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A guide to electronic case reporting (eCR) for birth defects surveillance (BDS)

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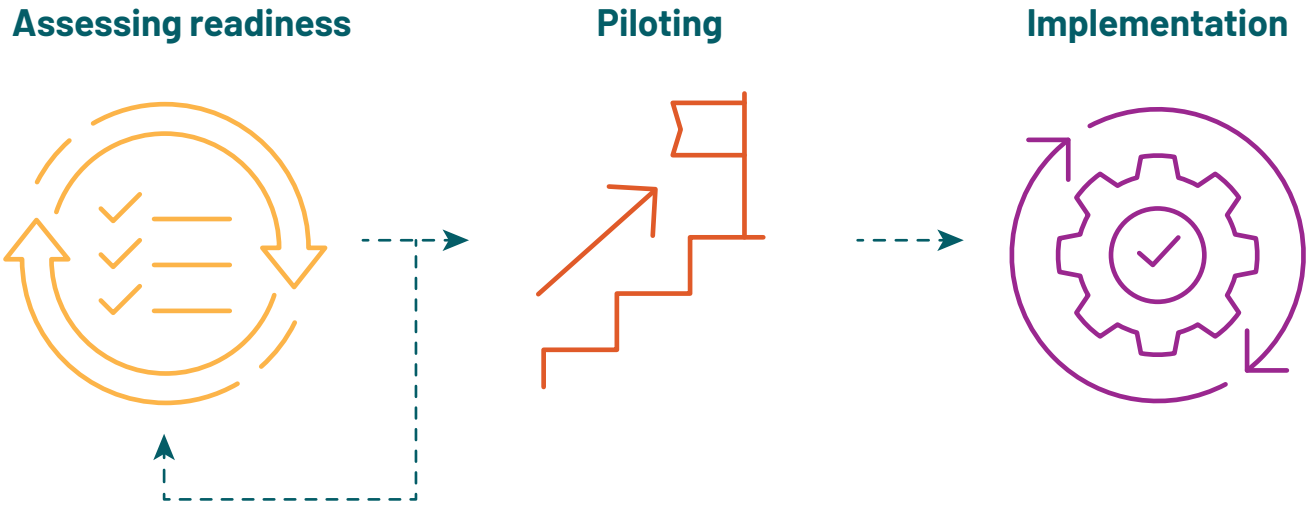
Overview

This guide outlines key questions and considerations for jurisdictions as they navigate the structured process of readiness assessment, piloting, and production deployment for electronic case reporting (eCR) in birth defects surveillance (BDS). Users of this guide, including BDS program managers, can decide if eCR is right for the birth defects program based on available resources, partner engagement, and specific data needs. The guide is divided into three sections: assessing readiness, piloting, and implementation.



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Background

eCR was introduced to BDS programs in 2022 as a mechanism for timelier and more accurate BDS reporting. While the BDS community is still in the early stages of exploring eCR for BDS, eCR may supplement or replace current reporting systems for some healthcare organizations (HCOs), improving the efficiency and accuracy of data sharing with BDS programs.

eCR is made possible through partnerships across several organizations and agencies. The Centers for Disease Control and Prevention (CDC) eCR program provides general oversight and direction for the eCR program and is responsible for onboarding healthcare organizations to report health conditions to state and territorial health departments. The Council of State and Territorial Epidemiologists (CSTE) has undertaken the administrative work of including birth defects conditions in the Reportable Conditions Knowledge Management System (RCKMS), a web-portal for public health agencies to input, edit, and manage jurisdictional reporting, making it feasible for BDS programs to explore this technology. RCKMS sits on an intermediary services platform, the Association of Public Health Laboratories (APHL) Informatics Messaging Services (AIMS), a secure, cloud-based platform.

Each US health jurisdiction has an eCR program. The duties of a jurisdictional eCR program include ensuring reporting rules are followed, enabling data sharing between healthcare organizations and public health agencies, and enhancing public health monitoring and response.

