



AIRA
AMERICAN IMMUNIZATION
REGISTRY ASSOCIATION

INFORMATION REQUEST

Topic: Capture of Race and Ethnicity Data

Request Date: February 17, 2021

Information Requested:

As you are all aware, race and ethnicity are critical fields for capture in the COVID-19 response. We know the challenges of full capture of these fields are shared with our electronic health record, clinician, and pharmacy partners, but we're hoping to get a sense from you, the IIS community, of what facilitators and barriers exist today to capture these fields.

1. Are you able to accept data on patient race into your IIS?
 - a. If no, is there a law or policy that does not allow you to accept this data?
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
 - a. If no, is there a law or policy that does not allow you to accept this data?
3. Do you have a process in place for updating race data when more current data is submitted?
4. Are you able to accept data on patient ethnicity into your IIS?
 - a. If no, is there a law or policy that does not allow you to accept this data?
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
6. Are you able to share/publish data on patient race from your IIS?
 - a. If no, is there a law or policy that does not allow you to share this data?
7. Are you able to share/publish data on patient ethnicity from your IIS?
 - a. If no, is there a law or policy that does not allow you to share this data?
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?
11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?



Requesting Member: AIRA Staff

Responding Member(s):

Results: Hari Siva (AL), Kim Gulliver (CO), Laura Barrett (KY), Kathryn Ahnger-Pier (MA), Miriam Muscoplat (MN), Mary Woinarowicz (ND), Katie Cruz (NM), Vikki Papadouka (NYC), Veronica Rodriguez (PR), Jacqueline Logan (TN), Kristi Westfall (WY)

AL:

1. Are you able to accept data on patient race into your IIS?
Yes, we accept race data.
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Yes, we support multiple races.
3. Do you have a process in place for updating race data when more current data is submitted?
Yes, race data is updated as per the latest data submission.
4. Are you able to accept data on patient ethnicity into your IIS?
Yes, we accept ethnicity data.
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
Yes, ethnicity data is updated as per the latest data submission.
6. Are you able to share/publish data on patient race from your IIS?
Yes, we can share if needed to.
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes, we can share if needed to.
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
Apart from immunizing providers, we accept race/ethnicity from Vital Statistics if submitted to us.
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
We have not published/shared race/ethnicity yet.

Below are the race values we accept:

- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander



- Black or African-American
- White
- Other Race
- Unknown

And below are the ethnicity values we accept:

- Hispanic or Latino
- None Specified
- Not Hispanic or Latino

10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?

We do not have any suggestions at this point in time.

11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?

We do not have anything else to share.

CO:

1. Are you able to accept data on patient race into your IIS?

Yes

2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Multiple races can be entered by manual users of CIIS, but for electronic reporting the import process cannot accept multiple races. Currently, if multiple races are sent then the first race is the one that is imported.

3. Do you have a process in place for updating race data when more current data is submitted?

During the import process, a race is not updated if it is different from the one listed on the IIS record because we don't know which one is accurate. Our process currently just adds an additional race to the patient record.

4. Are you able to accept data on patient ethnicity into your IIS?

Yes

5. Do you have a process in place for updating ethnicity data when more current data is submitted?

During the import process, if the Ethnicity on the CIIS record is unknown and any value that isn't unknown comes in then that data will override the CIIS data. If there is a non-unknown value on the CIIS record then a value of unknown will not override this data during the import process.



6. Are you able to share/publish data on patient race from your IIS?
Yes, our COVID-19 race data is currently displayed on our public facing website.
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes, our COVID-19 ethnicity data is currently displayed on our public facing website.
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
In an attempt to enhance our COVID-19 race/ethnicity data, Colorado recently worked with one of its HIEs to see if they could add this information. Of the records sent to the HIE, they were only able to match about 50% of the records and they were able to enhance race/ethnicity on about 16% of that data. This helped decrease our Unknown Race/Ethnicity from 22% down to 14%. Vital Statistics does track race/ethnicity data on the mom and dad, but this data is not added to the patient record during the import process. We do not get this data from any other sources.
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
Here is a [link](#) to the Colorado public facing website that currently captures vaccination data. Click on Demographics to see Race/Ethnicity data.
10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?
To ensure more accurate data it would be helpful if HL7 had a standard code for Declined to Answer. Currently, we may get this in a description, but since there is not a code, everything gets dumped into an "Other" category. This makes it difficult to differentiate the data more.
11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction? Not at this time

