Lessons learned from the eCR implementation of birth defects surveillance (BDS) in Texas, Minnesota and California

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Executive summary

Overview

This report provides a synthesis of experiences and lessons learned from the initial implementations of electronic case reporting (eCR) for birth defects surveillance (BDS) across three states: Texas, Minnesota and California. The experiences documented in this report highlight the successes and challenges encountered as these states work to develop, pilot and implement eCR and offer guidance for other programs planning similar initiatives.

Background

The implementation of eCR for BDS represents a significant advancement in public health monitoring and surveillance. eCR is a collaboration among the Association of Public Health Laboratories (APHL), Centers for Disease Control and Prevention (CDC) and the Council of State and Territorial Epidemiologists (CSTE) that aims to enhance public health monitoring through the automated generation and transmission of case reports from electronic health records (EHRs) to public health agencies for review and action.[1] eCR aims to automate the transmission of case reports from EHRs to public health agencies and establish bidirectional, or two-way, information exchange between the two. eCR can result in more accurate, complete and timely data to support public health action. More timely detection of health-related conditions or events of public concern can result in rapid intervention and lowered disease transmission.[2]

eCR was introduced to BDS programs in 2022 as a mechanism that could be used for more timely and accurate BDS reporting. Most recently, CSTE has undertaken the administrative work of including birth defects conditions to the Reportable Conditions Knowledge Management System (RCKMS), making it feasible for BDS programs to explore this technology for routine surveillance needs.

Methods

A team from Public Health Informatics Institute (PHII) facilitated discussions with key BDS program members from Texas, Minnesota and California to gather insights into their experiences with eCR implementation. Between February and June 2024, program managers, data analysts and IT specialists involved in the eCR projects participated in these discussions. A question guide was used to ensure consistency across discussions and is attached in the report appendix. PHII spoke with staff from the Texas BDS program and staff from Minnesota and California provided detailed written responses to the questionnaire, which was then reviewed by PHII, who followed up with additional questions. All responses were synthesized for key themes.

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[1] https://ecr.aimsplatform.org/
[2] https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0198845

Of note, all three BDS programs are in the initial phases of developing and implementing eCR for BDS and have not completed implementation for routine use. At the point of information gathering, the BDS programs were either piloting eCR and evaluating data coming in or in the data extraction and structure phase.

Key findings

The initial implementation of eCR in BDS programs across Texas, Minnesota and California impacted workflow integration, data accuracy and timeliness, resource management, staff training and support, and data exchange infrastructure. Each program faced unique challenges and developed innovative solutions. These results highlight the importance of shared learning and collaboration. The following summarizes the key insights from all three programs' initial implementation and continued development of eCR for surveillance.

Workflow Integration

- **Texas**: The BDS program employed an iterative approach to workflow integration, adjusting plans based on pilot projects and strategic developments. As a result, the program is improving workflow adaptability and process efficiency.
- **Minnesota**: The BDS program added eCR data fields to its information system and employed Amazon Web Services (AWS) data lakes for data extraction and routing. This integration led to more effective data management and streamlined workflows.
- **California**: The BDS program used SQL Server scripts and SQL Server Integration Services (SSIS) for data transformation and importation, evolving its process through active participation in workgroups. Consequently, the implementation led to more efficient data handling and process improvements.

Data accuracy and timeliness

- **Texas**: The BDS program is receiving more timely data acquisition but has identified gaps in critical data elements. The eCR implementation has the potential to enhance the speed of data collection and case identification, as well as faster referrals to services, thus improving service delivery to families.
- **Minnesota**: The BDS program improved timeliness and case confirmation with dual reporting systems (eCR and manual flat file reporting). This led to better data accuracy and quicker case verification, ensuring comprehensive data capture.
- **California**: The BDS program focused on structuring and validating data with third-party partnerships for initial quality control checks. The eCR implementation improved data quality and the timeliness of reporting, setting a foundation for statewide surveillance.

Resource management

- **Texas**: The BDS program addressed initial resource gaps through CDC cooperative agreements and a strategic hire. The eCR implementation included securing necessary resources and improving staff capacity ensuring program sustainability.
- **Minnesota**: The BDS program managed staffing needs with data-sharing agreements and dedicated reporting websites. As a result, resource allocation was optimized and data management efficiency was enhanced.
- **California**: The BDS program increased staffing capacity with new hires and third-party contractors, though ongoing resource needs persist. The eCR implementation strengthened staffing and resource management, contributing to the program's long-term goals.

Staff training and support

- **Texas**: The BDS program focused on continuous training in interoperability, data exchange and external expertise. This approach increased staff capabilities and improved handling of eCR processes, resulting in a more skilled workforce.
- **Minnesota**: The BDS program used training videos and internal documents to prepare staff for eCR processes. This led to a well-prepared team capable of managing new data workflows effectively, ensuring smooth program operations.
- **California**: The BDS program emphasized extensive training and collaborations with established programs for successful eCR implementations. This resulted in a knowledgeable workforce and effective eCR integration, promoting ongoing learning and adaptation.

Data exchange infrastructure

- **Texas**: The BDS program used the State Health Analytics and Reporting Platform (SHARP) and Snowflake repository for effective data management. As a result, data integration and analysis became more efficient and effective, supporting enhanced decision-making.
- **Minnesota**: The BDS program employed AWS data lakes for efficient data extraction and integration. This infrastructure led to seamless data management and improved analysis capabilities, ensuring robust data handling.
- **California**: The BDS program developed and automated data import processes using SQL Server scripts and SSIS. The eCR implementation provides streamlined data integration and improved system efficiency, facilitating better data processing.

Recommendations

The implementation of eCR in BDS programs has revealed insights and recommendations to ensure successful adoption and sustainability. Based on the experiences of BDS programs in Texas, Minnesota and California, PHII synthesized the following recommendations for other states and public health programs:

Adaptive strategy development
Recommendation: Implement flexible planning with real-time adjustments based on feedback and pilot outcomes.
Rationale: Texas BDS program staff used an iterative process, while Minnesota BDS program staff followed a defined plan due to funding constraints.

Both states adjusted their plans as implementation progressed, demonstrating the importance of flexible and adaptive strategy development. California BDS program staff also emphasized early planning, evolving through active participation in workgroups.

