

# **Data at Rest**

**Frequently Asked Questions** 

Updated December 2023

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#### Basics about Data at Rest

1. What is the Measurement and Improvement (M&I) content area Data at Rest? In 2016, The American Immunization Registry Association (AIRA) convened the Measurement for Assessment and Certification Advisory Workgroup (MACAW) to develop and propose measures for IIS Assessment. The Data at Rest (DAR) content area within the Measurement and Improvement (M&I) Initiative focuses on the data residing in an IIS database. Measures and tests are shared with the full IIS community to ensure broad community input and agreement.

MACAW defined the scope, measures, tests, outcomes, and testing methods for measuring data quality of the data at rest within an IIS. This work was founded by the <u>IIS Functional Standards</u>, CDC's <u>IIS Data Quality Blueprint</u>, and <u>IIS Data Quality Practices – To Monitor and Evaluate Data at Rest.</u>

2. How is DAR different from other M&I content areas?

Other content areas (i.e., Transport, Submission, Query, Clinical Decision Support) only need credentials provided from IIS staff in order to be measured. DAR will require more involvement from IIS staff to be measured, uses de-identified data from within a production environment instead of test data from within a preproduction environment, and IIS discretion may require a <u>partner agreement</u> <u>between AIRA and the IIS program</u>.

3. What additional involvement will IIS staff need to provide to be measured?

The IIS team will need to perform three major activities:

- Review the extract specification and determine which data elements can be extracted
- Extract data into the predefined file format. This will most likely be performed through SQL scripts. It is possible that your IIS (or some other tool) will be able to extract the data without SQL scripts, but for planning purposes, it would be best to assume SQL scripts will be needed.
- Run the AIRA-provided transformation tool and upload data into AART through the jurisdictional dashboard.

#### How to Get Started

4. How does my IIS participate?

IIS can initiate their participation in DAR entirely on their own by following the steps on the <u>Data at Rest website</u>. Alternatively, IIS may also access AIRA's online technical assistance <u>form</u> and choose "Data at Rest" as the category of your request. Complete the requested fields and a member of the Standards and Analytics team will follow-up with you.

5. Do I have to have a partner agreement?

No, each jurisdiction will determine the need for a partner agreement with AIRA to share the de-identified data. AIRA, however, does not require this agreement, and discretion resides with the IIS.

- 6. If needed, where do I find the partner agreement?

  Submit a request via AIRA's online technical assistance form.
- 7. What staff would AIRA recommend be involved in this process?

AIRA recommends that IIS program staff currently involved in other M&I efforts participate in any related DAR activities. In addition, others may need to be involved, such as central IT, IIS vendors/implementors, or other policy staff.

#### DAR Process

8. What are the major steps in the process to be measured in DAR?

The process entails six specific steps (each links to the corresponding step in this document:

- Project Initiation
- Data Extraction
- Data Transformation
- Data Loading
- Data Analysis
- <u>Data Quality Improvement</u><sup>1</sup>
- 9. What is the purpose of the Data Extraction step, and what is entailed?

The purpose of this step is to extract all the necessary patient and immunization data from the IIS into a predefined flat file format. The following materials are available by AIRA to help with the extract:

- CDC-Endorsed Data Element Flat File Specification This format specification defines a patient and immunization extract for all CDCendorsed data elements.
- Data Extract Specification This specification defines the birth cohort and other extract guidance related to DAR.
- DAR Extract Files:
  - i. DAR Extract Job Aid This job aid can be used to help an IIS determine which data elements can/can't be extracted.
  - ii. Example extract queries Extract queries are available upon request from AIRA via the <u>online webform</u>.

<sup>&</sup>lt;sup>1</sup> Not required as part of being measured but will help with IIS improvement initiatives.

- iii. Sample Extract files- These files, located in the DAR Command Line Tool zip file, can be used as examples to help your technical staff get started with extracting data.
- 10. What is the purpose of the Data Transformation step, and what is entailed?

  The purpose of this step is to transform the patient and immunization data into a aggregate summary of data quality indicators. The files to support data transformation are located <a href="here">here</a>. These tools were developed by the National Institute of Standards and Technology (NIST).
- 11. What is the purpose of the Data Load step, and what is entailed?

  The purpose of this step is to submit the encrypted aggregate detections file (ADF) created during the previous step to AIRA for analysis. This file can be uploaded to AART through the jurisdictional dashboard.
- 12. What is the purpose of the Data Analysis step, and what is entailed?

