

A Report on the Status of
Fetal and Infant Mortality
Review in the United States
2016



Source of Information:

The National Center for Fatality Review and Prevention Reports from Fetal and Infant Mortality Review Programs



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Acknowledgement and thank you to the many local FIMR programs and state FIMR coordinators who contributed this information. Their dedication and commitment to the community is what improves the health of families.

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Introduction

The beginnings of Fetal and Infant Mortality Review (FIMR) date back to the mid-1980s, when concern over high infant mortality rates intensified nationwide. The Maternal and Child Health Bureau (MCHB) conceptualized Infant Mortality Review (IMR), the forerunner of FIMR, as a promising method to improve understanding of local factors contributing to infant mortality and to motivate community response. FIMR is a community-based, action-oriented process to review fetal and infant deaths and make recommendations to spark systemic changes to prevent future similar deaths. Most FIMR teams operate at the local level (usually the county) to examine medical, non-medical, and systems-related factors and circumstances contributing to fetal and infant deaths.

Among the various types of fatality reviews, the FIMR approach is unique because cases are de-identified; they may include a family interview to determine the family's perspective on factors that may have contributed to the infant's life and death; and many of the teams have a Community Action Team (CAT) that, after completion of the review, works to take the case review team's recommendations to action. From the very beginning, the FIMR model strongly emphasized the importance of a community-based two tiered process that promoted the use of separate groups to carry out an analytic function and a subsequent action function. The Community Review Team has the role of reviewing cases and drafting recommendations, while the Community Action Team helps to disseminate findings, and facilitates implementation of recommended policies and interventions.

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For many years, HRSA funded a National Center for Child Death Review as a resource center for FIMR programs. In 2015, HRSA released a Funding Opportunity Announcement for a new Center that would combine FIMR and Child Death Review training, technical assistance, and data services. The result is the National Center for Fatality Review and Prevention at the Michigan Public Health Institute, which came into being on July 1, 2015. In the first grant year, the National Center contracted with the American College of Obstetricians and Gynecologists to provide the FIMR technical assistance and training. In year two, the Michigan Public Health Institute (MPHI) brought its FIMR support services in-house.

The Center provides training and technical assistance to the field, is creating a web-based FIMR database; facilitates collaboration between FIMR and CDR; is developing a website and portal where FIMR teams may post their outcomes; and has developed a regional network of FIMR programs.

In late 2016, the National Center surveyed 175 FIMR teams in 29 states were surveyed about their structure, process, and activities during 2016. Figure 1 is a map showing the states and number of FIMR programs in each state. One hundred and thirty-six programs in 25 states and Puerto Rico responded to the survey. Of the 136 respondents, 128 (94%) were from local FIMR programs, and 8 (6%) were state FIMR coordinators. Both local and state program responses are represented together in aggregate. Figure 2 provides an overview of the respondents.

Trends in Fetal and Infant Mortality Review

FIMR PROGRAM STRUCTURE

Many FIMR teams are well established in their communities. Almost three-quarters of respondents stated that their health department (whether state, county or city) is the lead agency for FIMR in their jurisdiction. Healthy Start is the lead for another 11% of responding programs, and the rest are led by a variety of agencies, such as perinatal coalitions/networks and hospitals. The majority (96.6%) of reviews are conducted at the local level. Only 4.4% of FIMR programs conduct state level reviews: Puerto Rico, Utah, and West Virginia.

Funding sources vary among the responding programs. For 71.4% of programs, the primary sources of funding are state and federal Maternal Child Health/Title V block grant funding through local health departments and other state funding. Federal funding, including federal Healthy Start funding, accounts for 34.7% of programs; and local foundations and charities such as United Way fund 10.2% of programs, with 28.6% of respondents indicating “other” sources of funding. Figure 2 illustrates the breakdown of how respondents answered the question on funding source for their FIMR.

The authority to access medical records and conduct FIMR reviews varies greatly across states and local jurisdictions. About half of FIMR programs who responded (47.4%) operate under state statute or language in the Public Health Code that enables or permits the local FIMR to operate. In 36% of the sites that responded, there is a state law or mandate to conduct FIMR.

Most communities select cases for review based on risk and/or population factors such as vital statistics data and other information about the causes of infant mortality and how these statistics change over time. Many communities attempt to review all cases of fetal and infant death to give them a better picture overall of the community and its services and resources. Of the respondents, 54.2% report that they review cases of fetal and infant death of residents of their county. Some programs focus on known high risk areas such as a city (2.4%) or residents of certain zip codes (7.2%) In more rural settings, a FIMR program may include multiple counties for case selection and review (25.3%). In 2016, state and local FIMR teams reviewed a total of 2,335 (n=113) infant deaths, babies born alive who did not survive until their first birthday, and 2,315 (n=113) stillborn infants.

The selected de-identified cases are then abstracted by an individual, usually a nurse. In many teams, the case abstractor interviews the mother or other family member about the circumstances of the death, which can yield valuable information about social and environmental aspects surrounding the fetal or infant death. This information is included in the case abstract. The abstracts are then shared and discussed with the multidisciplinary case review team (CRT), which then makes recommendations for improvements in care and systems change. Many teams also utilize a second tier of review, the Community Action Team (CAT), which usually includes other community leaders. The CAT works to take the CRT recommendations to action.