Training
Recommendation: Develop continuous training programs, including periodic updates and advanced sessions, to keep BDS staff proficient with evolving technologies and processes.
Rationale: Leveraging training resources ensures that BDS program staff are well-equipped to handle new technologies. Texas BDS program staff focused on continuous training in interoperability, while Minnesota and California BDS program staff used various training resources to prepare staff for eCR processes.

Data governance
Recommendation: Establish a robust data governance framework ensuring data quality, security and compliance through regular audits and evaluations.
Rationale: Regular evaluation of pilot data for completeness, timeliness and accuracy is essential. Both Texas and Minnesota BDS program staff created new workflows for reviewing eCRs, while California BDS program staff partnered with a third-party entity to streamline data processing and ensure quality control.

Cross-state collaboration
Recommendation: Foster collaborative environments across the states and jurisdictions, creating platforms for sharing insights, challenges and best practices.
Rationale: Sharing experiences and best practices can help overcome common challenges. The collaborations seen in the experiences of the different state BDS programs highlight the value of shared learning and cooperative problem solving.

Technology optimization

Recommendation: Regularly review and optimize the use of existing data management, analytics and reporting platforms and vendor-developed data lakes, ensuring full integration into operations.

Rationale: Texas BDS program staff used their state's Health Analytics and Reporting Platform (SHARP) for eCR data feeds, Minnesota BDS program staff employed AWS data lakes, and California used SQL Server scripts and SSIS.

Regular review and optimization of these tools are crucial for effective data management.

Resource allocation efficiency

Recommendation: Focus on strategic resource allocation, prioritizing high-impact areas and maintaining flexibility to reallocate resources as needed.

Rationale: Addressing resource gaps through strategic hires and funding, as seen in Texas and California BDS programs, ensures adequate staffing and resources for eCR implementation. The Minnesota BDS program managed resources effectively through data-sharing agreements and dedicated reporting websites.

Continuous improvement

Recommendation: Promote continuous improvement with regular feedback loops, open communication channels and proactive problem-solving.

Rationale: Documenting lessons learned and continuously refining processes based on these findings are key to maintaining efficient processes and addressing workflow and system issues.

The continuous refinement observed in all three states underscores the importance of a proactive approach to problem-solving.

Long-term sustainability planning

Recommendation: Plan for the long-term sustainability of eCR systems by braiding different funding sources to secure ongoing funding, building resilient infrastructure and developing scalable processes.

Rationale: Ensuring long-term sustainability involves securing funding, as the Texas BDS program did through CDC cooperative agreements, and building an infrastructure capable of supporting ongoing and future needs, as demonstrated by the California BDS program's strategic hiring and third-party partnerships.

Introduction

The implementation of eCR for BDS represents a significant advancement in public health monitoring and surveillance. eCR is a collaboration among the Association of Public Health Laboratories (APHL), Centers for Disease Control and Prevention (CDC), and the Council of State and Territorial Epidemiologists (CSTE) that aims to enhance public health monitoring through the automated generation and transmission of case reports from EHRs to public health agencies for review and action.[3] eCR aims to automate the transmission of case reports from EHRs to public health agencies and establish bidirectional, or two-way, information exchange between the two. eCR can result in more accurate, complete and timely data to support public health action. More timely detection of health-related conditions or events of public concern can result in rapid intervention and lowered disease transmission.[4]

eCR was introduced to BDS programs in 2022 as a mechanism that could be used for more timely and accurate BDS reporting. As the eCR initiative grew across the United States, CDC's BDS program assessed the implementation of eCR specifically to support the reporting of birth defects to public health. Most recently, CSTE has undertaken the administrative work of including birth defects conditions to the Reportable Conditions Knowledge Management System (RCKMS), making it feasible for BDS programs to explore this technology for routine surveillance needs.

Why implement eCR?

California: The California BDS program's initial motivation for implementing eCR stemmed from the California Future of Public Health Initiative, which presented an opportunity to enhance workforce capacity, evaluate and modernize existing processes and expand interoperable platforms through the standardized electronic initial case report (eICR). Currently, the BDS program is actively working on transforming and importing eICR data into an SQL Server database using SQL Server scripts and SSIS, aiming to improve public health surveillance and response.

Minnesota: The BDS program in Minnesota added a redesign of data fields in the information system (IS) to accept eCR data to the scope of this project. AWS data lakes are in the process of being used to help extract data appropriately and route that data to the BDS system so data can be used more effectively.

Texas: The BDS program in Texas used the State Health Analytics and Reporting Platform (SHARP) for a new data feed for eCR that can be queried by Snowflake. The instant update of patient information in eCR is crucial for timely referrals, as many birth defects require early intervention and services for better outcomes.

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[3] https://ecr.aimsplatform.org/
[4] https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0198845

Additionally, instead of periodically requesting discharge lists from hospitals, staff can identify potential cases using Snowflake. Therefore, in the future, if we can incorporate eCR into our surveillance system and registry, it will have a significant positive impact on timeliness, accuracy, and completeness.

Methods

A team from PHII facilitated discussions with key BDS stakeholders from Texas, Minnesota and California to gather insights into their experiences with eCR implementation. The discussions took place between February and June 2024, and participants included program managers, data analysts and IT specialists involved in the eCR projects. A question guide was used to ensure consistency across discussions and is attached in the report appendix. PHII spoke with staff from the Texas BDS program, and staff from Minnesota and California completed the questionnaire, which was then reviewed by PHII, who followed up with additional questions. The answers were synthesized for key themes and then validated with the BDS programs.

Overview of the BDS programs

The Texas, Minnesota and California BDS programs are state-based initiatives focused on the surveillance of birth defects. These programs aim to collect, analyze and use data on birth defects to improve public health outcomes. By implementing eCR, these programs seek to enhance the efficiency, accuracy and timeliness of data collection and reporting.

The BDS programs in California, Minnesota and Texas are in the initial phases of developing and implementing eCR for BDS and have not completed implementation for routine use. At the point of information gathering, the BDS programs were either piloting eCR and evaluating data coming in or in the data extraction and structure phase.

Results

After reviewing the responses from the three eCR implementation states, five key themes emerged: workflow integration, data accuracy and timeliness, resource management, staff training and support, and data exchange infrastructure. These themes highlight important aspects of the eCR implementation process in BDS programs, providing insights into the successes and challenges encountered by the Texas, Minnesota and California BDS programs.

