identifiers

- We are going to talk more about additional IDs later, particularly potential laboratory identifiers. This set of four data elements is just a starting point to which we may add additional values to in our future conversations. With what we've talked about so far, I'd like to hear if anyone has any thoughts or questions on these four identifiers as potential core data elements?
- Discussion

- Suzanne: What would the legacy case identifier be? Is this like for systems that were in transition, or totally switched over from one system to another and they reset their automatic case ID or disease, incident or even or whatever they call their ID. It gets reset b/c of changing electronic systems...is that what this is?
 - Sam: yes, that type of situation where the case has previously been reported to an NNDSS through some other ID assigned by something else and now it's being reported with a different ID, but it's the same case information.
- Misty Johnson: At least 3 of these, I don't know why these couldn't go in that first proposed example of repeating group where we can have the flexibility of adding to it. It's another ID that we want to associate with that case and this would be just some of those flavors of those ID that you could put in there instead of having 3 new elements here. That's my suggestion
 - Sam: So what we're talking about right now, it seems like 2/3 of the group was leaning towards that repeating group structure I think before we officially made a poll for "definitely – let's do this repeating group structure" we wanted to hear from the group and see if we needed to tweak it at all. And so in the case "these are core" then yes, these 4 would be part of essentially a minimum value set for that first identifier type data element there. In the case that for some reason, we don't go with a repeating group for identifiers, it would be that "yes, these are 4 individual data elements on their own"
- Suzanne: I think we defined it as how it would actually show up, it would be text is what we're saying for most of these too, b/c there would probably be inconsistencies in how our different jurisdictions create our outbreak or cluster identifiers.
- Steve: If you're going with a repeating group, it may be technically more difficult when you're trying to do things with it stored in that fashion. If you're trying to match records between systems. And secondly from a linguistic perspective, looking at the descriptor in Legacy case identifier, you might want to revise the text a little bit to case notifications submitted by previous system to something to modify that b/c it's a little unclear as to what you're linking to, if that makes sense.
 - Sam: yes, so a better description is needed there that links current case notification to a case notification submitted under previous case identifier
 - Steve: or case notifications in this system, whatever the system is, to another system
 - Sam: we can work on the language
 - Steve: and not find a word method here but just from a clarity standpoint so that everybody's abundantly clear about you're linking A to be whatever A and B is
- Chat
 - Katherine: since core data elements are supposed to be condition agnostic, is there potential to change the NORS ID to a CDC assigned outbreak ID or something similar so it could potentially be used outside of enterics (and for enterics, it would just be the NORS ID)?
 - Angie Agunloye: Is this what would go into the repeating group or these are individual data elements. Sorry same question as MJ 😊
- Suzanne: When it says CDC assigned, that's a case ID and not an outbreak ID? (Sam: yes)

Poll 2 – Minimum Value Set

- Discussion:

- Misty: I selected “only some of them” because I want to be careful how many we’re going to add to core. At least in WI for our Gen V2 we pull off of tabs that are available across all diseases, and any changes to those tabs takes an act of God, it’s quite a change to our surveillance system. So if we get real creative with adding a bunch of things to core at least in WI it’s going to take us awhile to implement that. So I want to be a little careful of what we’re putting in and I also am in favor of the first option of that repeating group set. Go for it, you know we can add whatever you want whether it be a NORS, CDC-assigned.
- Sam: I see Laura says legacy for me. I think that is a slightly more complicated one in that you wouldn’t necessarily be able to capture that in your system right? b/c it was in this old system and now this new system has a new ID. I think legacy case identifier is maybe a more important feature for CDC to have available as an option in that value set or available as an option in there for someone who needs it. But that one is less something that a jurisdiction would need to be prepared to send.
- Suzanne: I think that would be a very exceptional case as well. I chose all of them could be, and I see where CDC might want to use it but we’re talking diseases that you’re still investigating when you’re switching over systems. TB would probably be the one example that I can think of that takes forever to get to and they have an actual report that has to go back to them. And possibly those get moved around between systems over the years, but I just don’t even know if we would have the capability in WI. We switched over to WEBs in 2007 and we put as much as we could into our current system. It’s hard to imagine digging that up for the sake of what you know. I see Laura’s point, should it be core is the main thing. I think it’s good to have it as an option but if we have it repeating, then we don’t have to always be looking for it anyway, but I guess the expectation is that you would have the ability to do it if it was necessary for your jurisdiction, is that the way to look at it?
- Sam: yes
- Sara Johnston: I’ll clarify that the legacy case ID is not meant to be something that you had in a system years ago. This is used typically during the transition to Gen V2 or to a disease-specific MMG where your data is in a different system, different IDs, or you’re transitioning systems at that time. So it’s not something where you need to dig up IDs from a long time ago, it’s just an aid for transition basically.
- Chat
 - Laura Erhart: legacy, for me
 - Meredith Eddy: Identifiers could also change if they were merged
- Poll Question: Should these identifiers be part of the core minimum value set/data elements for identifiers?
- Options: Yes | Only some of them | None are core