COMMUNITY ACTION TEAMS

As stated above, a unique feature of FIMR programs is the use of a Community Action Team as a second tier of review and action. While there may be some overlap in membership, the role of each team is quite distinct. The CRT acts as the information processor, reviews and analyzes the information collected in interviews and case abstractions, identifies gaps in care, and makes recommendations for how to improve systems and delivery of care. The CAT translates the CRT recommendations into strategies for action and participates in implementing interventions designed to address the identified problem. Based on the survey responses, over two-thirds of teams (67.4%) have a two-tiered structure (CRT and CAT). Some have CATs developed solely for the FIMR program, and many have CATs that are part of existing community coalitions.

The membership on CRT and CAT teams varies among teams: the professions that are included on half or more of the teams are local health departments, social workers, obstetric/pediatric nurses; pediatricians; obstetricians; nurse home visitors; mental health professionals; child welfare workers; and educators.

MATERNAL INTERVIEWS

A unique feature of the core FIMR model is its focus on obtaining a family interview as part of the review process, which provides their perspective of their baby's death and allows them to describe their experiences in their own words. The maternal/family interview is emerging as a major strategy for helping teams understand mothers'/families' experiences of racism and other inequities, and how those experiences may have impacted maternal and child outcomes. Most family interviews are conducted with the birth mother, but teams report that the father of the infant, grandparent, or other caregiver may also be included. The interviews yield information not usually captured in routinely collected health records. Over three quarters of responding teams (78%) report that they typically include information from an interview with a family member as part of their reviews. The mean response of respondents who reported the percentage of reviews which include a maternal interview is 29.4% (n=88). Of the respondents, 12.5% report that they get completed interviews for 75 – 100% of their cases, 6.8% report having interviews for 51 – 75% of their cases, 18.2% report having interviews for 26 – 50% of their cases, and 62.5% of respondents report that they have maternal interviews for less than 25% of their cases reviewed. There are many barriers that FIMR teams identify to obtaining maternal/family interviews. Both respondents who use the family interviews and those who do not described reasons for their difficulties obtaining the interviews. The majority of FIMR teams (58.3%) identified challenges locating and finding the mother or other family member as the primary reason for low number of interviews. Lack of funding to allow staff to do maternal interviews was identified as a barrier for 47.6% of respondents, and a significant number of programs (17.9%) identify lack of staff training/comfort level with grief as a barrier to obtaining maternal interviews. An additional 11.9% identify that FIMR staff are uncomfortable with the interview process. These findings suggest that the maternal/family interview should be a major focus of technical assistance for FIMR teams in the coming year.

COLLABORATION WITH MATERNAL AND CHILD HEALTH INITIATIVES

The Healthy Start Program is an initiative to eliminate disparities in perinatal outcomes through grants to project areas with high infant mortality. There are 100 Health Resources and Services Administration (HRSA), funded Healthy Start programs in 35 states. One third of respondents (33.8%) indicated that there is collaboration between Healthy Start and FIMR.

Respondents described a number of ways FIMR and Healthy Start collaborate including: FIMR findings may spur a community to apply for a Healthy Start grant; Healthy Start may fund FIMR in whole or part; Healthy Start members may serve on the FIMR Community Review Team (CRT) and/or Community Action Team; FIMR may ask a Healthy Start Community Action Network (CAN) to act as its FIMR Community Action Team. Frequently, Healthy Start may be the vehicle through which FIMR recommendations are implemented in communities. In 50% of the FIMR communities there is no federally funded Healthy Start, and an additional 15.4% of FIMR respondents described that there is a Healthy start in the community but there is no documented collaboration.

One of HRSA's areas of focus for the new Center is increasing collaboration between and among different types of fatality reviews. FIMR programs were asked to identify which fatality review processes operate in their communities and whether they collaborate with them. Of the 103 programs that responded to this question, 92.2% of respondents indicated they participate in Child Fatality Reviews. 15.5% of respondents indicated they participate in Maternal Mortality Reviews.

Many of the programs that participate in Child Fatality Reviews described their collaboration to be shared staff work on CDR and FIMR processes and/or attendance at each other's meetings. Other means of collaboration listed by the teams are leadership of both in one organization and joint prevention messages.

In addition to collaboration with other death review processes, FIMRs were asked if they play a role in collaborating with and informing their Title V programs. The Title V Maternal Child Health Services Block Grant Program is authorized under Title V of the Social Security Act to ensure the health and well-being

of women, mothers, infants, children (including children with special health care needs), adolescents and their families. Of the 126 respondents to this question, 72.2% reported collaboration with State MCH or Title V.

DATA

FIMR teams use a variety of data systems to enter information about their reviews and actions. Some use systems created by their state and/or community. Some use the non-web-based system developed by the National Fetal and Infant Mortality Review program (NFIMR). Others use a web-based database pilot developed in 2015 by the American College of Obstetrics and Gynecologists, the State of Michigan, and the Michigan Public Health Institute (MPHI). Still others use an Infant Enhancement Module that is also part of the existing MPHI web-based National Child Death Review-Case Reporting System (CDR-CRS). HRSA's goal is one web-based system used by all FIMRs and all CDRs, for consistency and aggregate data, and to facilitate national reports. To that end, a workgroup of FIMR coordinators from around the country has been working with the National Center to develop a FIMR module to be integrated with the existing CDR-CRS system. The new module is expected to launch in January, 2018. Figure 14 details the breakdown of the current type of reporting system being used by respondents, and Figure 15 indicates the high number of FIMR programs (89.3%) that are interested in a standard and uniform data reporting systems for both CDR and FIMR.