Clarify the intent of eCR for BDS

As programs begin to explore eCR for BDS, they must clarify their intent for eCR, both why there is interest in its use and how they would like to use eCR for BDS. While data received through eCR is standardized, programmatic use of eCR and data contained within electronic initial case reports (eICRs) can vary. Setting expectations early for partners, staff and leadership can inform methods for piloting eCR and frame evaluation activities.

Regarding how BDS can use eCR, programs will want to consider if they expect to use eCR primarily as a case identification/notification method, or a case identification/notification method and a case investigation method. At this stage, BDS programs may be unsure which approach is best suited to their needs. In that case, evaluating eCR for case identification and investigation is recommended.

1. **eCR for Case Identification/Notification Only:** eICR serves as an alert for potential cases, requiring separate, more detailed case investigation methods like medical record abstraction. Limited data elements (e.g., name, date of birth [DOB], medical record number [MRN]) are sufficient for this use.

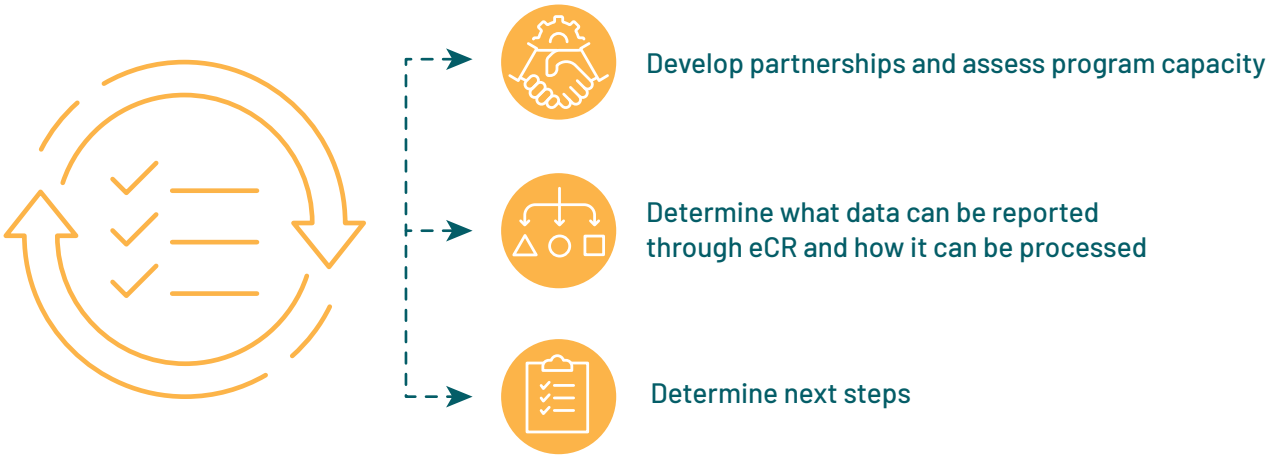
2. **eCR for Case Identification/Notification AND Case Investigation:** eICRs are the primary source for comprehensive case information directly from healthcare facilities. This requires a broader range of data elements (e.g., detailed birth defects descriptions, procedures). More information about data elements contained in eICRs can be found here.

eCR has the potential to reduce manual data collection processes, improve the completeness and accuracy of BDS data, and/or improve data timeliness. Having a clear understanding of why the BDS program wants to explore eCR to supplement or replace surveillance methods can help engage leadership, focus pilot methods, and inform the interpretation of evaluation results. Establishing objectives early—both how and why—directly impacts the ability of the program to understand how well eCR can supplement or replace existing surveillance methods and help the surveillance system function effectively and efficiently. This intent should be communicated to partners throughout the process.

While eCR is a well-supported program with the potential to enhance BDS, it also has limitations: it does not currently cover all birth defects conditions and adoption amongst healthcare facilities is voluntary, which means not all healthcare facilities in a jurisdiction necessarily participate. Currently, over 40 birth defects and infant disorder conditions are available in RCKMS. All data elements needed by the birth defects program may not be populated on eICRs so traditional methods of birth defects reporting will remain necessary to fill gaps and ensure comprehensive data until eCR is more widely adopted in a jurisdiction.