DSWG_5.17.24_Q2

Poll | 1 question | 28 of 59 (47%) participated

1. Should these identifiers be part of the core minimum value set/data elements for identifiers? (Single Choice)

28/28 (100%) answered



Birthing Parent Linkage

- Now we're going to move on to talking about linking cases for infants with the birthing parent.

Birthing parent-infant linkage

- NNDSS collects data on several congenital conditions where it is important to have information for the birthing parent as well as the infant, such as congenital syphilis, perinatal hepatitis B and C, congenital toxoplasmosis, and congenital rubella syndrome. For these conditions, demographic and epidemiologic information about the birthing parent is typically included in the infant's case notification. Sometimes this is done by requesting data from the parent's case be re-entered into the infant's record. As you can see in this example from the congenital rubella MMG, information about the mother's clinical history is included in the infant's case notification, in addition to being included in the mother's case notification. In this particular case, the infant's case notification also includes information on the mother's demographics, testing, vaccination, and birth history.

Birthing parent-infant linkage, 2

- It is also valuable to be able to link the parent's and infant's case notifications. As you can see in this example from the congenital syphilis MMG, the mother's local record ID and mother's national reporting jurisdiction are included in the infant's case notification. These two fields are used to uniquely identify cases within NNDSS and allow CDC programs to associate the parent's and infant's case notifications. While it may require extra work to include the parent's local record ID in the infant's record, providing the linking ID reduces the need to re-enter information and supports analysis that can provide additional richness and detail.

Birth parent-infant linkage, 3

- Before we talk about whether or not any of this should be core, we wanted to talk about which of these methods is easier to implement for jurisdictions. Does anyone have any considerations for what the preferred method is for transmitting this type of information?
- Discussion
 - Suzanne: What happens when the birthing parent is identified as a case in a different jurisdiction then gives birth elsewhere and that's where the child is identified as having the condition?
 - Sam: yes so that's why the first bullet there would really require to send the birthing parents case ID and also the birthing parents' national reporting jurisdiction. So you have that ID number but also the jurisdiction associated with that ID number.
 - Suzanne: That seems hard to do for individual follow-ups. If what we have as a child that was diagnosed in our system, going back and requesting information from another state or country could be challenging.
 - Sam: In that case you think putting just the mother's information in the case might be easier than identifying an ID number from a different date?
 - Suzanne: epidemiologically, doing interviews and stuff, yes
 - Sam: in the chat we have a similar comment from Rob.
 - Suzanne: what did we do for Zika?
 - Sam: that's a great question. Gillian replies in chat.
 - Misty Johnson: I do know for perinatal hepatitis we at least have both the parent's case ID is noted in the case as well as information that we pull into our system. Eliminating the need of somebody having to key that, but that is assuming that the parent's case is in our WI system. So in the perfect scenario, great, we kind of have the best of both worlds. I can't answer off the cuff if this information is transmitted in the perinatal case notification method, but right now we have both for purposes of surveillance.
 - Suzanne: May have situations as well where the child is diagnosed with the disease, and then the follow-up goes back to the birthing parent to see so it may not always flow in the direction of parent identified first and then baby. Some things aren't recognized right away at birth as well
 - Sam: yes, this is a lot of good reasoning for that second method being more of a preferred approach here.
 - Misty: one other thought I had here too, if we're strictly talking about case notification, I don't know what it would serve the CDC if we just sent the parents' case ID. I mean that proves that we have a case ID, well great. But unlike if the case notification contained the data elements that you need to know from the parents' case, that at least gives the CDC more information to run metrics of what percentage of this disease did the parent have these symptoms. Otherwise if you have a case ID, ok the state can look up that case ID

and get more information. I would be good for the reporting jurisdiction to have the case ID so that their epi can dig in further but I would think that second option is what you'd want in a case notification