PREVENTION INITIATIVES

The hallmark of FIMR, is the way in which team and communities use their findings and translate them into meaningful actions. Teams are very active in seeking solutions to prevent the types of deaths they review. Their responses are a rich repository of prevention initiatives, as indicated in the tables and charts below in Section E. The following are specific examples of successful interventions.

- In Alabama, FIMR reviews found that many cases of infant deaths due to prematurity were linked to physical abuse of the mother. FIMR personnel provided educational trainings to emergency room staff so they are equipped and confident to identify and refer pregnant women who are victims of domestic violence to appropriate community shelters and resources.
- The Alameda County, California FIMR Program found that the mothers in a high number of their reviews had not been routinely screened or referred for mental health conditions, so that maternal depression often went undiagnosed and unaddressed, contributing to poor pregnancy outcomes. The team obtained maternal depression screening and referral at all County Public Health WIC sites for pregnant and postpartum WIC clients.
- Weld County, Colorado's FIMR program, the only one in the state, began in 2012 after a local physician became concerned about the county's high infant mortality. Despite many challenges, there has been an increased awareness of the issue of infant mortality in the community and a subtle shift in individual agencies to make changes that will enhance maternal health and infant survival. The Weld County Safe Sleep Campaign (2013, 2014, 2016) involved creating tool kits and presentations for providers, proclamations by city and county government, attendance at community events, parades, fairs, press conference, public showing of a PBS documentary. Increased public awareness of infant mortality issues via newspaper articles, community forums, attendance at health fairs, and networking of agencies involved in FIMR process has drawn much attention from the State Health Department and within the community. FIMR is proud that the infant mortality rate in Weld County has decreased from 7.5 in 2011 to 4.7 in 2015.
- Baltimore's FIMR program findings pointed to a high number of mothers with a previous pre-term birth who gave birth to a subsequent baby born too early and too little to survive. They researched the efficacy of the use of 17-P ((alpha-hydroxyprogesterone caproate - a buffered steroid) and found there was a profound increase in survival of infants born to mothers who had a history of previous loss in early pregnancy when used as a weekly injection during a subsequent pregnancy beginning around 12 to 14 weeks gestational age. The FIMR team also partnered with

a local hospital and the Maryland Society for Maternal-Fetal Medicine physicians to sponsor interdisciplinary OB/GYN Grand Rounds for all OB/GYN providers. As a result, the use of 17-P has increased, leading to greater survival among infants and shorter hospital stays.

Another important prevention tool for FIMRs is disseminating findings from reviews. Many programs (68%) report that they use an annual report for enhancing the credibility and visibility of issues related to women, infants and families within the broader community. Getting the annual report to the right people is also important, as reflected in Figure 18.

Looking Forward to 2017

DATA

In 2015, the National Child Death Review Case Reporting System (NCDR-CRS) was updated to Version 4.0, and work is now underway on Version 5.0. Since the merger of the centers, NCFRP is the national data center for both CDR and FIMR. Version 5.0 will add a FIMR module for the approximately 175 FIMR teams in 29 states to enter data about their reviews.

The purpose of the Case Reporting System is to learn from the data to prevent further deaths. In the coming year, NCFRP will begin publishing a series of reports summarizing and analyzing the data about specific types of death. The purposes of the reports are to broaden availability of summary data from fetal, infant, and child death reviews and to inform prevention policies and activities in the states and nationally.

The Center is also working in partnership with the U.S. Centers for Disease Control and Prevention (CDC) in a pilot of a Sudden and Unexplained Infant Death Case Registry in 18 states, and is partnering with CDC and the National Institutes of Health on a Sudden Death in the Young Case Registry in 10 states. The states use the NCDR-CRS as the foundation for reporting into the registries.

SUPPORT FOR THE FIMR PROCESS

The National Center, working closely with HRSA, will continue to support the Fetal Infant Mortality Review Program and will be working with all Healthy Start grantees to make sure that they work closely with existing FIMR programs in their communities. A priority in this next calendar year will be to reach out to Healthy Start grantees with no FIMR program and to assist them in establishing a FIMR program in collaboration with their state/local/ or city health departments.

With HRSA's strong focus on outcomes, the National Center will roll out a new website in 2017 with a portal where FIMR (and CDR) programs will be encouraged to post their prevention activities and outcomes. The Center will also create a prevention playbook resource, including case studies of teams moving from reviews to action.

Respondents were asked to identify what they want from the Center. The most frequent responses were the new database; training, either in-person or through webinars; regional activities; regional and/or national meetings; increasing capacity for family interviews; and technical assistance regarding obtaining medical records and death notices, taking recommendations to action, and updating the abstraction tool.

PREVENTION

In 2017, the Center will also continue its focus on prevention activities. FIMR teams are working hard to craft better recommendations and implement evidence-based and promising practices that can prevent fetal and infant deaths. NCFRP is proud of and excited by the prevention activities taking place around the country as a result of FIMR activities and will continue to provide states with links to resources to support their prevention work and to showcase programs that have moved from reviews to improvements in systems and services for women, infants, and families.

NATIONAL PARTNERS

Many national organizations and agencies are working to reduce infant mortality. The Center is a member of several national coalitions to help translate FIMR work into prevention at the national policy level, and Center staff present, attend, exhibit, and network at numerous conferences and meetings of these organizations. FIMR programs also report important partnerships with a variety of partners in their communities and states.

All efforts to improve CDR are possible because of the dedication of state CDR leaders and the thousands of professionals and child advocates who attend review state and local review meetings. Their participation on more than 1,350 local teams and 43 state boards is a key reason that CDR has become a powerful system to help Keep Kids Alive.

Tables/Charts Describing the Status of FIMR in the U.S.

