Office of the Secretary Patient-centered Outcome Research Project

Improving the Timeliness and Quality of State Electronic Death Registration Systems
National Center of Health Statistics
Final Report

The following report is submitted as the final requirement associated with **Inter-Agency Agreement (IAA) REMIS # HP-15-012 between** the Assistant Secretary for Planning and Evaluation (ASPE) and CDC's National Center for Health Statistics (NCHS). NCHS agreed under the IAA to address three objectives:

- **Strengthen mortality data infrastructures of the states and NCHS/Division of Vital Statistics (DVS) for more timely delivery of state records to the National Death Index (NDI) database.**

- **Conduct intersystem exchanges between electronic health records (EHRs) and an electronic death registration system (EDRS) in one state using draft national HL7 standards.**

- **Link the National Hospital Care Survey inpatient and emergency department data with the NDI data to measure within and posthospital mortality.**

This report will serve as the final summary of the aforementioned project, outlining key strategies employed by awardees addressing challenges identified by local vital record offices essential to the collection and reporting of data to NCHS. Each of the objectives presented above were met; current and ongoing activities related to improving mortality timeliness and increasing capacity to link mortality data across various data systems are directly related to the work associated with this Patient Outcomes Research (PCOR) project.

In July 2015, NCHS launched the project **"Improving the Timeliness and Quality of State Electronic Death Registration (EDR) Systems."** Task orders were awarded to a total of 19 jurisdictions: 12 in July of 2015 (first cohort of awards), and an additional 7 (second cohort) in April of 2016, targeting specific strategies to advance the timeliness of mortality reporting. The awards provided jurisdictions the opportunity to address specific self-identified challenges impeding more timely mortality reporting to NCHS, essential to collection of mortality data for the nation. Previous mortality data reporting shared in earlier PCOR Quarterly reports and the final reporting in this report reflect improvement among awarded jurisdictions. This improvement significantly contributed to the nation's overall improvement in the timeliness of mortality reporting (see Figures 1–3)**.**

Objective 1: Strengthen the mortality data infrastructure of the states and NCHS for more timely delivery of state records to the NDI database, by assisting states in strengthening their EDRSs to provide mortality records to the NDI database.

NCHS awarded task orders under the existing Vital Statistics Cooperative Program (VSCP) contract to states to improve the timeliness of mortality reporting. The scope of work for the 2-year project is to improve the timeliness and quality of the mortality records submitted to NCHS. The national goals associated with this effort include the following:

a) Receive at least 80% of its mortality records electronically through its EDRS;

b) **Transmit death information collected through EDRS to NCHS within 10 or less days after the date of the event for at least 80% of death events occurring within its jurisdiction;** and

c) Transmit the deaths related to state-specified causes of deaths to the state epidemiologists within 1 day of the registration of the death certificate or receipt of the specified cause.

There were 19 awarded states in total: 12 states awarded in July 2015, and an additional 7 states in April 2016. Project period: **July 7, 2015–July 6, 2017**

Florida, Georgia, Hawaii, Kansas, Michigan, Missouri, Nebraska, New Hampshire, New York (state), Oklahoma, Oregon, and Pennsylvania.

Project period: **April 15, 2016–April 14, 2018**

California, Indiana, Iowa, Maryland, Minnesota, Virginia, and Washington (state).

States submitted proposals that included a work plan outlining challenges, obstacles, and strategies to address self-identified issues. Within the submitted proposals and work plans were a range of identified issues presented as impacting EDRS progress and a range of activities and strategies to address identified items. Almost all the issues cited by jurisdictions impeding advancement could be categorized by a few common themes: a) Limited stakeholder participation in EDRS (medical certifier or physician, medical provider, funeral director, etc.), b) Need for enhanced technology (mobile application for certifying deaths, limited browser compatibility and functionality to address various systems), c) Limited capacity to expand training due to scarce resources and support regarding EDRS, and d) Internal assessment of aged systems and processes.

As common as the challenges identified, the respective strategies presented among jurisdictions varied. Below is a list of the activities or strategies most commonly employed to improve timelines, as well as the number and percentage of the states reporting the activity or strategy.