Key themes

Below are the key themes that emerged from the discussions with each of the BDS programs regarding their implementation of eCR for surveillance.

Workflow integration

This theme covers the process of embedding eCR into regular BDS surveillance activities, ensuring seamless and efficient data handling.

Based on the responses from the Texas BDS program staff, an iterative approach to workflow integration and adjusting plans based on pilot projects and strategic developments was emphasized. Initially, no defined plan was in place, but an iterative process and a series of pilot projects during the discovery phase proved helpful. A workgroup charter was developed to include strategic planning for the program and eCR flow within the agency. Exploration of eCR began without initial funding, with gaps later addressed through a CDC cooperative agreement. To support the integration, the Texas BDS program hired a project manager and an interoperability project manager. The interoperability workgroup played a critical role in embedding eCR into the regular BDS workflow by coordinating efforts, managing resources and ensuring alignment with the state's surveillance objectives.

Based on the responses from Minnesota's BDS program staff, eCR was integrated by redesigning data fields in the information system to accommodate eCR data. A defined plan was required due to funding constraints, which included a detailed work plan with a project manager and business analyst. Dual reporting systems (eCR and manual flat file reporting) were implemented to ensure comprehensive data capture. New workflows were developed to review eCRs as they arrived, and reports and import rosters were created within the surveillance system to track data quality and completeness. This methodical approach ensured that eCR data could be seamlessly integrated into the regular BDS surveillance activities.

The primary impetus for the California Birth Defects Monitoring Program (CBDMP) to explore eCR was the opportunity under California's Future of Public Health Initiative for an increase in workforce capacity to evaluate and modernize current processes and explore opportunities for expansion and interoperability. The program started without detailed plans but evolved through active participation in workgroups and the development of a comprehensive roadmap. Currently, eCR reports are being transformed and imported into the SQL Server database using SQL Server scripts and SSIS. This transformation involves structuring and validating the data, collaborating with third-party entities for initial quality control checks, and organizing the data in alignment with the established framework. This phased approach allows the California BDS program to incorporate eCR data into the regular BDS surveillance workflow effectively.

Data accuracy and timeliness

Data accuracy and timeliness are critical components in the implementation of eCR for BDS. Data accuracy refers to the correctness and precision of the data collected, ensuring that all information is complete and free from errors. Timeliness involves the speed at which data is collected and made available for analysis and action, enabling prompt response and intervention. The implementation of eCR significantly impacts these

components by automating data collection and streamlining processes, thus improving both accuracy and timeliness.

Texas' BDS program staff achieved more timely data acquisition with eCR. Notwithstanding, they also identified gaps in certain critical data elements necessary for comprehensive BDS. eCR enabled faster case identification, which facilitated faster service provision. However, gaps were identified in the mother's delivery record and it remains uncertain whether eCR captures all the data necessary to document prevalence or make referrals. In these cases, the medical record has to be referenced to ensure completeness.

Minnesota's BDS program staff improved timeliness and case confirmation of birth defects with the implementation of eCR, although dual reporting systems (both eCR and flat file reporting) are still used to ensure comprehensive data capture. A new workflow was created to review eCRs as they come in, requiring monitoring by staff. Additionally, reports and import rosters are being developed within the surveillance system to track data quality and completeness. This allows the program to compare the accuracy, timeliness and other features of eCR and manual flat file reporting.

California Birth Defects Monitoring Program (CBDMP) is currently in the data extraction phase and has an extended timeline for the full use of eCR data, focusing on structuring and validating the data. Efforts are being advanced by partnering with a third-party entity to streamline data processing. This collaboration includes extracting necessary data from reports, organizing them in alignment with the established framework, and conducting initial quality control checks. Once the data structure is established, the analytical team will proceed with comprehensive evaluations to assess completeness, quality and accuracy, ensuring alignment with stringent quality standards.

Resource management

Resource management refers to the strategic planning, allocation and usage of resources, including staff, funding and technology, to support the implementation and sustainability of eCR systems for BDS. Effective resource management ensures that eCR systems are well-supported, adequately staffed and properly funded, leading to more sustainable and efficient surveillance programs.

The Texas BDS program addressed initial resource gaps through CDC state-awarded cooperative agreements and strategic hires, ensuring adequate staffing and resources for eCR implementation. eCR development was initiated without funding, with gaps later addressed through the CDC cooperative agreement. To support the implementation, Texas BDS hired an interoperability project manager. Additionally, new internal and external connections were established to identify others within the Department of State Health Services (DSHS) who could assist with eCR implementation.

The Minnesota BDS program managed staffing needs by leveraging data-sharing agreements and developing dedicated reporting websites, facilitating efficient data management and resource allocation. A website was

created for reporting birth defects, including eCR with standard reporting via flat files. Data-sharing agreements specific to the BDS program were also established to streamline the process.

The California BDS program increased staffing capacity with new hires and third-party contractors, although ongoing resource needs for sustaining the eCR initiative continue to exist, which included the hiring of three new positions: a senior evaluation/data scientist, a junior research scientist and a health program specialist for project management activities. At the time of this report, the process of completing the final hire is currently underway. Additional informatics/systems analyst capacity is needed and this gap is being covered by leveraging a third-party contractor under the direct supervision of the Registry Manager.

Staff training and support

Staff training and support involve the provision of necessary education, resources and ongoing assistance to ensure that staff members are well-prepared and capable of managing eCR processes effectively. Training is critical to the successful implementation of eCR, as indicated by the experiences of the Texas, Minnesota and California BDS programs. Continuous training on interoperability and the importance of partnerships were emphasized across all three jurisdictions. Key strategies included leveraging external expertise, using training resources like the RCKMS and CSTE documentation, and employing training videos from various sources. The establishment of strong partnerships and collaborations was also highlighted as beneficial. These efforts collectively contributed to building a knowledgeable and capable workforce, essential for the effective management of eCR processes. Specific examples and detailed strategies can be found in Attachment I.

Data exchange infrastructure

Data exchange infrastructure refers to the systems and platforms used for managing, integrating and analyzing eCR data, ensuring that data can be efficiently processed and utilized within BDS programs. Effective data exchange infrastructure is crucial for the seamless operation of eCR systems, facilitating the timely and accurate processing of data to support public health interventions.