  The purpose of this step is for AIRA to use the NIST-provided tool to analyze the aggregate detections file (ADF). This step is complete when the data are ready to be displayed in AART.
- 13. What is the purpose of the Data Quality Improvement step, and what is entailed? Similar to previous content areas (i.e., Transport, Submission, Query, etc.), this step includes logging into AART, reviewing test results, and determining the best path forward to improve data quality. This step could also include using the NIST tool to dive deeper into your data to find specific areas of concern or submitting provider data where targeted outreach could potentially increase quality of the data that are being sent to the IIS.
- 14. What materials will AIRA supply to help my IIS in the process?

AIRA has developed resource materials <u>available online</u> to support participation for this content area.

- DAR Participation Checklist This checklist is provided to DAR participants as a guide to help IIS complete the necessary steps.
- DAR Brief Summary This document is ideal for leadership and those being introduced to the project.
- CDC-Endorsed Data Element Flat File Specification This format specification defines a patient and immunization extract for all CDCendorsed data elements.
- DAR Extract Specification This specification defines the birth cohort and other information related to DAR.
- DAR Extract Job Aid This job aid can be used to help an IIS determine which data elements can/can't be extracted.
- DAR Command Line Tool This zip file provides instructions, sample patient and immunization files, and tooling to perform the transform step.

15. What are the major activities involved throughout this process?

Once a general understanding of the extract concepts and data elements is achieved, the Extract Job Aid is the best document to review next. The job aid will allow for all IIS team members to work from the same artifact to capture the IIS-specific nuances. These can later be used by technical staff to develop the extract (usually using an SQL script).

The second major activity in this step is to build and perform the extract into the defined flat file format per the CDC-Endorsed Data Element Flat File Specification. The provided Example SQL Functions should be leveraged at this point to help build the extract.

The <u>Data Extraction</u> step is finished once both the patient and immunization file have been produced. The next step (<u>Data Transform</u>) will verify the extracted files are formatted properly. It is likely you will need to return to this step and tweak the format and/or data selection based on feedback in the Data Transform step.

#### Benefits of Measurement

16. What are the anticipated benefits to IIS from participating in M&I's DAR content area?

M&I provides IIS with an independent, objective testing process; the available data will enable individual IIS to share their progress toward meeting standards with the broader community. This in turn will build confidence in IIS across other communities and will help prioritize essential improvements and community-wide adoption of standards across both IIS and electronic health record (EHR) systems. This content area will specifically help IIS to understand their data quality within the data that is "resting" in their database.

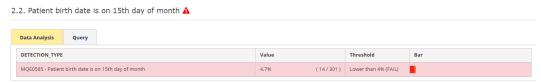
DAR in Assessment formally measures:<sup>2</sup>

- 24 Completeness indicators
- 20 Validity indicators
- 1 Timeliness indicator

Results from this content area can be used to highlight a potential data entry problem.

<sup>&</sup>lt;sup>2</sup> There are ten additional measures included in <u>DAR Testing and Discovery</u>.

For example, the image below highlights a potential data entry problem for this IIS where data are skewed to the 15<sup>th</sup> of the month.



This may or may not indicate an actual data quality problem, but it is statistically unlikely that 4.7% of patient records reflect birth dates on the 15<sup>th</sup> of the month, which therefore exceeds the normal birthdate distribution threshold of 4%.

17. What about IIS that are not yet ready to be measured in the DAR content area?

M&I participation is strongly encouraged among the IIS community. As of September 30, 2023, 100% of jurisdictional IIS programs are participating in at least one M&I content area. IIS control and select participation and sharing settings within the <u>AART</u> application. Based on M&I business rules, each participating IIS will automatically move along new content areas and stages; however, AART users can change <u>participation and sharing settings</u> at any time, and "no" responses will be rolled forward as well.

18. Is technical assistance available if my IIS is not sure how to get started or needs help along the way?

<u>Technical assistance</u> is available to IIS programs and vendors as needed to support all measurement and improvement efforts. IIS are encouraged to be measured, even if they won't meet specific measures.

### **Operational Questions**

19. Who oversees the M&I DAR process?

All measures and tests included in M&I are developed by MACAW, vetted for comment with the full IIS community via a town hall meeting webinar format, and reviewed by AIRA and CDC leadership prior to implementation.

20. How will the testing be conducted?

AIRA technical staff are responsible for implementing and conducting all testing efforts within the M&I Initiative. For DAR, the testing methodology involves IIS sending aggregate data quality indicators from IIS production systems through secure methods. The aggregate data quality indicators are void of any identifiable information and are a summary of IIS data quality rather than individual recordlevel information. NIST is partnering with AIRA in the testing process to develop conformance test tools to support this content area.