A. FIMR PROGRAMS

1. Map of FIMR Programs in the U.S.
2. Overview of Survey Respondents
3. Location of In-Depth Case Review
4. Funding Source

B. CASE SELECTION AND REVIEW STRUCTURE

5. Catchment Areas
6. Statute/Rules/Grant of Authority
7. Two-Tiered Team with a Functioning Community Action Team (CAT)
8. Maternal Interviews Conducted
9. Cases with a Maternal Interview
10. Barriers to Maternal Interviews

C. COLLABORATION WITH OTHER MATERNAL AND CHILD HEALTH INITIATIVES

11. Coordination with Federal Healthy Start
12. Coordination with Other Death Review Programs
13. Coordination with Maternal and Child Health

D. FIMR REPORTING

14. Type of Reporting System
15. Interest in National Center's Fatality Review - Case Reporting System

E. FIMR PROGRAM ACTIVITIES

16. FIMR Action Categories
17. Action Categories by Percent of Responses
18. Annual Reports Produced
19. Annual Reports Released to Whom

SECTION A
FIMR PROGRAMS

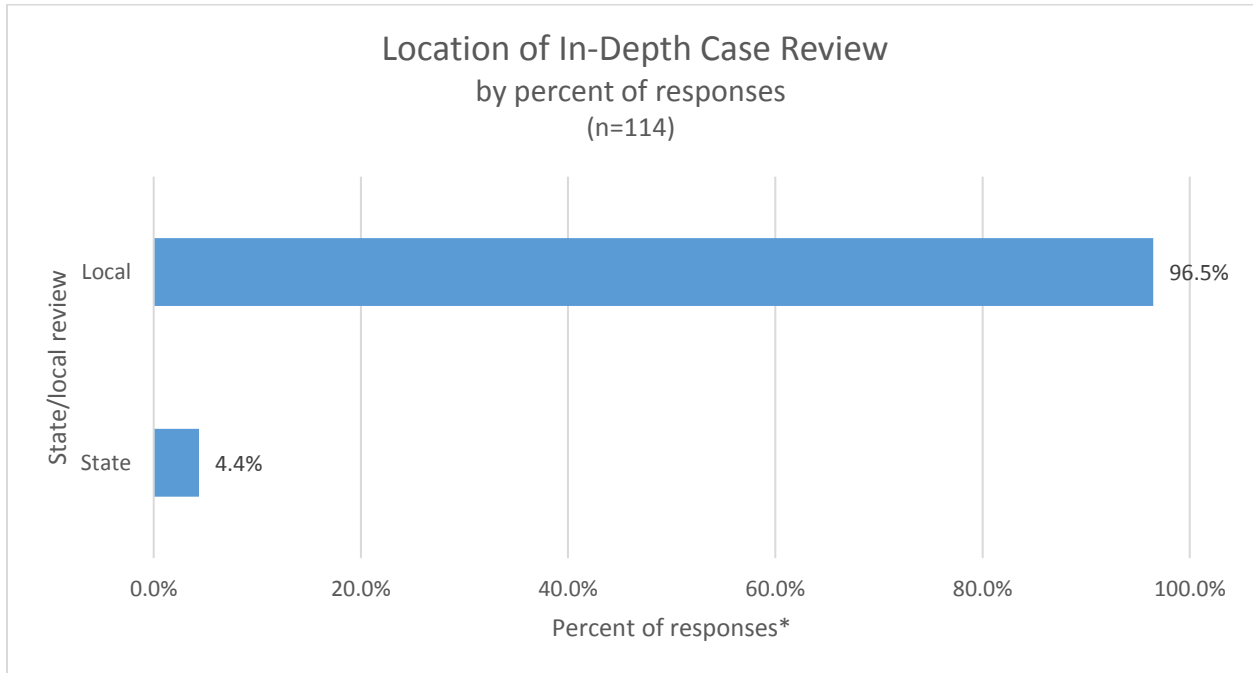
1. Map of FIMR Programs in the U.S.