- Sara Johnston: in the case of congenital syphilis both cases would be sent to CDC. So the parent case is sent as a syphilis case and then the congenital case as well and can be linked at CDC if CDC has the case ID and jurisdiction for the pair.
- Misty: got it
- Suzanne: we're not talking about this as core, we're talking about this just in general right? Like how we could potentially link these? (Sam: in this moment, yes just in general)
- Morrow: one of my questions and maybe this is more for the CDC if you're receiving both the parents' case ID, and then also data elements, it sounds like maybe some jurisdictions are pulling in data elements from the parents' case ID and sending that in the notification, but if we're also just re-entering data elements from the parents' case into the child's case, is there ever discrepancies that you see there from the parents? If you were linking to the parents' case ID and then also looking at the manually entered data elements from one case to another. Or is there just a preferred way at least at the CDC's end to do the analysis and linking with the parents' case?
 - Sara: We don't have a lot of data on that scenario b/c for congenital syphilis it's not all of the information that's coming across in the child record, and for congenital rubella, it is not a common condition. So going back and looking at the parent record if we have it and being able to link it with that child record, I would suspect we don't have good data on that to answer that question.
 - Morrow: thank you, when I saw this slide originally I was thinking just sending the parent...I guess I was thinking like could it be both...could you be resending the data elements but also sending the case ID if you had it
 - Sam: review chat
- Chat:
 - EJ Klingler: For congenital rubella sometimes the mother's information is not a case we reported (different jurisdiction, presumed infection outside of the US)
 - Rob Arciuolo: Also congenital rubella is extremely rare and not very burdensome to double enter into the case
 - Gillian Haney: reminder that this needs to be disease agnostic... unsure whether this would be the case for other conditions like zika
 - Misty: Taking into consideration Sara's comment, I think that just sending the Parent's ID is enough. As @Morrow Toomey, AK DOH notes, what if there was a data entry error, with the re-reporting of the parent information.
 - Hanna: In general I prefer to send the linking identifier, because double entry is not efficient. However, since there are issues with always having a parent case and I suppose we can't assume that all conditions will have the parent as reportable... that leads me to the latter.
 - Agree. Even for rubella if we had the parent case ID we could include it with extra fields.

Poll 6 – Birthing Parent-Infant Linkage

- Chat
- Poll Question: What is your preferred “default approach” to mother/infant case linkage?
- Options: Transmitting birthing parent’s case ID/Jurisdiction in infant case | Transmitting relevant data elements from the birthing parent’s case in the infant case
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DSWG_5.17.24_Q6

Poll | 1 question | 21 of 55 (38%) participated

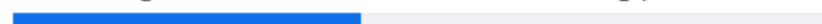
1. What is your preferred “default approach” to mother/infant case linkage? (Single Choice)

21/21 (100%) answered

Transmitting birthing parent's case ID/ jurisdiction in in... (12/21) 57%



Transmitting relevant data elements from the birthing p... (9/21) 43%



Poll 7 – Birthing Parent-Infant Linkage

- Since the preferred method is to transmit the ID for the birthing parent, should these data elements be considered core? As we talked about before, core in this sense is those identifiers that jurisdictions and CDC are prepared to transmit and receive across conditions, although they may be blank. Not including as core would mean these are only included in a condition specific manner.
- Poll Question: Should these birthing parent – infant linkage data elements be considered part of core data for surveillance?
- Options: Yes- Add to minimum set | No- Just support a standard approach

DSWG_5.17.24_Q7

Poll ended | 1 question | 26 of 52 (50%) participated

1. Should these birthing parent - infant linkage data elements be considered part of core data for surveillance? (Single Choice)

26/26 (100%) answered

Yes - add to minimum set (13/26) 50%

No - just support a standard approach (13/26) 50%

Next steps

- Upcoming team meetings
 - 7/12 1-2pm ET – Medications
 - 7/19 1-2pm ET – Identifiers
 - Identifier structure, linking labs and cases
- Next full DSWG call will be June 28th, 1-2pm ET
 - Medication/Treatment discussion
- ERU and Clinical Manifestations documents will go out to their respective DEST teams soon