KY:

1. Are you able to accept data on patient race into your IIS?
Yes
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Yes
3. Do you have a process in place for updating race data when more current data is submitted?
Yes



4. Are you able to accept data on patient ethnicity into your IIS?
Yes
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
Yes
6. Are you able to share/publish data on patient race from your IIS?
Yes
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from?
Vital Statistics
9. Do you have good examples of published race/ethnicity data you could share?
Not currently
10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?
Not currently
11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?
No

MA:

1. Are you able to accept data on patient race into your IIS?
Yes
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Yes
3. Do you have a process in place for updating race data when more current data is submitted?
If a patient's race in the IIS is "Unknown" and a new race code comes through with an immunization, the race is updated to that code. If a different race code is sent, the IIS appends that race to the record and keeps the old race code as well.
4. Are you able to accept data on patient ethnicity into your IIS?
Yes, presently we collect "Hispanic/Latino" and "Not Hispanic/Latino" only.
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
Same as above for race



6. Are you able to share/publish data on patient race from your IIS?
Yes, provided that the aggregate totals for any one race are 30 or higher (internal data privacy rule)
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes, same as for race above, each group needs to have an aggregate total of 30 or more.
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
We also collect race/ethnicity from Vital Records birth certificate information.
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
Our current best example is our COVID vaccine dashboard, updated weekly here: <https://www.mass.gov/info-details/massachusetts-covid-19-vaccination-data-and-updates#weekly-covid-19-vaccination-dashboard>
10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?
We have recognized that some providers send "Other" when they actually are not collecting race/ethnicity and should be sending no race/ethnicity. This leads to an "Other" race code being appended to the record and increases the appearance of multi-racial patients. We have also identified providers that use non-standard race codes in their EHR, which also is transmitted via HL7 as "Other".
11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?
Collecting race/ethnicity data is a priority for the Department and we will likely continue to prioritize improving the quality of R/E data in our IIS in the coming months.

MN:

1. Are you able to accept data on patient race into your IIS?
Yes, we can accept this information.
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
No, we are unable to capture multiple race or ethnicities.
 - a. If no, is there a law or policy that does not allow you to accept this data?
No legal barriers, just technical



3. Do you have a process in place for updating race data when more current data is submitted?
Yes, new race/ethnicity data will update the existing information unless the newly submitted data is “unknown.”
4. Are you able to accept data on patient ethnicity into your IIS?
Yes, we can accept this information.
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
Yes, new race/ethnicity data will update the existing information unless the newly submitted data is “unknown.”
6. Are you able to share/publish data on patient race from your IIS?
Yes, though we haven’t to date because of concerns about the quality of the data
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes, though we haven’t to date because of concerns about the quality of the data
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
Vital records, potentially from “[state COVID connector app](#)” (though this is theoretical at this time)
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
All published data to date is based on vital records analyses.
 1. Tdap in pregnancy:
<https://www.cdc.gov/mmwr/volumes/66/wr/mm6602a4.htm>
 2. Timeliness of early childhood vaccines:
<https://www.cdc.gov/mmwr/volumes/66/wr/mm6602a4.htm>
10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?
N/A
11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?
There has been a recent shift in interpretation of the immunization data sharing law. We are working through this, but it sounds like we will now have an easier time asking for this data from providers. Happy to answer more questions on this.