The Texas BDS program used the State Health Analytics and Reporting Platform (SHARP) and Snowflake for effective data management. SHARP was used for new data feeds for eCR, which could then be queried by Snowflake. This combination facilitated the integration and analysis of eCR data, ensuring data was managed effectively and efficiently.

The Minnesota BDS program employed AWS data lakes for efficient data extraction and integration. AWS data lakes were used to appropriately extract and route data to the surveillance system, enabling seamless data management and analysis. This infrastructure supports the effective handling of eCR data within the existing systems.

The California BDS program developed and automated data import processes using SQL Server scripts and SSIS. This approach streamlined the integration of eCR data into existing systems. The current focus is on transforming and importing eCR reports into the SQL Server database using SQL Server scripts and SSIS, which has significantly improved the efficiency of data integration processes.

Key resources and support structures

In addition to the key insights elucidated in the themes above, the BDS programs from Texas, Minnesota and California contributed their successful exploration of eCR to this point to key resources and support structures. The key support structures for each program are listed below.

The Texas BDS program attributed key support from the Texas Public Health Informatics and Data Exchange unit (PHIDE), CSTE, DSHS IT, and the National Birth Defects Prevention Network (NBDPN), who played key roles in the implementation process. Tools such as the SHARP platform, training videos, internal documents, and partnerships with CDC and NBDPN were used to increase understanding of eCR data and data management.

The Minnesota BDS program identified key support from the informatics staff and the MEDSS Operations team who were integral to the successful implementation. Resources such as eCR/RCKMS training, RCKMS documentation and AWS data lakes were used for efficient data extraction and integration.

The California BDS program obtained key support from new hires and third-party contractors who increased staffing capacity, although ongoing resource needs persist. In addition, the Registry Systems Manager and the CalREDIE eCR Unit played crucial roles in exploring eCR.

Challenges and solutions

The section below describes some of the challenges experienced by the BDS programs as they implemented eCR. The solutions that they identified are listed as well.

Challenges:

- Initial challenges included a lack of financial resources and expertise.
- Experienced difficulties in grasping the workflow of eCR and had issues with handling duplicate data entries.
- Insufficient staff to handle the workload and complicated data processing requirements.

Solutions:

- Addressed gaps through continuous training and forming partnerships. Secured funding and support through a CDC cooperative agreement. Focused on practical learning and refining processes through hands-on experience.

- Engaged in practical learning to better understand the eCR process. Continuously refined processes to address workflow issues. Developed structured communication strategies to manage data flow and duplication.

- Increased staffing through hiring and contracting third-party experts. Regularly assessed and addressed resource needs for long-term sustainability.

Recommendations for eCR implementation– BDS programs

The implementation of eCR in BDS programs across Texas, Minnesota and California has provided invaluable insights into effective strategies and best practices. Each of the BDS programs that PHII had discussions with were asked to provide recommendations for other BDS programs that may be interested in considering eCR for routine BDS. Their responses are categorized and summarized below.

Early planning

Develop comprehensive and flexible plans from the start, engaging all partners to refine strategies based on real-time data and feedback. Early planning allows for adaptive strategy development, ensuring that programs can adjust their plans as implementation progresses. The Texas BDS program used an iterative approach, while the Minnesota BDS program followed a defined plan due to funding constraints, demonstrating the importance of flexibility. The California BDS program also emphasized the importance of early planning, evolving through active participation in workgroups.

Quality improvement

Regularly evaluate pilot data for completeness, timeliness and accuracy, and continuously refine processes based on these findings. Documenting lessons learned and refining processes ensures that programs can maintain high standards of data quality. The Texas and Minnesota BDS programs created new workflows to review eCRs as they come in, developing reports and import rosters within the surveillance system to track data quality and completeness. The California BDS program partnered with a third-party entity to streamline data processing efforts, conducting initial quality control checks and comprehensive evaluations to ensure data alignment with stringent quality standards.

Resource management

Focus on strategic resource allocation, prioritizing high-impact areas and maintaining flexibility to reallocate resources as needed. Addressing resource gaps through strategic hires and funding is essential for program sustainability. The Texas BDS program addressed initial resource gaps through CDC cooperative agreements and a strategic hire, while the Minnesota BDS program managed staffing needs with data-sharing agreements and dedicated reporting websites. The California BDS program increased staffing capacity with new hires and third-party contractors. Ensuring efficient resource management supports the long-term success of eCR initiatives.

Staff training and support

Develop continuous training programs, including periodic updates and advanced sessions, to keep staff proficient with evolving technologies and processes. Continuous training is crucial for maintaining staff capabilities and improving the handling of eCR processes. The Texas BDS program focused on continuous training in interoperability, data exchange and external expertise, while the Minnesota BDS program used training videos and internal documents to prepare staff for eCR processes. The California BDS program emphasized extensive training and collaborations with established programs for successful eCR implementations, promoting ongoing learning and adaptation.

Data exchange infrastructure

Optimize the use of existing data management tools like SHARP and AWS data lakes, ensuring full integration into operations. Efficient data exchange infrastructure is vital for seamless data management and improved analysis capabilities. The Texas BDS program used the SHARP platform and Snowflake for effective data management. The Minnesota BDS program employed AWS data lakes for efficient data extraction and integration. The California BDS program developed and automated data import processes using SQL Server scripts and SSIS. Regular optimization of these tools supports robust data handling and integration.

Cross-state collaboration

Foster collaborative environments across states and jurisdictions, creating platforms for sharing insights, challenges and best practices. Sharing experiences and best practices can help overcome common challenges and enhance the overall effectiveness of eCR implementation. The collaborative efforts seen in the Texas, Minnesota and California BDS programs highlight the value of cooperative problem-solving and shared learning in advancing public health monitoring.

Conclusion

The implementation of eCR for BDS in Texas, Minnesota and California has demonstrated the significant benefits of strategic planning, effective resource management, continuous evaluation, and robust collaboration. Each state encountered unique challenges but successfully navigated these through the use of existing tools, partnerships and adaptive processes, thereby enhancing their surveillance capabilities.

The experiences of these states have yielded key insights for other states and programs considering the implementation of eCR. The lessons learned underscore the importance of flexible and comprehensive planning, robust training initiatives, advanced data management, and ongoing support. By integrating these best practices and recommendations, states can significantly enhance the timeliness, accuracy and efficiency of their BDS programs, contributing to improved public health outcomes.