Stakeholder engagement (14 or 19 states, or 74%)

- Targeted outreach to medical community (certifiers)
- Established alliances with medical and hospital associations
- Marketing campaigns to stakeholder community, recruited community leaders
- Expanded certification authority beyond physicians to APRNs and PAs

Enhance technology (16 of 19 states, or 84%)

- Developed mobile application (medical certification)
- Increased user functionality (network access, password management, etc.)
- Expansion of web browser or increased compatibility of multiple networks
- Introduction of VIEWS 2 editing software

Training (19 of 19 states, or 100%)

- Increased training capacity (personnel, contract services, etc.)
- Developed and conducted webinars and distribution of targeted materials
- Increased face-to-face access and number of trainings
- Produced videos that increased reach

Internal system (16 of 19 states, or 84%)

- Conducted assessment of mortality data flow, identifying efficiencies and streamlining process
- Implemented automated features and alerts within EDRS that reduced manual tasks
- Instituted systems identifying edits to data and essential information
- Instituted a schedule that allowed for daily transmission of mortality data

The activities reference above represent a sample of the activities that jurisdictions employed to advance mortality reporting to NCHS. These activities also underscore the foundation of improvement recognized during the project period. A small sample of state activities that resulted in improved reporting includes the following:

1) Stakeholder engagement—**Kansas** successfully partnered with Kansas Healthcare Collaborative, an entity supported by two key stakeholders: Kansas Medical Society and Kansas Hospital Association. This collaboration served an integral role in convening, promoting, and facilitating much of the communication and negotiation between state vital records programs and local providers to accelerate participation in EDRS. The peer-to-peer communication was invaluable when engaging this community and the reporting metrics reflect that fact. The distinction between jurisdiction that engaged the stakeholder community effectively and those that were not as successful is notable.

2) Enhance technology—**Hawaii, Nebraska, and New Hampshire** each reflect the positive impact of enhancing or adopting newer technology or related advancement in the field of technology. Although each of these states differed in their approach and specific activity, the common positive impact was the same. **Hawaii** automated many features of their EDRS to support maximizing internal processes, reducing manual support; **New Hampshire** successfully automated death files to where mortality records were forwarded to NCHS twice daily and realized a nearly 300% increase in reporting timeliness, in addition to developing NECo, a mobile application designed specifically to facilitate mortality certification and related features; **Nebraska**, in response to the medical certifier community, developed a mobile app to provide greater access to EDRS, allowing physicians to access files virtually at any time, promoting a "user-friendly" mentality that has been acknowledged by the targeted community. The "mobile app" practice is so successful that Nebraska and New Hampshire provide consultation to several states on their development and implementation experience. Several states are now currently pursuing or are engaged in developing mobile apps to facilitate certification of death records. **Indiana** is currently in the process of developing a new EDRS schedule to launch January 2019, and **Washington** completed an overhaul of their EDRS in the last quarter of 2017. **California** piloted HL7 format to exchange death information from electronic health records to local and state electronic EDRS, and from state EDRS to NCHS, demonstrating the technical feasibility of facilitating mortality reporting.

3) Training—most states directed significant resources in developing a training plan or strategy to accomplish this critical component of enhancing participation in state EDRS. **Florida, Kansas, and New York** are just a few examples of jurisdictions effectively addressing their critical training needs. All three states exercised creativity in addressing training needs, including multimedia approaches and increasing staffing to support training or entering into partnerships to support this activity. Training videos were developed, onsite trainings (large hospitals and similar facilities) were scheduled, online trainings were instituted, continuing education credits were sanctioned, etc. The common factor related to training was the ability to address an overwhelming need with limited resources to support the large pool of certifiers needing training to utilize EDRS.

4) Internal operations or systems—many of the awarded jurisdictions performed an internal review of their processes and identified processes that could be addressed to support a more efficient and effective mortality reporting system. Frequently, this caused program officials to reassess current practices and ask why they were continuing to perform activities in the same way despite technology advancements or

other changes in the industry. Engaging in this activity frequently identified opportunities to readjust or reassign a function, or modify the sequence of a certain activity within a function, resulting in a remarkable improvement in the timeliness of mortality reporting. On most occasions, the project presented the awarded states with an opportunity to do a comprehensive review of their processes and related activities, leading to the identification of a more efficient process. In addition, in some cases it required minimal additional resources, staff, procurement activities, or executive approval to implement. This underscores the need for continuous support for the identification of standards and measures relating vital records operations. Several jurisdictions recognized first-hand how a small change in the process or some step within the process contributed substantially to advancing EDRS.