#### 21. What data indicators are measured in DAR?

The following data quality indicators are measured in DAR. These are categorized into three quality dimensions as defined within the *IIS Data Quality Practices – To Monitor and Evaluate Data at Rest.*<sup>3</sup>

- **Completeness:** The degree to which full information about a data set, record, or individual data element is captured in the IIS (i.e., the proportion of stored data measured against the potential of "100%")
- Validity: The degree to which the data conforms to the syntax (format, type, range) of its definitions, (i.e., to the rules of what is accepted or expected by the IIS)
- **Timeliness:** The amount of time between the occurrence of the real-world event and its documentation in the IIS (i.e., the time lag between the date of vaccination or birth and the date the record is received by the IIS)

#### 22. What data elements are measured by DAR Assessment?

The final measures and tests for DAR Assessment are located on AIRA's website.

#### The following fields are measured for completeness:

Patient completeness measures

- 1.1 Patient first name is present.
- 1.2 Patient middle name is present.
- 1.3 Patient last name is present.
- 1.4 Patient birth date is present.
- 1.5 Patient gender is present.
- 1.6 Patient address street is present.
- 1.7 Patient address city is present.
- 1.8 Patient address state is present.
- 1.9 Patient address ZIP code is present.
- 1.10 Patient complete address is present.
- 1.11 Patient race is present.
- 1.12 Patient ethnicity is present.
- 1.13 Patient phone number is present.
- 1.14 Patient email is present.
- 1.15 Mother's maiden name is present.
- 1.16 Responsible person first name is present.
- 1.17 Responsible person last name is present.

Vaccination event completeness measures

1.18 Vaccine administration code is present.

<sup>&</sup>lt;sup>3</sup> https://repository.immregistries.org/resource/iis-data-quality-practices-to-monitor-and-evaluate-data-at-rest/

- 1.19 Vaccine administration date is present.
- 1.20 Vaccine information source is present.
- 1.21 Vaccine lot number is present.
- 1.22 Vaccine lot expiration date is present.
- 1.23 Vaccine eligibility code is present.
- 1.24 Vaccine funding source is present.

As noted in the <u>data quality practices document</u>, the Validity and Accuracy dimensions are closely related and often measured using a shared set of indicators. As such, they have been combined.

#### Patient validity measures

- 2.1 Patients born on the first of the month do not exceed normal distribution of birth dates.
- 2.2 Patients born on the 15th of the month do not exceed normal distribution of birth dates.
- 2.3 Patients born on the last day of the month do not exceed normal distribution of birth dates.
- 2.4 Patient has more vaccinations than expected.

#### Vaccination event validity measures

- 2.5 Vaccine administration date is after vaccine lot expiration date.
- 2.6 Vaccine administration date is before birth date.
- 2.7 Vaccine administration dates on the first day of the month do not exceed normal distribution of administration dates.
- 2.8 Vaccine administration dates on the 15th of the month do not exceed normal distribution of administration dates.
- 2.9 Vaccine administration dates on the last day of the month do not exceed normal distribution of administration dates.
- 2.10 Vaccine administration code was administered at an improbable age.
- 2.11 Vaccine administration code is not specific for administered vaccination event.
- 2.12 Vaccine lot number has an invalid prefix.
- 2.13 Vaccine lot number has an invalid infix.
- 2.14 Vaccine lot number has an invalid suffix.
- 2.15 Vaccine lot number is invalid.
- 2.16 Vaccine lot number is too short.
- 2.17 Vaccine administration code is unrecognized.
- 2.18 Vaccine manufacturer is unrecognized.
- 2.19 Vaccine administration route is unrecognized.
- 2.20 Vaccine body site is unrecognized.

Timeliness is the amount of time between the occurrence of the real-world event and its documentation in the IIS, (i.e., the time lag between the date of vaccination or birth and the date the record is received by the IIS).<sup>4</sup>

#### Vaccination event timeliness measures

3.1 Administered vaccination events are entered into the IIS within one clinical day from administration date.

#### 23. What types of reports will be available?

- As a standard within each M&I content area, each IIS receives an individualized report within AART.
- Each IIS will have control over who—if anyone—is allowed to see its report in either named or unnamed fashion.
- Each IIS will also have access to additional reports based on its data on the NIST tool, qDAR.
- AIRA will develop aggregate reports based on all IIS that submit data in the Assessment phase.
- This will be a once-a-year activity as opposed to quarterly like other content areas.

#### 24. What results will be shared?

AART admin users can set sharing settings in AART. These sharing settings continue to function as they do in other content areas (i.e., Transport, Submission, Query, etc.). Refer to the <u>AIRA repository</u> for more information on managing sharing and participation settings.

25. How often will data need to be pulled and sent to AIRA?

AIRA anticipates receiving, measuring, and providing results for the DAR content area once per year.

26. Does an IIS have to submit two separate ADF files to participate in DAR measurement in both Assessment and Testing & Discovery?

No, only one ADF file per IIS jurisdiction is needed for DAR. The measurement processes in each stage can leverage the same ADF file.