Assessing readiness

This section contains questions and considerations to help a jurisdiction assess its readiness to use eCR for BDS. Programs should use the questions to evaluate their current partnerships, program capacity, data needs, and support for eCR. The last questions in this section serve as criteria to determine if it is time to take the next step, piloting eCR for BDS.



Other considerations for assessing the capacity of eCR in a jurisdiction

It is highly recommended to collaborate with other public health agencies that have already implemented birth defects conditions via eCR to become aware of potential data flow and eICR processing options. For contacts in this area, request to join the National Birth Defects Prevention Network Electronic Health Record Workgroup (NBDPN EHR WG) using this email: nbdpn@nbdpn.org.

Develop partnerships and assess program capacity

Leadership

Senior-level support is the single most critical success factor for projects involving change. Depending on the program's organizational structure, it may want to engage birth defects/Maternal and Child Health (MCH) program or other critical leaders to address the questions below.

- Is program leadership supportive of exploring the feasibility of eCR?
- If yes, are they supportive of transitioning BDS to eCR if determined to be appropriate/feasible?
- If not, what is needed to gain their buy-in to explore the feasibility of eCR?

Consider the BDS business case in the BDS requirements toolkit if additional help is needed.

Jurisdictional eCR and BDS programs

Each state and territory has an eCR team that needs to be engaged as jurisdictions assess if BDS is ready for eCR. Some eCR programs have limited bandwidth or only focus on specific conditions, and this needs to be defined early in the process.

- Can the jurisdictional eCR team support the birth defects program at the current time?
- Operational questions:
  - Are there IT resources (e.g., developers) available to support the eCR for BDS specific work?
  - Will the eCR team or the BDS program author the rules in RCKMS?
  - How will data files/eICRs be shared with the BDS program? (e.g., file type, transmission mechanism, and cadence of sharing eICRs)
  - What quality control, if any, does the eCR program perform before eICRs are sent to the BDS program? What quality control would the BDS program need to do?

Determine what data can be received through eCR and how it can be processed

Part of assessing readiness is understanding which birth defects can be reported through eCR and which still need to be reported in other ways. Knowing what information (data elements) can be sent through eCR is also key. eICRs include data elements broadly identified as necessary for public health to initiate a case investigation and may include demographic or clinical information. But they may not include all the data elements deemed necessary for BDS by each jurisdiction.

- Which defects are included? Refer to RCKMS Content Repository for BD Condition Codes for the latest information.
- Which data elements are included in the eICR?

The National Birth Defects Prevention Network (NBDPN) data elements have been mapped to eICRs. BDS programs will need to identify gaps in the reporting of non-NBDPN data elements and take action to close any identified gaps.

Determine which healthcare facilities are reporting through eCR

Healthcare organizations may be at varying stages of eCR implementation, reporting all, some, or no birth defects conditions. In 2025, all healthcare organizations participating in eCR that use electronic health record (EHR) products other than Epic began reporting all conditions contained in RCKMS, including birth defects. HCOs using Epic have the option to report all or selected conditions in RCKMS. The BDS program should inventory the healthcare facilities currently reporting to BDS and then answer the questions below. This information will help assess the anticipated healthcare facility coverage possible through existing eCR connections.

- Which healthcare facilities currently participate in eCR?
- Which healthcare facilities are reporting birth defects conditions, specifically?
  - Programs should map BDS reporting facilities to the list of facilities participating in eCR provided by CDC to each jurisdictional eCR program. Since healthcare facility names can differ across systems, apparent discrepancies or uncertainties can be discussed with the jurisdictional eCR program.
  - BDS programs can discuss the timeline for a HCO that is onboarded to eCR but not reporting birth defects cases to initiate reporting of all conditions and can discuss outreach and onboarding of new HCOs that are not participating in eCR.

How data will be processed

Once the data is received, it is critical to determine how the birth defects data from eICRs will be received, processed, and managed within the birth defects program. This can be done by answering the following questions and documenting workflows in collaboration with the jurisdictional eCR team.