Looking forward, fostering a culture of continuous improvement, optimizing the use of technology, ensuring sustainable resource allocation, and promoting cross-state collaboration are essential steps. These measures will not only strengthen eCR implementations but also enhance the overall effectiveness of public health surveillance systems.

The benefits of eCR identified by the programs include more timely data acquisition, improved case confirmation, efficient data extraction and integration, and the ability to handle complex data processing requirements. However, while ongoing pilot evaluations from these BDS programs have demonstrated the value of eCR as a source of timely data, they have also identified areas for improvement since some of the programs indicated dual reporting systems are still in use. Still, these insights provide a valuable guide for other programs looking to implement eCR in BDS, with the potential to significantly improve the timeliness, accuracy and efficiency of their surveillance programs.

Appendix A

Lessons learned–eCR implementation for birth defects questionnaire

Overview: The outcome of the lessons learned will be a summary documenting the experiences of 3 state birth defects programs as they implemented electronic case reporting (eCR) for birth defects surveillance (BDS). This summation will provide insight into the programs' successes and challenges, providing a guide or roadmap for other programs to follow as they implement eCR for BDS.

Audience: California, Minnesota and Texas

Objective: Obtain lessons learned from the implementation of eCR for birth defects within the state program birth defects program.

Medium: 60-minute recorded (for transcription and summation) interview with each state

Questions: We would like to use the following questions to gain a better understanding of your program's experience in implementing eCR including the successes, challenges and benefits eCR has on BDS.

Planning and Implementation

1. What was the impetus for wanting to use eCR for BDS?

2. Did you start with any defined plans? Did that change as you began development/implementation?

3. In the needs assessment a couple of months back, you identified resource gaps that needed to be addressed to support successful eCR implementation for birth defects in your program. In what way(s) have you or will you seek to close resource gaps that you identified prior to and during the eCR implementation for birth defects reporting in your program (this could include financial, policy, staffing, etc.).?

Support for Implementation

4. What or who played a key role in your successful implementation?

5. What tools, techniques, or resources were primarily useful to your program/department?

6. Can you describe any interactions or collaborations you needed to develop with sending facilities (medical offices, hospitals, etc.)?

Implementation Outcomes

**If you have not moved into production or finalized implementation, please answer these questions based on your expectations.

7. Did you get the results you expected? How has the implementation helped the program's ability to continue BDS?

8. How has incorporating eCR data into BDS impacted your program and surveillance methods?

    i.   *Have you made modifications to your surveillance system?*

    ii. *Changed business processes?*

    iii. *Updated data management approaches?*

    iv. *Changes in staffing needs?*

    v.   *Changes to follow legal restrictions?*

9. If you have considered the impacts from question 8, have you documented those impacts and strategies that supported changes?

10. What would you say worked well during this process?

11. What challenges did you experience? How did you overcome them?

12. Is there anything you would have done differently? Or wish you thought about?

13. Has your program developed performance metrics for data quality/timeliness?

    i.   If so, are you willing to share any of those metrics? (if they are documented)?

Wrap-up

14. What are the next steps in using eCR for BDS in your program?

15. Any suggestions for other programs that would like to implement eCR for BDS?

Attachment I: Comparison of eCR implementation responses for birth defects surveillance (BDS) in Texas, Minnesota and California

Category	Texas	Minnesota	California	Similarities	Differences	Actions
Impetus for eCR	Timely and standardized source of case finding	Timely, standardized source leveraging existing infrastructure and Odyssey funds	Part of Future of Public Health Initiative to expand workforce capacity and processes	All states aimed for more timely and standardized data for birth defects surveillance (BDS)	Minnesota leveraged specific funding; California focused on workforce expansion	Ensure funding mechanisms and program goals align with the need for timely and standardized data collection
Initial planning	No initial plan; iterative approach	Required defined plan due to funding; included redesigning data fields	No highly defined plans initially; evolved through workgroups	Each state's planning evolved over time	Texas and California started without defined plans; Minnesota required a defined plan	Develop flexible initial plans that can evolve with project requirements

Resource management	Addressed gaps with CDC cooperative agreement, hiring project managers, continuous training	Leveraged data-sharing agreements and dedicated reporting website	Increased staffing through new hires and third-party contractors	Addressed staffing gaps through strategic hiring and resource allocation	Different approaches to staffing and resource gaps (e.g., data-sharing agreements versus third-party contractors)	Tailor resource management strategies to specific state needs, utilizing available funding and partnerships
Key roles/support	PHIDE, CSTE, DSHS IT, NBDPN	Informatics staff, MEDSS Operations team	Registry Systems Manager, CalREDIE eCR Unit	Each state had dedicated teams and support units	Specific roles and units varied between states (e.g., PHIDE in Texas, MEDSS in Minnesota)	Identify and involve key support roles early in the project
Tools and resources	SHARP platform, training videos, internal documents, CDC and NBDPN partnerships	eCR/RCKMS trainings, RCKMS documentation, AWS data lakes	XML files transformation and import, SQL Server scripts, SSIS	Used a mix of internal and external tools and resources	Different data management tools used (e.g., SHARP versus AWS data lakes)	Leverage existing tools and resources and invest in necessary training for staff
Collaborations	PHIDE handled onboarding; communication with variable-specific questions	Facility partners aware of BDS addition; Data Strategy and Interoperability team onboard	Collaborated with CalREDIE team for onboarding	Developed collaborations with facilities and internal teams	Different levels of direct interaction with sending facilities	Foster strong collaborations and clear communication channels with facilities and internal teams