Given the multiple required actions by various sectors within the stakeholder communities impacting mortality reporting, it only magnifies the complexities associated with developing, implementing, and sustaining an effective, user-friendly EDRS. Despite challenges facing local and state vital records offices, there is definitive evidence that many of the activities conducted yielded substantial improvement and, more importantly, established a foundation for continued improvement.

The data found at the end of this report reflects a comparison of the timeliness of mortality reporting prior to receipt of award and after receipt. The tables below represent the recent national mortality timeliness performance and the data illustrates the substantial contribution of this project to mortality reporting.

Although improvements to mortality reporting continue to be challenging, significant progress has and is being made, as reflected in the graph at the end of this report titled, "Percentage of U.S. mortality records received" (see Tables 1 and 2). Comparing the NCHS goal (receiving death records within 10 days of the date of death) to the awarded jurisdictions' reporting performance and to the 2017 national performance average, 10 of the 19 awarded states exceed the national average of 52%, reporting 73% of their mortality records within 10 days. The total average of all 19 awarded states was 55%, again exceeding the national reporting average. Over the course of the project period, the first cohort of states increased timeliness of mortality reports by 18%, and second cohort increased timeliness by 16%.

NCHS early on recognized a need for additional technical assistance to support awardees efforts. It was viewed as important to assist and support awarded jurisdictions with their efforts to advance their EDRS and related activities. NCHS contracted with Westat to support jurisdictions in their development, implementation, and sustainment of EDRS in various stages across multiple jurisdictions. Those tasks (previously reported and materials shared) included:

Analysis and reporting on timeliness success factors

The completed November 2016 report generated from interviews with key informants previously funded in 2013 and 2014 supported the implementation of EDRS to improve the timeliness of mortality reporting. The purpose of the task was to conduct an assessment to identify critical factors that lead to the success of their project and share experiences and insights gained. The seven factors identified were: legislation mandating electronic death reporting, stakeholder support, technical support, planning, training, sustainability, and engagement plans. The report articulates the significance and value of these factors within the scope of state and local vital records programs, and is intended to assist jurisdictions with their EDRS efforts by leveraging the experiences of previous efforts in other jurisdictions and programs.

EDRS online reference manual

Completed December 2016 and posted to NCHS external website at https://www.cdc.gov/nchs/nvss/mortality_methods.htm, the online manual serves a reference for state and local programs on implementing and sustaining EDRS. It also provides best practices and illuminates the various roles and functions essential to establishing a quality EDRS. The manual provides graphic representations, specific feedback and suggestions from officials who earlier implemented EDRS, reviews the value and outcome of a functional EDRS, and presents options for a pathway to implementing EDRS.

Consultation and technical assistance to awarded states

Completed June 13, 2017, several activities under this specific task directly relate to supporting vital statistics program efforts in advancing EDRS. During this project period, direct attention and efforts were focused on jurisdictions where timeliness was dire and in need of immediate support. The states of New York and Pennsylvania were identified and agreed to pursue opportunities where Westat could assist them with their efforts to develop and implement a functional statewide EDRS.

In addition, on July 27, 2016, the first in a series of technical assistance (TA) forums were held to foster peer-to-peer engagement and sharing. The last TA forum was concluded on June 13, 2017. The jurisdictions selected specific topics to discuss, including stakeholder engagement and support, mobile applications supporting death certification, training, planning, and implementation. The sharing and exchange of knowledge and experience was reported as valuable by awardees. Jurisdictional officials actively lead the discussion among their peers, promoting a peer-to-peer atmosphere that fostered engagement and support.

The TA provided in Pennsylvania contributed to securing additional resources and a redesign of Pennsylvania's EDRS rollout and implementation plan, and New York State re-examined drafting a revised plan specifically addressing components earlier identified by Westat during a previous technical assistance visit. Although both states remain in need of substantial improvements, improvements occurred during the report period.

Establish medical examiner and coroner directory

Completed June 2017, this task was intended to capture knowledge about the landscape of an essential stakeholder in the vital statistic ecosystem. Medical examiners (ME) and coroners have an instrumental role in the certification of sudden and unexpected death specifically and depending upon locality, and its statue and practices can significantly impact morality reporting timeliness. The ability to know the location of ME and coroners' offices, how and where to disseminate reporting guidance, tools, and related information aligned with their position and responsibilities, and the governance structure they function will support local engagement with this key community and stakeholder group.