- What format will the data be in? eICRs can often be shared with programs in two different formats:
  - HTML documents can be read easily by people and are ideal when a BDS program needs to enter case data into its surveillance system manually.
  - XML files are machine-readable and are ideal when the BDS system can ingest data files into the surveillance system.
- How will data be parsed or loaded into the birth defects database?
  - Will it be done using manual data entry or automated uploads? A health department may choose manual data entry for smaller case volumes to ensure accuracy, while larger programs may use automated processes to handle high volumes and minimize errors.

Determine next steps

At this point, consider if it is appropriate to move forward with piloting eCR for BDS in a jurisdiction by answering the following questions. This should be a collaborative decision between the program, leadership and jurisdictional eCR, and should be based on what has been learned so far.

- Does the BDS program and jurisdicitional eCR program have support and resources to pilot?
- Is there sufficient coverage across facilities (e.g.,% of current reporters participating, % of cases anticipated from participating facilities)?
- Is there sufficient coverage across defects (e.g., % of conditions, % of cases across all conditions)?
- Is there sufficient coverage across data elements?
  - If eCR is used for case identification with subsequent medical record review for additional case investigation, assess if the required variables to identify and access the medical record (e.g., infant name, DOB, MRN, diagnosis) are present and sufficiently complete.
  - If eCR is used for case investigation, then assess if the required data elements are sufficiently complete.

If the program determines that it cannot move forward with eCR, it can consider other ways to improve the timeliness, efficiency and/or quality of birth defects reporting with either existing or new technologies that are available in its jurisdiction. If it cannot move forward with eCR, the program can document the reasons why eCR does not work at the time. Then it can consider reevaluating if eCR is a good fit for the jurisdiction in 6 months. Depending on the barriers the jurisdiction faces, it may need to alter this timeframe. For additional considerations, visit: cdc.gov/ecr/php/index.html.

Piloting eCR

This section provides guidance on piloting eCR for BDS for programs whose readiness assessment indicates they are ready to move forward.

Determine and document processes

It is recommended to pilot eCR in parallel with existing surveillance methods to facilitate evaluating the impact of implementation.

For BDS programs exploring eCR for case identification/notification, selected eICR data elements should be compared to data elements received through current case identification/notification methods (e.g., data elements on the hospital discharge/diagnosis index, etc.). There may be a delay between receipt of an eICR and receipt of case notification via current methods. These dates should be recorded if the program is evaluating the impact of eCR on data timeliness.

For BDS programs that conduct medical record abstraction and want to evaluate eCR as a case investigation method, they may conduct abstraction immediately after eICR receipt–even if the BDS program has not received notification of the case through other current methods–to facilitate more timely evaluation.

Existing surveillance systems will need to incorporate eCR data upon receipt. Testing will ensure seamless operation before full implementation. Finish these steps to complete the piloting stage of eCR implementation.

Suggested steps for piloting eCR for BDS

1. **Define your evaluation questions, methods and data requirements (e.g., surveillance data elements, staff surveys, etc.) to ensure you're collecting the information needed to assess the impact of eCR on BDS and your program and determine if you will move forward with full implementation after the pilot.**
   - If evaluating data timeliness, ensure you record critical dates (e.g., date eICR was received, date case was reported to the BDS program on a disease/discharge index).

2. **Review BDS and jurisdictional eCR program data privacy, confidentiality and security requirements to ensure compliance.**
   - Establish Data Use Agreements (DUA), Memorandums of Understanding (MOUs) and other documentation, as necessary.

3. **Document the BDS processes that will be introduced or changed to incorporate eCR. This is a multi-step process.**