ND:

1. Are you able to accept data on patient race into your IIS?
Yes
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
No, we only accept one race.
 - a. If no, is there a law or policy that does not allow you to accept this data?
There is no legal or policy issue, our system was built to only store one value for patient race.
3. Do you have a process in place for updating race data when more current data is submitted?
Yes, our user interface requires race and our HL7 messaging engines are set up to add/update race with the data is missing or set to “unknown” in the IIS. If an EHR sends an empty value for race, no update or add action is taken.
4. Are you able to accept data on patient ethnicity into your IIS?
Yes
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
Yes, our user interface requires ethnicity and our HL7 messaging engines are set up to add/update ethnicity with the data is missing or set to “unknown” in the IIS. If an EHR sends an empty value for ethnicity, no update or add action is taken.
6. Are you able to share/publish data on patient race from your IIS?
Yes, at the state level
 - a. If no, is there a law or policy that does not allow you to share this data?
We have a data policy that does not allow us to publish any data where the denominator or patient population is <5. This happens frequently in our rural areas, so we generally don’t publish data at a county or local level by patient race.
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes, at the state level.
 - a. If no, is there a law or policy that does not allow you to share this data?
We have a data policy that does not allow us to publish any data where the denominator or patient population is <5. This happens frequently in our rural areas, so we generally don’t publish data at a county or local level by patient ethnicity.
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?



We receive race data from Vital Records for newborns. That is the only other current data source.

9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.

We are currently publishing COVID-19 coverage rates by race and ethnicity on our vaccine dashboard. Here is the link:

<https://www.health.nd.gov/covid19vaccine/dashboard>. I also had an article published in the September 2020 issue of Public Health titled *Comparing vaccination coverage of American Indian children with White children in North Dakota*.

10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?

We send interoperability data quality report cards to all of our interoperable providers/health systems quarterly. These reports include data completeness for race and ethnicity at the health system level as well as at the individual provider level. We also recently assessed race and ethnicity data completeness by provider site for our COVID enrolled providers and sent emails to all of our providers with their % complete for these data elements for their COVID vaccine doses administered. We plan to re-assess the data completeness in a couple of weeks and do another round of follow-up.

11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?

I would love to see more education and communication within health systems and even small providers. The staff doing the vaccinations and documenting the vaccine administration information are not always the same people capturing the patient's demographics. The staff actually entering patient demographic information may not know or understand how important it is to have these data elements completed for every patient. We also do not consider a value of "unknown" as complete even though it may be a valid option in our systems.

NM:

1. Are you able to accept data on patient race into your IIS?
Yes, it is a required field.
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Yes, we have an option for "Other" that would be selected for multiple races.



3. Do you have a process in place for updating race data when more current data is submitted?
Our IIS accepts the most currently submitted data and will overwrite previously submitted data.
4. Are you able to accept data on patient ethnicity into your IIS?
Yes, it is a required field.
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
Our IIS accepts the most currently submitted data and will overwrite previously submitted data.
6. Are you able to share/publish data on patient race from your IIS?
Yes
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
We can receive race/ethnicity data from Vital Records for birth data and can receive that data when we do mass flat file uploads from Medicaid.
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
<https://cvvaccine.nmhealth.org/public-dashboard.html>
10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?
No, capturing this data is relatively new for us.
11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?
Our Epidemiologist department adjusts our data fields so that race/ethnicity can be portrayed together, rather than separate demographics.

NYC:

1. Are you able to accept data on patient race into your IIS?
Yes
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
No, we can't accept multiple races, but we have an option to select "Two or more



racess" as one of the race options.

a. If no, is there a law or policy that does not allow you to accept this data?

No

3. Do you have a process in place for updating race data when more current data is submitted?

Yes, race information can be updated, unless the existing race values come from Vital Records. In those cases we retain the race value from the vital record.

4. Are you able to accept data on patient ethnicity into your IIS?

Yes

5. Do you have a process in place for updating ethnicity data when more current data is submitted?

Yes, ethnicity information can be updated, unless the existing ethnicity values come from Vital Records. In those cases, we retain the ethnicity value from the vital record.

6. Are you able to share/publish data on patient race from your IIS?

In general, we don't share patient-level information other than names, address and immunizations.

a. If no, is there a law or policy that does not allow you to share this data?

No

7. Are you able to share/publish data on patient ethnicity from your IIS?

In general, we don't share patient-level information other than names, address and immunizations.

a. If no, is there a law or policy that does not allow you to share this data?

No

8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?