2. Overview of Survey Respondents

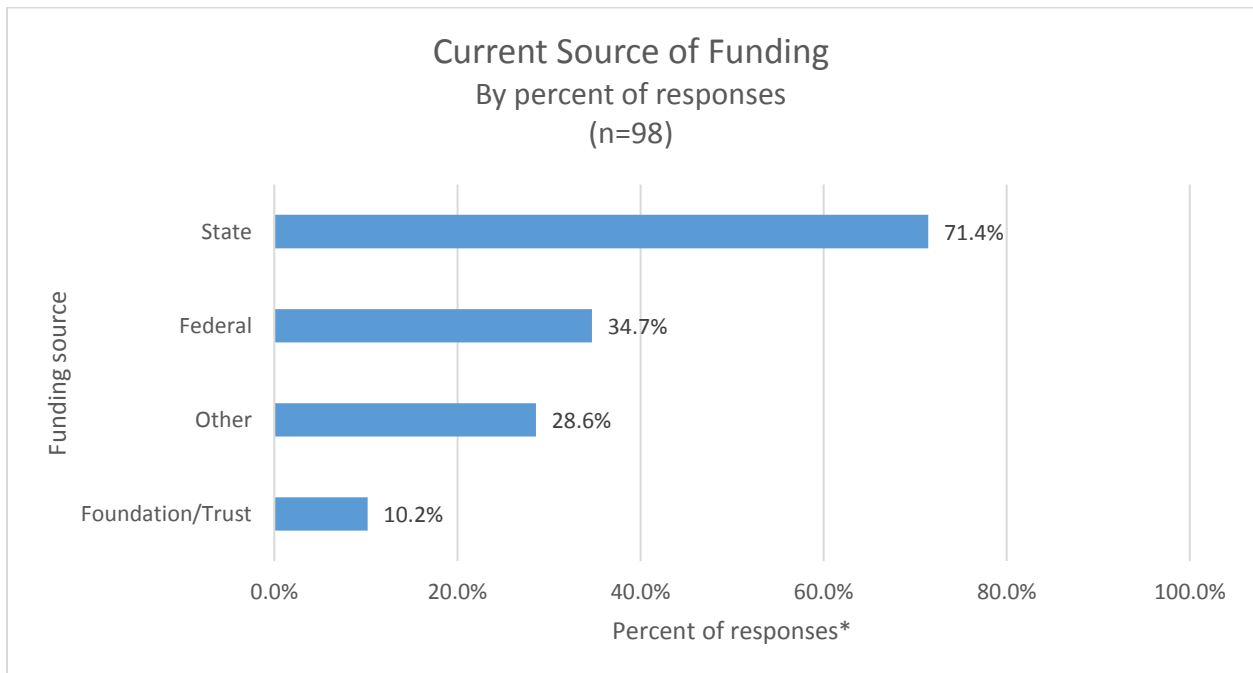
State	Number of respondents	State	Number of respondents
Alabama*	3	Missouri*	3
California	13	Montana*	19
Colorado	1	Nebraska	1
Delaware*	2	Nevada	1
Florida	12	New Jersey*	3
Illinois	1	Ohio*	10
Indiana	6	Oklahoma	2
Kansas	3	Tennessee*	6
Kentucky	1	Texas	3
Louisiana*	7	Utah	1
Maryland	20	West Virginia	1
Michigan	10	Wisconsin	3
Mississippi	3	Puerto Rico	1
* Indicates that a state coordinator responded to the survey in addition to local program coordinators.		Number of states	25 and Puerto Rico
		Number of respondents	136

3. Location of In-Depth Case Review



*Responses are not mutually exclusive.