- **Ensure all data elements needed to answer the evaluation questions can be collected and stored in the BDS database**
  - It is important to note that some eICRs will be triggered from the maternal medical record (e.g., a prenatally diagnosed anencephaly triggered on ICD-10-CM code 035.02) and some will be triggered from the infant medical record (e.g., an infant diagnosed with anencephaly at delivery triggered on ICD-10-CM code Q00.0).
  - Regardless of whether BDS programs automatically upload or manually enter data from the eICR into their database, procedures should be in place to distinguish between eICRs triggered on maternal records versus infant records, since data elements on the eICR would map to different data elements in the BDS database (e.g., name on the eICR could map to maternal name or infant/case name).
- **Storage of data elements:** It is recommended to store data elements obtained through eCR separately from data elements from current surveillance methods to facilitate data management and evaluation tasks (e.g., store infant date of birth from the eICR in a field labeled BABY_DOB_ECR and date of birth from the medical record or Vital Record in a field labeled BABY_DOB)
- **Document where/how/when data are received/accessed/stored**
  - Who sends/receives the eICR?
  - How are the data stored?
  - What cadence is used to send the data?
- **Document data quality processes before and/or after uploading/entering eICR data to the BDS database**
  - Data quality assurance (what checks are completed by the eCR staff? Which need to be monitored by program staff?)
  - Multiple eICRs: It is critical to decide how to handle multiple eICRs for the same case while in the pilot stage. Consider the following:
    - Multiple eICRs may be flagged automatically to prevent duplicate reporting and ensure record consistency. This process should be established in collaboration with the jurisdictional eCR program.
    - Determine the implications for multiple eICRs with different information that might be more accurate over time, as diagnoses evolve after delivery. Questions to consider include the following:
      - How will duplicate eICRs be detected?
      - Once they are detected, how will they be managed? Should the records be merged or nullified?

4. Document staff roles and responsibilities for receiving and managing eICRs at the BDS program. Train staff, if needed.

- For a successful pilot, document the roles and responsibilities of those involved in the project. Refer to the Appendix for details on the specific roles of partners in eCR.
- Include name and contact info for jurisdictional eCR program staff responsible for transmitting (or making available in a shared data environment) eICRs to the BDS program.
- Include name and contact info for staff responsible for receiving and managing eICR data within the BDS program.

5. Document, test and implement BDS system/database changes to facilitate data collection and management.

- The pilot may require updates to surveillance systems. Some programs may update fields or may automate the uploading of eICRs to the system. If major system updates are required, BDS programs should follow the systems development life cycle to accept eCR data for automated processing, evaluation and routing of eCRs.

6. Work with your jurisdictional eCR team to author birth defects conditions in RCKMS and determine timeboxing requirements.

- Confirm the rules in RCKMS have been authored and align with jurisdiction-specific reporting requirements.
- Consider timeboxing as rules are authored.
  - Timeboxing sets a time limit to check if a diagnosis in an eICR is recent enough to report, ensuring only timely and relevant cases are included.

7. Receive eICR data, following documented data management procedures.

- Receive the eICR data for a pre-determined amount of time.
  - When receiving eICRs, document and compare the data that comes from the eICRs and what is received through traditional reporting.

8. **Review initial data (e.g., after one month of data collection) and processes to determine if changes are needed.**
   - Run comprehensive tests with controlled environment specifications before moving to production.
   - Select at least 100 cases for the sample with the specific date of birth range rather than sampling HCOs. The quality of eICRs differs by facility and this sample provides a better sense of sensitivity.
   - Continue to identify and address issues and make iterative improvements throughout the pilot phase based on ongoing results.
   - Work with the jurisdictional eCR program to gather feedback during the pilot phase, including information on system usability, data quality and completeness and technical performance. During this phase, refine data elements and improve system interfaces as needed while ensuring alignment with birth defects program needs.

9. **Complete pilot. Then analyze data and interpret results in the context of the evaluation questions.**
   - As you are wrapping up the pilot, determine if eCR is a good fit for the BDS program. Considerations include the impact on staff and data quality and the evaluation questions you drafted in Step 1. Consider the CDC evaluation framework to assess timeliness, accuracy, completeness, and resources. (Link to be added when available).

Determine next steps

At this point, consider if it is appropriate to move forward with implementing eCR for BDS in the jurisdiction by answering these questions:

- Determine if it's appropriate to move forward with implementation
  - Would full implementation replace some or all of the current processes?
  - Does the program have the support and resources to move to full implementation?
  - What did the evaluation results tell you?

Implementation

Once piloting testing is complete, it is time to transition to full implementation. It is important to update processes and documentation based on the pilot and lessons learned. This could include the roles of the BDS program and the jurisdictional eCR team.