Please find at the end of this report the <u>results of a poll (Figures 4–9)</u> of awardees sharing insight about the PCOR program. Awardees responded to the following questions:

- What has been your greatest accomplishment?
- What future support would you recommend be provided to advance EDRS?
- What are your priorities and goals for the future?

Objective 2: Conduct intersystem exchanges between electronic medical records (EHRs) and an electronic death registration system (EDRS) in one state using draft national HL7 standards.

Another essential component of the IAA involved efforts to introduce HL7 technology to facilitate the exchange of data between EHR and a state's EDRS intended to support the advancement of timely mortality reporting. The development and implementation of this effort included the collaboration and support of various entities within the vital statistics ecosystem to include medical provider(s), state and local vital statistics programs, NCHS, and other targeted members of the vital statistics ecosystem. The collaboration realized the bidirectional exchange of data illustrating the feasibility and potential future opportunity to elevate efficiency and expediency with necessary data to facilitate the registration and exchange of mortality data.

On August 17, 2015, NCHS awarded a 2-year task order to the California Department of Public Health (CDPH). A task associated with that award was to demonstrate the exchange of relevant death information between EHRs and a state's EDRS. This project required various partners to work together.

Integral to this effort was the Division of Vital Statistics' (DVS) ability to modify systems to receive, accept, and parse HL7 messages and Clinical Document Architecture (CDA) with death information received from states. NCHS worked closely with representatives from CDPH vendor the University of California Davis Health System (UCDHS), which facilitates their mortality reporting. UCDHS served an integral role in advancing the standards, activities, and plans for pilot implementation at CDPH. Representatives from UCDHS collaborated with DVS and the CDC Public Health Information Network Messaging System (PHIN MS) team to install PHIN-MS nodes and successfully transmit test HL7 messages to NCHS.

UCDHS was instrumental in the development of the required interfaces to support this endeavor. UCDHS collaborated with the Epic EHR integration team to test the interface with the Epic EHR system and the EDRS integrating medical information in EDRS, also known as the IMAGINE module. EPIC successfully launched IMAGINE and submitted cause-of-death information from the EHR system to populate EDRS. The EPIC Death Interface was delivered to UCDHS on August 31, 2016.

Once the technology was developed to support the exchange of mortality reporting via HL7 format, a pilot was designed to demonstrate the feasibility of mortality data exchanges between CDPH and NCHS using the HL7 2.6 format. The pilot established and demonstrated a viable process within the UCD health system, linking the state EDRS, with a medium and small county to demonstrate an automated process throughout the reporting practice, from event documentation through state registration and transmission to NCHS. Return acknowledgement and return of coded cause-of-death data were included in the test. The pilot began on March 7, 2017, and concluded on May 9, 2017. A total of 3,252 records were processed for the pilot. Please see the table below showing the total numbers of HL7 records processed and auto-coded during the pilot period (1,987 records). The total HL7 records processed represents about 7% of all deaths registered in CA during that time. The remaining 1,265 records were sent for manual coding for cause of death.

HL7 records processed	HL7 records auto-coded with cause of death	Percentage of auto-coded with cause of death
3,252	1,987	64.5%*

All reports outlining and summarizing pilot's effort and related organizational actions were forwarded to ASPE September 2017 in a summary, which included a step-by-step account of the HL7 pilot and associated work. The report also provided a real-world perspective on the implementation factors related to such an effort and important lessons learned in operationalizing such an effort.

Objective 3: Pilot the linkage of the National Hospital Care Survey inpatient and emergency data with the NDI data to measure within- and post-hospital mortality for analysis.

This effort was undertaken to determine the feasibility of linking emergency department visit data and inpatient discharge data collected by the National Hospital Care Survey (NHCS) to state-specific mortality data in various data systems to enhance clinical research and the research community in general. NCHS through this project specifically leveraged the various data with NDI data to better understand it and to provide additional insight, with the intent of exploring mechanisms to make linked data available to the research community per NCHS confidentiality policies and procedures.

NCHS accomplished the prescribed objective above and all associated tasks. This included securing essential support from NHCS-sampled hospitals to participate in the effort; collecting and linking the NHCS and NDI data, including the storage and analysis of data in compliance with policies that regulate the governance of data; and conducting a matching process via rigorous scientific methodology that ensured the fidelity of the process and outcome of the project. The results of which have been shared prior to this summary in previous reports at the required intervals throughout the life of the project.