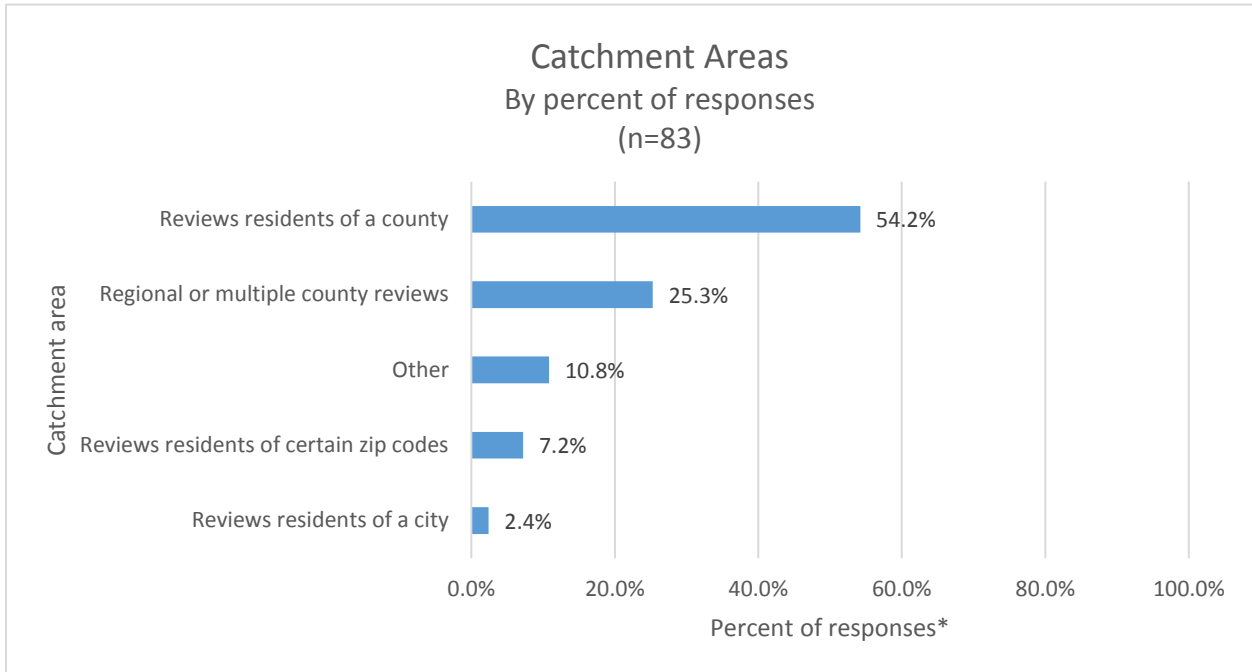
4. Current Source of Funding



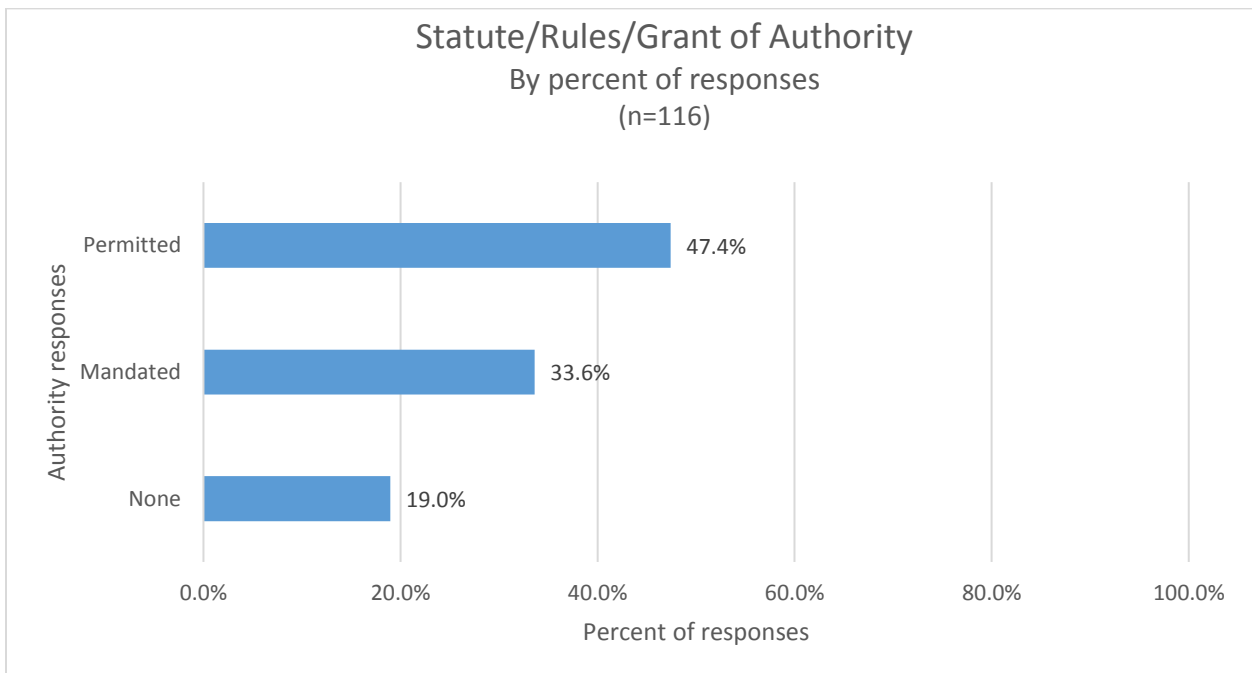
*Responses are not mutually exclusive.