Vital Statistics

9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.

We currently publish race/ethnicity data for COVID-19 Vaccinees in NYC's public dashboard. <https://www1.nyc.gov/site/doh/covid/covid-19-data-vaccines.page>

10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?

Make reporting of race and ethnicity required in data submissions. Expand



race/ethnicity categories to be more inclusive. Outreach to providers to assure that race/ethnicity information is included in submissions.

11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?

During the COVID19 vaccination campaign, race/ethnicity missingness became a very significant issue to address. Race and ethnicity are two of the few SES indicators we have that can help us measure equity in vaccine administration. At the beginning of the pandemic, we had 40-50% capture of race ethnicity, but through extensive campaigning, by requiring race/ethnicity reporting, and outreach to providers, completeness has increased to 60-70%.

PR:

1. Are you able to accept data on patient race into your IIS?
Yes
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Yes
3. Do you have a process in place for updating race data when more current data is submitted?
If you refer when received through exporting data, the answer is yes.
4. Are you able to accept data on patient ethnicity into your IIS?
Yes
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
If you refer when received through exporting data, the answer is yes.
6. Are you able to share/publish data on patient race from your IIS?
As statistical data reports, the answer is yes.
7. Are you able to share/publish data on patient ethnicity from your IIS?
As statistical data reports, the answer is yes.
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
Yes, with EHR
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
At this moment, we do not have a good sample.



10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?

Review the data through quality reports to make correction.

TN:

1. Are you able to accept data on patient race into your IIS?
Yes
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Yes
3. Do you have a process in place for updating race data when more current data is submitted?
Any provider submitting data (via HL7 or direct data entry) can update race data.
4. Are you able to accept data on patient ethnicity into your IIS?
Yes
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
Any provider submitting data (via HL7 or direct data entry) can update ethnicity data.
6. Are you able to share/publish data on patient race from your IIS?
Yes, publish aggregate data in publicly available datasets and the vaccine dashboard
7. Are you able to share/publish data on patient ethnicity from your IIS?
Yes, publish aggregate data in publicly available datasets and the vaccine dashboard
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
We receive data from Vital Records (birth data) and TennCare (and other MCOs).
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
Dashboard: <https://www.tn.gov/health/cedep/ncov/covid-19-vaccine-information.html>
Public Datasets: <https://www.tn.gov/health/cedep/ncov/data/downloadable-datasets.html>
10. Recognizing that race/ethnicity may not be captured completely or accurately at the source, do you have suggestions for data quality interventions that could improve quality?



We opted to require race and ethnicity when entering vaccines via the mass immunization (knowing that “Unknown” is an option to select and that we can’t require via HL7). We also implemented a completeness and timeliness report (using SAS) to identify providers submitting missing or invalid data.

11. Is there anything else you would like to share about race/ethnicity data in your jurisdiction?

We are working on cross-walking patients who have received vaccinations with patients who have been tested for COVID in an alternate database (NEDSS based system for reportable diseases) to update race/ethnicity data in TennIIS.

WY:

1. Are you able to accept data on patient race into your IIS?
Yes
2. Are you able to accept data on a patient that is multiple races (e.g., Black and Asian)?
Not specifically outside of "Multiracial" but the system does not allow for specific race if it is more than one
3. Do you have a process in place for updating race data when more current data is submitted?
If there is other data incoming, i.e., a new vaccine or updated vaccine, but not demographic update only
4. Are you able to accept data on patient ethnicity into your IIS?
Yes
5. Do you have a process in place for updating ethnicity data when more current data is submitted?
If there is other data incoming, i.e., a new vaccine or updated vaccine, but not demographic update only
6. Are you able to share/publish data on patient race from your IIS?
I am unsure
7. Are you able to share/publish data on patient ethnicity from your IIS?
I am unsure
8. In addition to immunizing providers, are there additional data sources you receive race/ethnicity data from (e.g., Vital Statistics, Medicaid, data warehouses, master patient indexes, etc.)?
Not at this time
9. Do you have good examples of published race/ethnicity data you could share? If so, please link or attach any documentation in your response.
Not at this time