In executing the project as outlined in the IAA, NCHS demonstrated the feasibility and mechanism to advance the linking of mortality data to further support opportunities for research to be conducted in comparing patterns of care in multiple healthcare settings. Please find below a synopsis of the activities and accomplishments supported by the Intra-Agency Agreement between ASPE and CDC supporting the **"Improving Mortality Data Infrastructure for Patient-centered Outcomes Research"** project.

NCHS met all tasks associated with this objective, which included:

- Secured approval and support of the NDI Advisory Board to undertake the linkage by obtaining a Letter of Approval to conduct activities related to this effort. Letter of Approval was reported and submitted to OS/ASPE (November 16, 2015).

- Matched the NDI records with 2012 NHCS inpatient and emergency department data collected from participating hospitals to create a person-level file. Multiple interdependent activities were executed to achieve this task, such as the transmission of 2012 NHCS inpatient and ED data to NDI and DHCS submission of 4,289,656 NHCD records via a secure share on the NCHS CIPSEA server to the NDI linkage group. Subsequent to the delivery of the linked NCHS-NDI files, 10% had a possible NDI match (reported November 16, 2015).

- Submitted a report on the methodology of clean and analyzed data to determine which cases have acceptable unique matches. This task was accomplished by sending NDI files to a DHCS contractor for sorting, cleansing, and analyzing cases to determine which had acceptable unique matches (report provided November 16, 2015).

- Delivered a matched file and report to DHCS/NCHS. Contractor submitted a report on NHCS-NDI data linkage methodology to NCHS in December 2015. The report summarized statistics for the quality and quantity of preliminary matches and the specific algorithms for determining acceptable matches and the level of manual review needed. Subsequent to the delivery of the file, a report was submitted to PCORI on January 5, 2016. In addition, in March of 2016, DHCS submitted a final report describing the methods and preliminary results of the data linkage project (report provided May 10, 2016).

- Established a process to annually link NHCS in patient and ED data with the NDI, and explored the best mechanism to make the data files accessible for clinical and health researchers. DHCS has established a linkage schedule based on final data delivery of NHCS data and the availability of final NDI data. The 2014 NHCS data were linked to the NDI in 2018 and the 2016 NCHS data in 2019. The linked files are available in NCHS' Research Data Center.

- DHCS explored the possibility of making NHCS-NDI linked data files available to researchers in the Research Data Center (RDC), supported by NCHS. For subsequent NHCS-NDI linked data files in 2014 and 2015, researchers will be able to submit a proposal to RDC to access the linked NHCS-NDI data files. The variables on the data files will include all NHCS variables and specific variables from the NDI death records outlined in the report provided earlier (Deliverable 3.6).

This final report provides an overview that outlines the merit of the activities funded under this task order and the valuable contribution of funded jurisdictions to **"Improving the Timeliness and Quality of State Electronic Death Registration (EDR) Systems."**
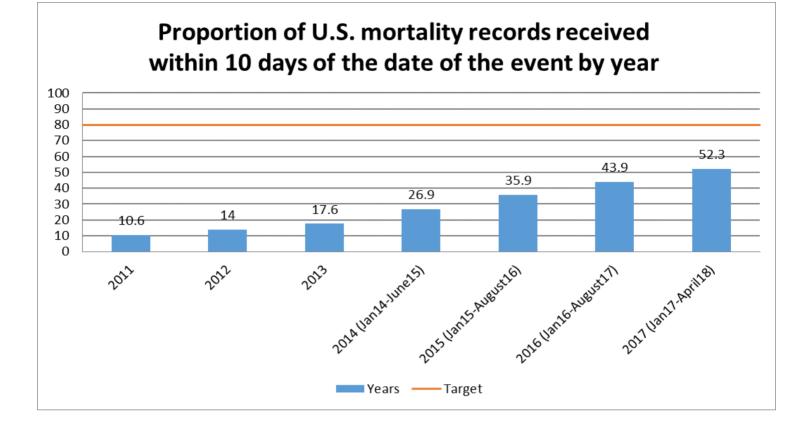
Proportion of U.S. mortality records received within 10 days of the date of the event by year