Update processes and documentation

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Establish ongoing monitoring and evaluation

Once the systems are operational, BDS staff should continuously monitor and track the performance of the eCR system and ensure data quality. Staff should set up feedback loops and establish plans for regular system improvements and evaluations. Staff should consider documenting lessons learned and sharing best practices to support other programs in implementing eCR.

- Regularly evaluate system performance.
- Collect feedback for improvements.
- Update systems as needed to optimize eCR functionality.
- Monitor healthcare facilites that initiate birth defect reporting through eCR so they can be rolled off current non-eCR reporting processes.

Communication

To begin using eCRs as a public health reporting option, gradually replace some manual reporting methods where appropriate while maintaining others as needed. This step will require all partners (see Appendix), key data reporters and receivers to be informed, trained and supported during the transition. Develop a communication plan to assist with this process.

Appendix

Partner-specific roles in eCR for Birth Defects Surveillance

The table below clearly outlines each partner's roles and responsibilities. BDS programs engage with these key partners to support eCR implementation and improve BDS.

Partner	Roles in eCR workflow activities
BDS program staff	■ Identify and engage interested parties (e.g., Maternal and Child Health [MCH] leadership, eCR leadership, IT resources, a developer and others) to support and commit to eCR implementation at the health department. ■ Collaborate with the jurisdictional eCR program to identify healthcare organizations (HCOs) that report through eCR. ■ Identify what data and conditions are being sent or can be sent through eCR from each HCO. ■ Determine and assess how eCR data can replace or supplement existing and historical reporting processes. ■ Document birth defects-specific data workflows for current and future BDS reporting.
Jurisdictional eCR programs	■ Identify and engage local healthcare entities and HCOs within the jurisdiction for eCR adoption and participation in BDS reporting. ■ Determine how birth defects data will be reviewed, stored and shared by the eCR program, a public health agency system, or directly with the birth defects program. ■ In collaboration with the BDS program, determine roles and responsibilities of processing eCR data, including quality control. ■ Work with the CDC eCR team to onboard new HCOs and test how birth defects data from eCR fits into state processes. ■ Oversee the rollout and day-to-day operations of eCR within the jurisdiction. ■ Assist BDS program with connections to APHL in onboarding activities with eCR Coordinator, if needed. ■ Participate in national eCR calls and forums to engage with other jurisdictions and eCR partner organizations.

Partner	Roles in eCR workflow activities
Healthcare organizations (HCOs)	■ Add the full trigger code list, which includes BDS conditions, to their eCR interface. ■ Participate in provider onboarding of eCR if not already actively sending eCRs. ■ Collaborate with EHR/Health IT products to build eCR capabilities, perform testing and coordinate with HCOs to implement eCR: cdc.gov/ecr/php/getting-started/index.html
Council of State and Territorial Epidemiologists (CSTE)	■ Provides access to the Reportable Conditions Knowledge Management System (RCKMS) for the responsible authoring party. ■ Provides technical assistance and training for setting up and managing reporting rules of BDS conditions in RCKMS. ■ Provides forums to facilitate discussion among public health agencies for eCR implementation, data flow and eICR processing options (CSTE eCR Workgroup, RCKMS/eCR Workgroup for Birth Defects and Infant Disorders, Newborn Screening eCR Workgroup, CSTE Connect/Basecamp communities).
APHL eCR team	■ Provide EHR vendor product testing and validation. ■ Provide HCO onboarding, AIMS connectivity testing. ■ Establish HCO policy path for eCR implementation. ■ Provide access to electronic Reporting and Surveillance Distribution (eRSD) for triggering eICRs from HCOs. ■ Offer direct support and technical assistance for public health agency. ■ Provide forums for discussion on EHR/HCO implementation and eCR data quality issues (eCR Data Quality Call). ■ ecr.aimsplatform.org/general/
CDC eCR team	■ Provide EHR vendor product testing and validation. ■ Supply HCO onboarding and AIMS connectivity testing. ■ Establish HCO policy path for eCR implementation. ■ Provide forums for discussion on EHR/HCO implementation and eCR data quality issues (eCR Data Quality Call). ■ cdc.gov/ecr


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