27. How much time is needed from IIS staff for developing the extract?

That amount of time will vary by IIS. However, after training and the initial data pull, AIRA does not anticipate this taking more than five hours of staff time for each extract. Reviewing and understanding the results after measurement will take more IIS staff time and will be at the discretion of each IIS. IIS should plan on the first extract taking more time.

<sup>&</sup>lt;sup>4</sup> https://repository.immregistries.org/files/resources/5c002cbde216d/aira dq guide data at rest - final.pdf

28. How much time is needed from IIS staff for the whole process?

During the Testing and Discovery implementation of DAR, AIRA found that IIS staff resources ranged from less than 10 to a maximum of 80 hours of time to perform the entire process from start to finish. The amount of time will depend on each IIS.

29. How much data needs to be included each time I send data to AIRA?

The DAR extract is composed of a cohort of patients born in the past two calendar years prior to submission and their vaccination information.

- 30. Are there computer minimum specifications to run the tool?
  - Yes, the only item the computer will need is a recent version of Java. No other specifications are required to use the tool provided by NIST.
- 31. Do you have a statement of assurance or validation of some kind for the software that I can provide to my IT department to support installation and use?

Yes, AIRA developed a <u>statement of support</u> for IIS. This statement and associated documentation to support the use of NIST tools can be found <u>here</u>.

32. Can an IIS verify what data are in the encrypted detections file that will be sent to AIRA?

Yes, NIST has created a way for the IIS to see what the encrypted detections file contains prior to sending it to AIRA.

- 33. Will the NIST tool need updates, or will IIS need to get newer versions?
  - We do not anticipate frequent changes to the NIST Data at Rest tool. However, updates may occur, and AIRA would provide the updated tool to IIS prior to the measurement time frame.
- 34. Does any protected health information leave the jurisdiction's IIS?

No, as with all content areas within M&I, AIRA is careful not to include any identified data. AIRA worked closely with NIST on a solution that sends only counts of data quality detections without any identifying information.

35. How long will the data I am sending to AIRA be retained? Will we receive confirmation when it is destroyed?

Currently, all data are hosted on a secure Microsoft Azure cloud environment. If AIRA's retention policy changes in the future, IIS will be notified of the timeline and process.

36. Who can access the data that are sent to AIRA?

Only AIRA technical staff have access to data from M&I content areas. AIRA periodically receives information requests from CDC and partners. We honor all

sharing settings when responding to these requests and mostly provide aggregate data across all IIS.<sup>5</sup>

#### 37. What will the data be used for?

The data will be used in the NIST tool only to determine detections for data at rest. Results from the analysis of the data will be displayed in AART. Settings within AART will function the same as they do with other content areas being measured as part of M&I (Transport, Submission, Query, etc.).

38. Could our jurisdictional firewalls or other permissions cause challenges?

Yes, if the user attempting to use the NIST-provided tool does not have appropriate permission, this could be a barrier. However, we anticipate that for most jurisdictions the use of this tool will fall within normal day-to-day computer use for IIS staff.

39. If I am cloud hosted, can my IIS vendor send AIRA the data?

Yes, AIRA will work with all IIS vendors and implementors as needed.

## Funding and Costs

40. What will it cost my IIS to be measured?

All testing is conducted by AIRA at no cost to immunization programs and IIS. Recommended system enhancements discovered through the testing process may have system modification costs. IIS may have other resource costs associated with participating in M&I; however, as independent third-party testing increases, costs associated with other self-reporting measures (e.g., IISAR) may decrease.

41. Who is funding AIRA to do this testing work?

The M&I Initiative is part of AIRA's Cooperative Agreement with CDC. The Cooperative Agreement charges AIRA with conducting evaluations of IIS adherence to standards and identifying gaps in adoption and implementation.

As a member-based organization, AIRA's primary mission is to serve our members. The AIRA board of directors guides the design and implementation of initiatives.

### Technical Assistance

42. Is there technical assistance available to help my IIS staff, immunization program manager, IIS vendor, or central IT partners prioritize and plan enhancements?

Yes, AIRA technical and programmatic staff are available to meet with teams to strategize on how best to prioritize enhancements. Technical assistance requests can be submitted via <a href="this web form">this web form</a>.

<sup>&</sup>lt;sup>5</sup> Aggregate IIS Assessment reports for Transport, Sub/Ack, QBP/RSP, CDS, and DQI are located here: https://www.immregistries.org/assessment

43. Where can I find more information about the M&I process?

Please visit the <u>AIRA website</u> for more information on the Measurement and Improvement Initiative.

## Record of Changes

Date	Description
12/6/2023	Minor editorial updates to all sections.
6/7/2023	Added link to the statement of support.