Results/ outcomes	Initial evaluations ongoing; valuable for timely case-finding but some missing data elements	More timely reporting and faster case confirmation; dual reporting systems still in use	In data extraction phase; extended timelines for full utilization	All states reported improved timeliness in data reporting	Differences in data completeness and ongoing evaluation phases	Continuously evaluate data for completeness and timeliness; address gaps as they are identified
Modifications	Future system modifications assessed; current applications, not eCR compliant	Modifications made to extract data from eCRs; AWS data lakes used	Modifications to integrate eCR data; developing additional applications/ systems interfaces	Modifications to surveillance systems were necessary	Different stages of system modifications and compatibility	Plan and implement necessary system modifications to ensure compatibility with eCR data
Business processes	Mapping current processes; evaluating future impacts of eCR	Created new workflow to review eCRs	Processes to be modified based on evaluation outcomes	Each state evaluated and adjusted business processes	Texas and California are still in the evaluation phase; Minnesota implemented new workflows	Map out and adjust business processes based on ongoing evaluations and data integration needs
Data management	Utilizing SHARP and Snowflake repositories	eCRs creating new events in the data system; AWS data lakes used	Developing automated data import and integration processes	Updated data management approaches to handle eCR data	Different data management platforms and integration methods	Utilize robust data management platforms; automate data import and integration processes where possible
Staffing needs	Additional staffing needs addressed through a new hire and redefined roles	Likely need for more staff time to review eCRs	Increased staffing capacity; ongoing evaluation of resource needs	Increased staffing needs to handle new data workflows	Specific staffing strategies varied (e.g., new hires versus redefined roles)	Regularly assess and address staffing needs; ensure roles are clearly defined to support new data workflows

Legal restrictions	No changes needed; state statute comprehensive enough	Still to be determined	Existing legislation covers statewide access to complete medical records	Legal frameworks generally supported eCR implementation	Different levels of clarity regarding legal changes	Ensure legal frameworks support eCR implementation; address any potential legal issues early in the project
Challenges	Funding and knowledge gaps; understanding eCR flow	Understanding eCR flow; dealing with duplicative messages	Staffing capacity and data processing complexity	Common challenges included understanding eCR flow and resource limitations	Different specific challenges based on state contexts	Address funding and knowledge gaps through training and partnerships; continuously refine understanding of eCR processes
Performance metrics	Metrics in development; will be shared once documented	Plan to compare eCR receipt date/time with flat file receipt	Awaiting final staff position to develop detailed evaluation plan	Developing performance metrics for data quality and timeliness	Different stages of developing performance metrics	Finalize and document performance metrics; share findings and best practices with other states

Attachment II: Interview transcripts

Interview transcript analysis for Texas

Planning and implementation:

Q1: What was the impetus for wanting to use eCR for birth defects surveillance?

- **Response:** The motivation was to find a more timely and standardized source of case finding for birth defects surveillance compared to manual requests and handling of facility discharge lists.

Q2: Did you start with any defined plans? Did that change as you began development/implementation?

- **Response:** There was no defined plan at the start. The process has been iterative, evolving with a workgroup charter that included strategic planning and pilot projects. The cooperative agreement with the CDC provided significant support.

Q3: How did you seek to close resource gaps identified prior to and during the eCR implementation?

- **Response:** Initial challenges included lack of funding and training. These were addressed through a CDC cooperative agreement, hiring a project manager, and continuous staff training. The current registry system's lack of interoperability was another gap, requiring new internal and external connections.

Support for implementation:

Q4: Who or what played a key role in your successful implementation?

- **Response:** The Public Health Informatics and Data Exchange unit (PHIDE) played a crucial role in authoring conditions for the Texas notifiable conditions list, providing pilot data, and implementing the data feed. Other key contributors included CSTE, agency IT, and the National Birth Defects Prevention Network.

Q5: What tools, techniques, or resources were primarily useful to your program/department?

- **Response:** Essential tools included the SHARP platform for data storage and analysis, online training resources, internal documents, and existing partnerships with CDC and NBDPN. Presentations were given to various audiences to advocate for the inclusion of more birth defect conditions in reporting systems.

Q6: Can you describe any interactions or collaborations you needed to develop with sending facilities (medical offices, hospitals, etc.)?

- **Response:** Though the birth defects program was a step removed from direct interactions with sending facilities, PHID handled onboarding facilities into the AIMS platform and addressed issues with variable extraction.

Implementation outcomes:

Q7: Did you get the results you expected? How has the implementation helped the program's ability to continue birth defects surveillance?

- **Response:** Initial pilot evaluations are ongoing. ECR data is seen as a valuable, timely case-finding source. The SHARP platform is improving data receipt processes. Key questions include whether ECR data alone is sufficient for prevalence documentation and referrals or if medical records are still needed.

Q8: How has incorporating eCR data into birth defects surveillance impacted your program and surveillance methods?

- **Response:** ECR data has the potential to make case identification more timely and facilitate faster referrals to services. However, current evaluations show missing variables crucial for a complete registry record.

Q9: Have you made modifications to your surveillance system?

- **Response:** Future modifications are being assessed; current registry applications are not ECR compatible.

Q10: Have you changed business processes?

- **Response:** Business processes are being mapped for future system integration.

Q11: Have you updated data management approaches?

- **Response:** Utilization of the SHARP platform and Snowflake repository.

Q12: Have there been changes in staffing needs?

- **Response:** Additional staffing and redefined roles (lead surveillance specialists, quality assurance training coordinators) are needed to handle increased workloads.

Q13: Have there been changes to follow legal restrictions?

- **Response:** No changes were needed due to the comprehensive existing statute.

Q14: Have you documented impacts and strategies that supported changes?

- **Response:** We are in the process of documenting these, with performance metrics for data quality and timeliness under development.

Reflection and recommendations:

Q15: What worked well during this process?

- **Response:** Strong partnerships, an internal interoperability workgroup, and proactive efforts despite initial funding gaps were crucial. Enthusiasm and leadership within the team also drove success.

Q16: What challenges did you experience, and how did you overcome them?

- **Response:** Major challenges included lack of funding and knowledge gaps. These were addressed through the CDC cooperative agreement, staff training, and leveraging external expertise and partnerships**.**

Q17: Is there anything you would have done differently or wish you thought about?

- **Response:** Knowing what we know now, we would have prioritized strategic planning and defined roles within the workgroup earlier. However, it's hard to predict unknowns as pioneers in this area.

Q18: Have you developed performance metrics for data quality/timeliness?

- **Response:** Metrics are being developed and will be shared once documented.

Wrap-up:

Q19: What are the next steps in using eCR for birth defects surveillance in your program?

- **Response:** Continue pilot data evaluation, data quality assessments, and develop recommendations for the program and other birth defects programs.

Q20: Any suggestions for other programs that would like to implement eCR for birth defects surveillance?

- **Response:** Start now, collaborate with other programs, and leverage national systems like RCKMS.