Table 1. July–June records

	2014–2015 records received July 1, 2014–June 30, 2015				2015–2016 records received July 1, 2015–June 30, 2016				2016–2017 records received July 1, 2016–June 30, 2017		
	0–10 days				0–10 days				0–10 days		
State	Frequency	Count	Total count	State	Frequency	Count	Total count	State	Frequency	Count	Total count
FL	76.7	148,955	194,161	FL	80.4	157,742	196,313	FL	76.9	155,899	202,630
GA	4.7	5,112	109,547	GA	30.5	25,783	84,443	GA	37.8	31,291	82,869
HI	12.0	1,376	11,433	HI	26.6	3,003	11,299	HI	55.2	6,378	11,547
KS	33.7	8,749	25,967	KS	38.9	9,945	25,561	KS	60.4	15,986	26,474
MI	0.5	486	90,088	MI	13.5	15,481	114,870	MI	57.0	54,990	96,458
MO	17.0	10,556	61,940	MO	26.9	16,610	61,720	MO	39.7	25,087	63,260
NE	25.0	4,207	16,847	NE	25.1	4,032	16,089	NE	43.0	7,530	17,501
NH	14.7	1,700	11,566	NH	31.0	3,722	11,989	NH	88.2	10,628	12,053
NY	0.1	52	71,141	NY	0.0	3	116,760	NY	5.6	5,586	99,162
OK	38.3	14,647	38,282	OK	42.8	16,256	37,977	OK	44.6	17,358	38,920
OR	21.1	7,196	34,160	OR	22.8	8,574	37,528	OR	27.8	10,273	36,977
PA	0.0	43	151,565	PA	0.4	556	133,059	PA	12.0	17,064	142,046
Total	24.9	203,079	816,697	Total	30.9	261,707	847,608	Total	43.1	358,070	829,897

Percentage of records received at NCHS within 10 days

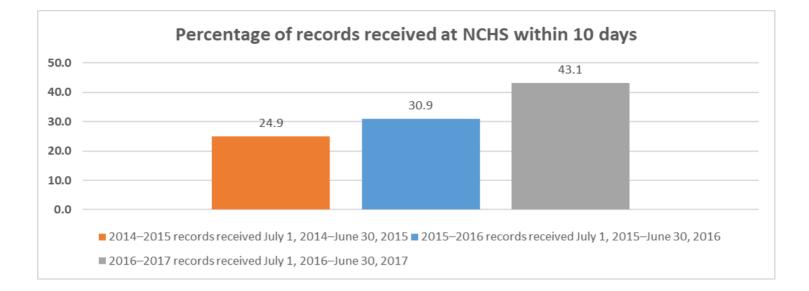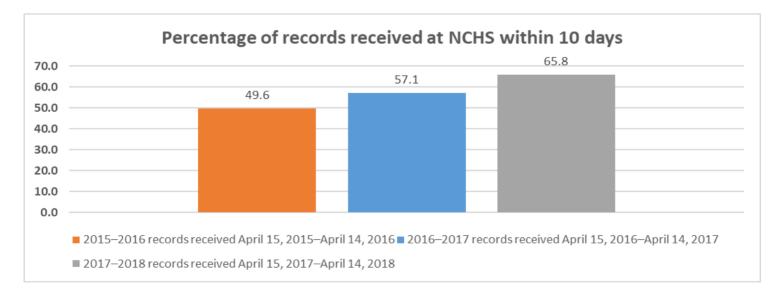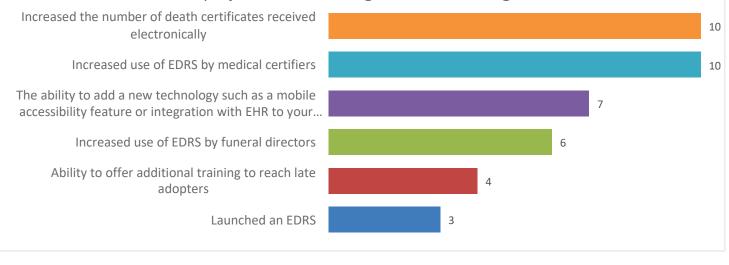|	
24.9	2014–2015 records received July 1, 2014–June 30, 2015
30.9	2015–2016 records received July 1, 2015–June 30, 2016
43.1	2016–2017 records received July 1, 2016–June 30, 2017