SECTION B
CASE SELECTION AND REVIEW
STRUCTURE

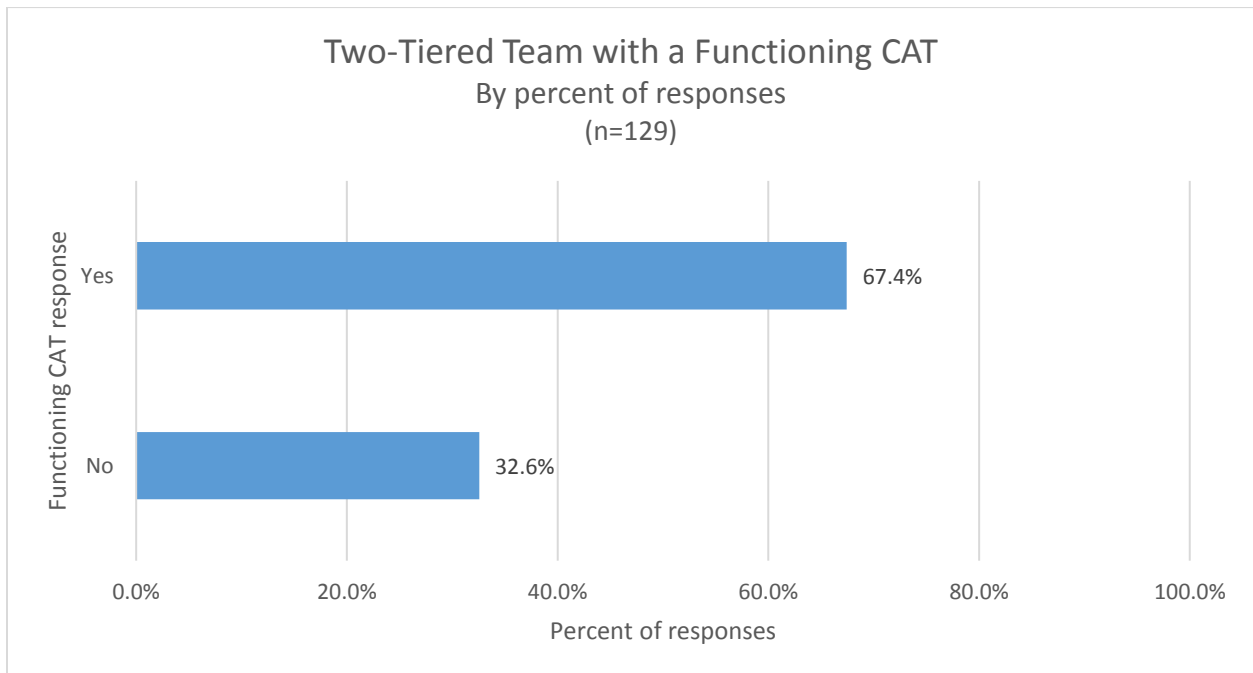
5. Catchment Areas



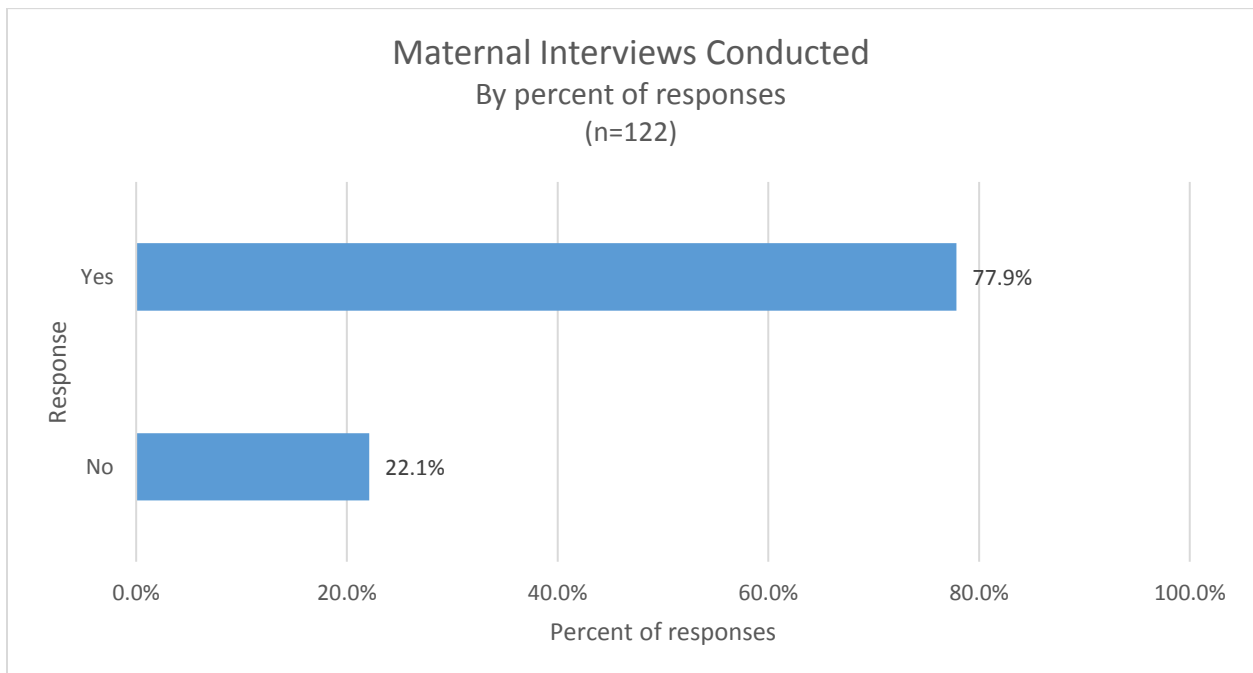
6. Statute/Rules/Grant of Authority



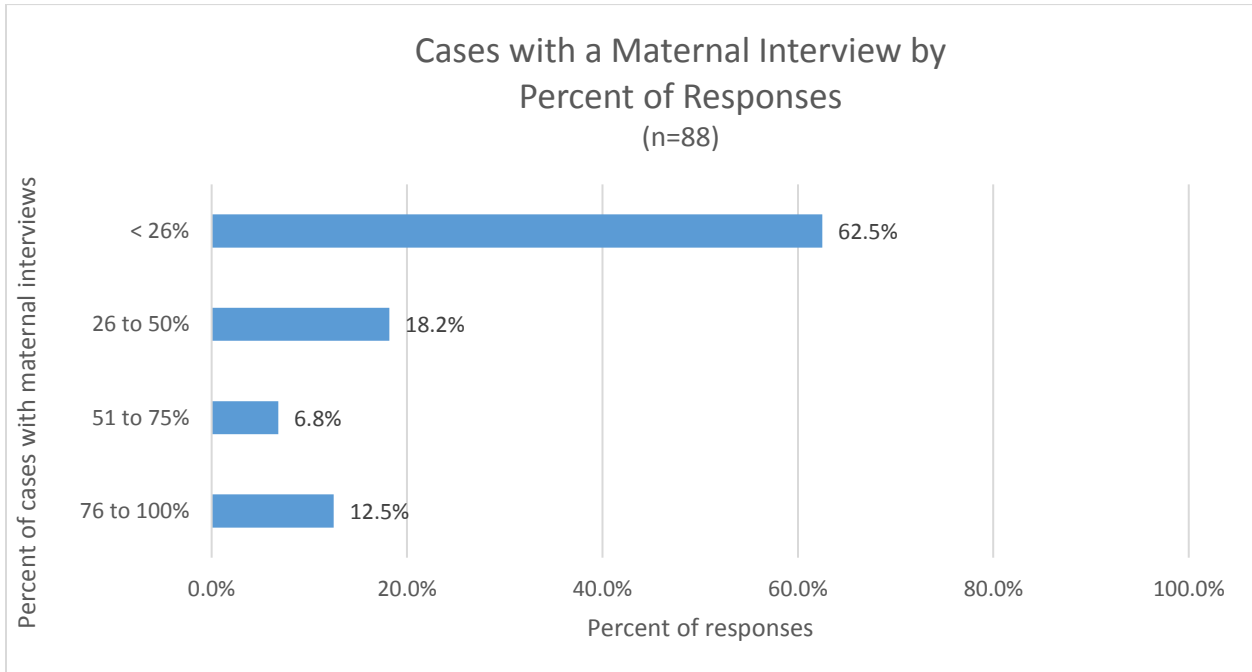
7. Two-Tiered Team with a Functioning Community Action Team (CAT)