Key insights and recommendations

Key insights:

1. Timeliness and standardization: eCR provides a more timely and standardized source of case finding compared to traditional manual methods.
2. Iterative process: Implementation has been an iterative process with evolving plans and strategic adjustments.
3. Resource challenges: Initial lack of funding and training were major challenges, successfully addressed through a cooperative agreement and continuous learning.
4. Partnerships and tools: Strong internal and external partnerships and effective use of tools like SHARP and Snowflake were critical.
5. Ongoing evaluation: Continuous evaluation of pilot data is necessary to understand the full impact and potential of eCR in birth defects surveillance.

Recommendations and next steps:

1. Continued evaluation: Continue evaluating pilot data for completeness, timeliness, and accuracy.
2. Strategic planning: Enhance strategic planning and role definition within the interoperability workgroup.
3. Collaboration and knowledge sharing: Foster collaboration with other birth defects programs and share lessons learned and best practices.
4. Performance metrics: Develop and document performance metrics for data quality and timeliness.
5. Future system integration: Prepare for future system integration to ensure compatibility with eCR data, including necessary staffing and business process changes.
6. Advocacy and training: Continue advocating for inclusion of more birth defects conditions in national reporting systems and provide ongoing training for staff on interoperability and eCR data usage.

Interview transcript analysis for Minnesota

Planning and implementation:

Q1: Why did programs want to use eCR for BDS?

- **Response:** To have a more timely, standardized source of data for birth defects surveillance. Existing ICD-10 discharge lists were not always complete or standardized. Using eCR leverages existing RCKMS infrastructure for a more standardized way to get case findings.

Q2: Did you start with a defined plan? Did it change?

- **Response:** Due to funding requirements, Minnesota called it an IT project and had a work plan with a project manager and business analyst. They added a redesign of their data fields in the information system (IS) to accept eCR data.

Q3: Have you closed resource gaps that you identified prior to and during the eCR implementation for birth defect reporting in your program?

- **Response:** They created data sharing agreements specific to the BDS program and developed a website for reporting birth defects, including eCR with standard reporting via flat files.

Support for Implementation:

Q4: What or who played a key role in your successful implementation?

- **Response:** Key roles included informatics staff dedicated to the BD program and the MEDSS Operations team. Their prior work on eCR infrastructure and facility onboarding was instrumental.

Q5: What tools, techniques, or resources were primarily useful to your program/department?

- **Response:** Useful resources included eCR/RCKMS trainings from CSTE, RCKMS documentation, understanding of SNOMEDs/LOINCs, and general understanding of interoperability and the eCR process.

Q6: Can you describe any interactions or collaborations you needed to develop with sending facilities (medical offices, hospitals, etc.)?

- **Response:** Facility partners were aware of the addition of BDS to eCR reporting. The Data Strategy and Interoperability team and MEDSS Operations worked with facilities to onboard them for eCR.

Implementation Outcomes:

Q7: Did you get the results you expected? How has the implementation helped the program's ability to continue birth defects surveillance?

- **Response:** They are still using dual reporting styles, resulting in more case reports requiring review. Timely reporting of BD cases has improved, allowing faster case confirmation.

Q8: How has incorporating eCR data into birth defects surveillance impacted your program and surveillance methods?

- **Response:** They made changes to their surveillance system to extract data from eCRs. They are utilizing AWS data lakes to help extract data and route it to their surveillance system.

Q9: Have you made modifications to your surveillance system?

- **Response:** Yes, modifications were made to extract data from eCRs into the surveillance system.

Q10: Have you changed business processes?

- **Response:** A new workflow was created to review eCRs as they come in, monitored by staff.

Q11: Have you updated data management approaches?

- **Response:** Since eCRs can create new events in their data system, this might affect the processing of monthly flat files.

Q12: Have there been changes in staffing needs?

- **Response:** They will likely need more staff time to review incoming eCRs. Faster case identification might reduce the need for frequent medical record requests.

Q13: Have there been changes to follow legal restrictions?

- **Response:** This is still to be determined.

Q14: Have you documented those impacts and strategies that supported changes?

- **Response:** Changes to the surveillance system have been documented in Jira and IT project documentation. They have previewed some eCRs with the surveillance team to familiarize them with the new data.

Reflection and recommendations:

Q15: What worked well during this process?

- **Response:** Collaboration with the MEDSS Operations team to implement eCR in test environments and partnerships leveraged from previous projects.

Q16: What challenges did you experience, and how did you overcome them?

- **Response:** Challenges included understanding the flow of eCR and dealing with duplicative messages. Overcoming these challenges involved hands-on learning and refining processes through practical experience.

Q17: Is there anything you would have done differently or wish you thought about?

- **Response:** They anticipated issues with duplicative messages and wish they had a better idea of how this would impact their information system before moving forward.

Q18: Have you developed performance metrics for data quality/timeliness?

- **Response:** Not yet implemented, but they plan to compare the initial date/time of eCR receipt with the date of flat file receipt for the same visit and condition.

Wrap-up:

Q19: What are the next steps in using eCR for birth defects surveillance in your program?

- **Response:** Developing reports and import rosters to track data quality/completeness, extracting more fields from eCRs to the data lake, and authoring upcoming BDs for RCKMS specifications.

Q20: Any suggestions for other programs that would like to implement eCR for birth defects surveillance?

- **Response:** Work with other programs to onboard partners, review eCRs without a surveillance system if possible, start now, use RCKMS, expect challenges, and share lessons learned.

Key insights and recommendations

Key insights:

1. Timeliness and standardization: eCR provides a more timely and standardized source of data for birth defects surveillance, leveraging existing RCKMS infrastructure.

2. Defined planning: Due to funding requirements, the project was planned with a work plan, project manager, and business analyst, including redesigning data fields in the information system to accept eCR data.

3. Resource gaps: Initial gaps in staffing capacity were addressed by creating data sharing agreements and developing a reporting website. The program leveraged existing IT and informatics resources.

4. Collaboration and partnerships: Effective collaboration with the MEDSS Operations team, Data Strategy and Interoperability team, and facility partners was crucial for implementation.

5. System modifications: Necessary changes were made to the surveillance system to extract and utilize eCR data, including using AWS data lakes.

6. Dual reporting: The program is still using dual reporting styles, resulting in more case reports requiring review but allowing faster case confirmation.