Table 2. April-April records

	2015–2016 records received April 15, 2015–April 14, 2016				2016–2017 records received April 15, 2016–April 14, 2017				2017–2018 records received April 15, 2017–April 14, 2018		
	0–10 days				0–10 days				0–10 days		
State	Frequency	Count	Total count	State	Frequency	Count	Total count	State	Frequency	Count	Total count
CA	70.9	97,929	138,070	CA	71.8	106,243	147,909	CA	76.4	114,840	150,350
IA	57.8	9,170	15,860	IA	60.4	10,192	16,869	IA	65.5	11,073	16,896
IN	48.9	15,461	31,600	IN	55.8	20,377	36,494	IN	62.5	22,470	35,934
MD	3.8	1,574	41,042	MD	18.1	6,637	36,709	MD	52.3	14,567	27,865
MN	67.5	16,161	23,937	MN	76.7	18,922	24,676	MN	82.4	20,470	24,854
VA	5.8	2,560	44,354	VA	13.7	5,216	38,037	VA	16.2	5,983	36,935
WA	60.3	19,836	32,914	WA	73.0	19,142	26,211	WA	78.1	21,291	27,246
Total	49.6	162,691	327,777	Total	57.1	186,729	326,905	Total	65.8	210,694	320,080

Percentage of records received at NCHS within 10 days

49.6	2015–2016 records received April 15, 2015–April 14, 2016
57.1	2016–2017 records received April 15, 2016–April 14, 2017
65.8	2017–2018 records received April 15, 2017–April 14, 2018

Question 1: What has been your **greatest accomplishment** related to this project since receiving the PCOR funding?

Increased the number of death certificates received electronically	10
Increased use of EDRS by medical certifiers	10
The ability to add a new technology such as a mobile accessibility feature or integration with EHR to your…	7
Increased use of EDRS by funeral directors	6
Ability to offer additional training to reach late adopters	4
Launched an EDRS	3

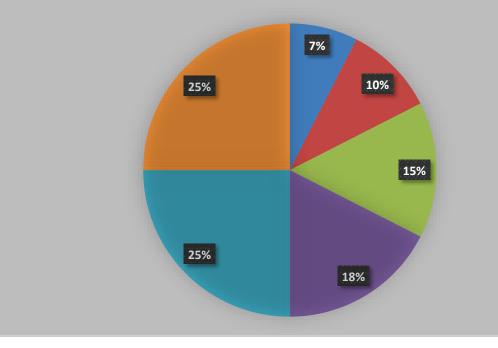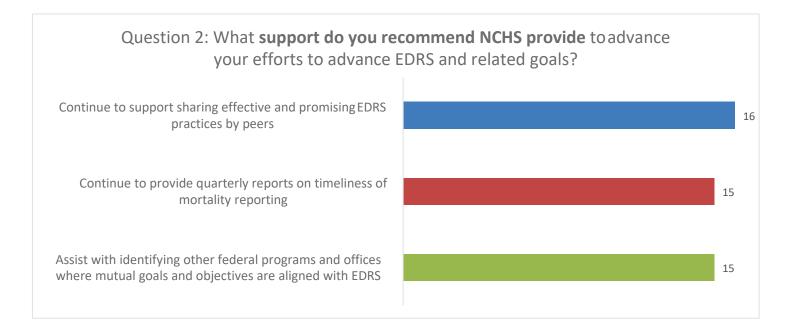***Reflects all responses; not mutually exclusive.**

Question 1: What has been your **greatest accomplishment** related to this project since receiving the PCOR funding?

*Reflects all responses; not mutually exclusive.

Question 2: What **support do you recommend NCHS provide** to advance your efforts to advance EDRS and related goals?

Response	Count
Continue to support sharing effective and promising EDRS practices by peers	16
Continue to provide quarterly reports on timeliness of mortality reporting	15
Assist with identifying other federal programs and offices where mutual goals and objectives are aligned with EDRS	15

Question 2: What **support do you recommend NCHS provide** to advance your efforts to advance EDRS and related goals?

Pie chart: 35% (blue), 32% (red), 33% (green)

Question 3: What are your **priorities and goals for 2017– 2018**?

Priority	Value
Add a new technology such as a mobile accessibility feature	14
Increased use of EDRS by medical certifiers	13
Increased the number of death certificates received electronically	11
Reach out and train late adopters	8
Increase use of EDRS by funeral directors	5

Question 3: What are your **priorities and goals for 2017– 2018**?

10%
16%
22%
25%
27%