Recommendations and next steps:

1. Continued collaboration: Maintain strong working relationships with IT and informatics teams, and seek collaborations with other programs experienced in eCR.

2. Data processing and quality control: Continue developing reports and import rosters to track data quality and completeness. Extract more fields from eCRs to the data lake for efficient use.

3. Flexible planning: Be prepared to adapt plans based on real-time data and evolving needs, refining processes through practical experience.

4. Performance metrics development: Finalize and document performance metrics for data quality and timeliness, comparing eCR data with traditional reporting methods.

5. Training and capacity building: Invest in training and capacity building for staff to handle new data processing and integration tasks.

6. Communication and documentation: Document changes and strategies, and develop a formal communication plan with timelines to ensure all stakeholders are informed and engaged.

Interview transcript analysis for California

Planning and implementation:

Q1: What was the impetus for wanting to use eCR for birth defects surveillance?

- **Response**: The impetus was the opportunity under California's Future of Public Health Initiative, which allowed for workforce capacity expansion to evaluate and modernize processes, explore statewide expansion, and ensure complete, accurate, and timely reporting of birth defects.

Q2: Did you start with any defined plans? Did that change as you began development/implementation?

- **Response**: No highly defined plans initially. They began by joining the CDC/CSTE/RCKMS workgroup and developing a roadmap for retrieving and incorporating eICR reports into the registry system. Initial plans evolved based on the data received, such as discovering the absence of certain critical data elements in the XML file structure.

Q3: How did you seek to close resource gaps identified prior to and during the eCR implementation?

- **Response**: Initial and ongoing resource gaps included staffing capacity. They hired three new positions and leveraged third-party contractors to cover specific capacities. They also emphasized the need for standardized guidance from CDC/CSTE for processing XML data.

Support for implementation:

Q4: Who or what played a key role in your successful implementation?

- **Response**: Key roles included:
    - Registry Systems Manager and data management team for planning and oversight.
    - CalREDIE eCR Unit for authoring birth defect conditions, providing data dictionaries, and ensuring system specifications.
    - Other established programs, such as CDPH Office of Occupational Health and Texas Birth Defects Program, for sharing insights and resources.

Q5: What tools, techniques, or resources were primarily useful to your program/department?

- **Response**: The CalREDIE team provided eICR reports as XML files, which are being transformed and imported into their SQL Server database using SQL Server scripts and SSIS.

Q6: Can you describe any interactions or collaborations you needed to develop with sending facilities (medical offices, hospitals, etc.)?

- **Response**: They do not directly interface with sending facilities as CalREDIE handles onboarding. They plan to reach out to facilities within their active ascertainment area for pilot evaluation and data validation.

Implementation outcomes:

Q7: Did you get the results you expected? How has the implementation helped the program's ability to continue birth defects surveillance?

- **Response**: They are in the data extraction and structure phase and have not yet used eCR reports. The timeline for statewide utilization is extended.

Q8: How has incorporating eCR data into birth defects surveillance impacted your program and surveillance methods?

- **Response**: They plan to modify registry systems for data integration, potentially replacing manual medical record review with eCR data for eligible conditions and participating facilities. Evaluation projects will determine if eCR contains sufficient information to create a birth defect registry case.

Q9: Have you made modifications to your surveillance system?

- **Response**: Modifications are planned for the future to integrate eICR data.

Q10: Have you changed business processes?

- **Response**: Business processes will be mapped and potentially modified based on evaluation outcomes.

Q11: Have you updated data management approaches?

- **Response**: They are working with developers to automate data import and integration, aiming to minimize manual data entry.

Q12: Have there been changes in staffing needs?

- **Response**: Additional staffing needs were addressed through new hires and third-party contractors.

Q13: Have there been changes to follow legal restrictions?

- **Response**: No changes were needed as existing legislation covers statewide access to complete medical records.

Q14: Have you documented impacts and strategies that supported changes?

- **Response**: General performance measures and public health impacts are outlined in the Future of Public Health Strategic Plan. Performance metrics are under development and will be shared once finalized.

Reflection and recommendations:

Q15: What worked well during this process?

- **Response**: Excellent relationships with CalREDIE eCR Team and leveraging previous collaborative work.

Q16: What challenges did you experience, and how did you overcome them?

- **Response**: Staffing challenges, including the retirement of a long-time data manager, were mitigated by using third-party contractors. Data challenges included processing complex XML structures and addressing multiple reports for the same patient.

Q17: Is there anything you would have done differently or wish you thought about?

- **Response**: Nothing specific mentioned.

Q18: Have you developed performance metrics for data quality/timeliness?

- **Response**: Performance metrics are under development, and they are willing to share finalized documents and evaluation findings with other programs.

Wrap-up:

Q19: What are the next steps in using eCR for birth defects surveillance in your program?

- **Response**: Partnering with a third-party entity to streamline data processing, conducting quality control checks, and evaluating data for completeness, quality, and accuracy.

Q20: Any suggestions for other programs that would like to implement eCR for birth defects surveillance?

- **Response**: Build strong working relationships with IT/informatics teams, seek collaborations with other programs experienced in eCR, and share experiences, code, and data uses.

Key insights and recommendations

Key insights:

1. **Workforce expansion**: The initiative allowed for hiring new positions and leveraging third-party contractors to address staffing capacity gaps.
2. **Iterative planning**: Initial plans evolved based on real-time data received, highlighting the importance of flexibility in implementation.
3. **Collaborative efforts**: Strong relationships with the CalREDIE eCR Team and other established programs were crucial for successful implementation.
4. **Data processing challenges**: Processing complex XML structures and handling multiple reports for the same patient were significant challenges, with plans to use new technologies like natural language processing.
5. **Performance metrics**: Development of performance metrics for data quality and timeliness is ongoing, with a commitment to share findings with other programs.

Recommendations and next steps:

1. **Continued collaboration**: Foster strong working relationships with IT/informatics teams and seek collaborations with other experienced programs.
2. **Data processing and quality control**: Partner with third-party entities to streamline data processing and conduct quality control checks.
3. **Flexible planning**: Be prepared to adapt plans based on real-time data and evolving needs.
4. **Performance metrics development**: Finalize and share performance metrics for data quality and timeliness.
5. **Training and capacity building**: Invest in training and capacity building for staff to handle new data processing and integration tasks.