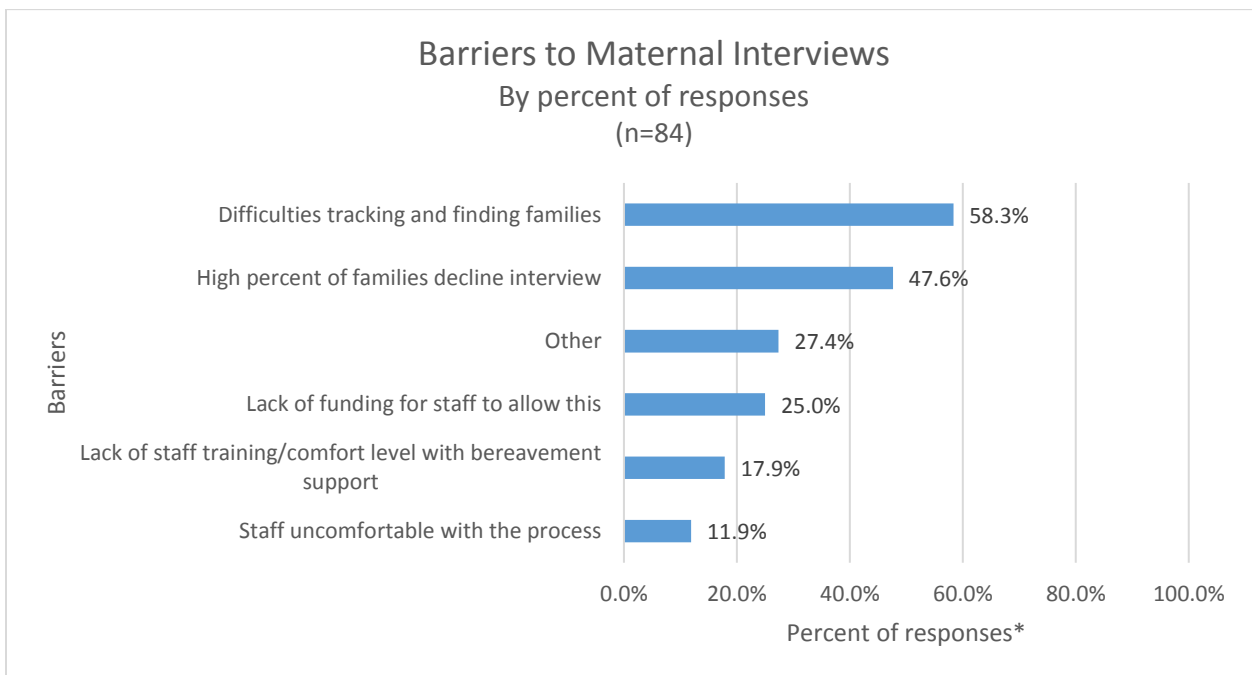
8. Maternal Interviews Conducted



9. Cases with a Maternal Interview



10. Barriers to Maternal Interviews

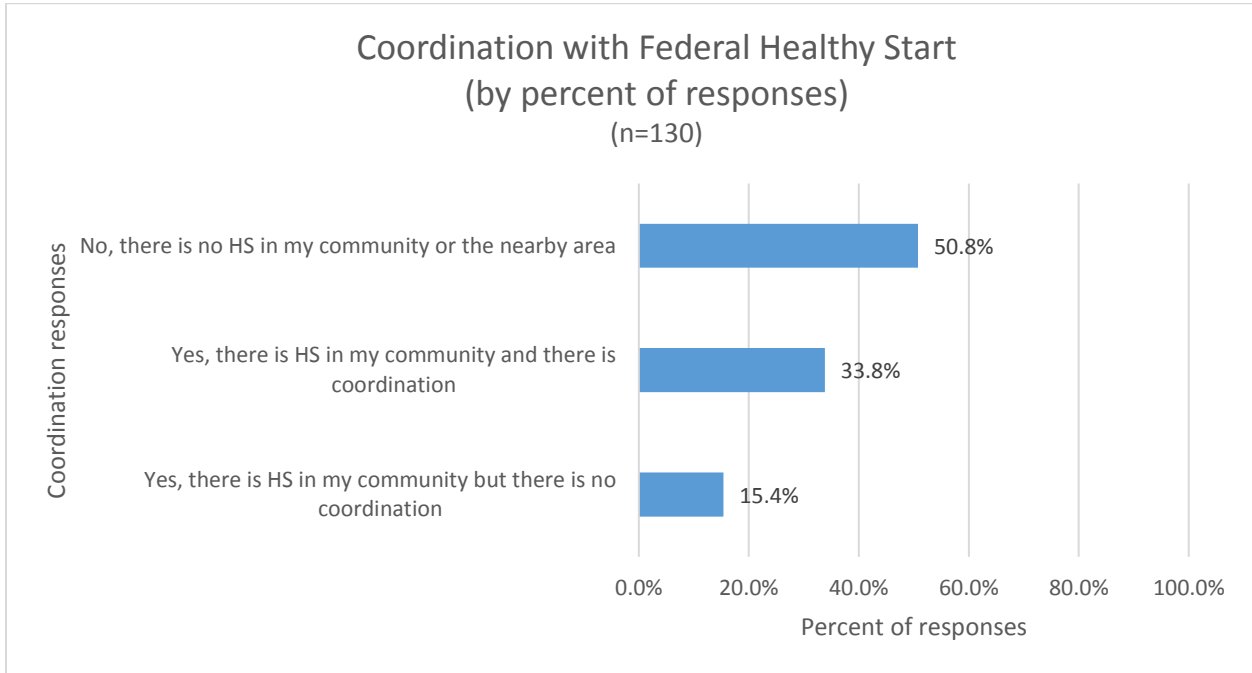


*Responses are not mutually exclusive.

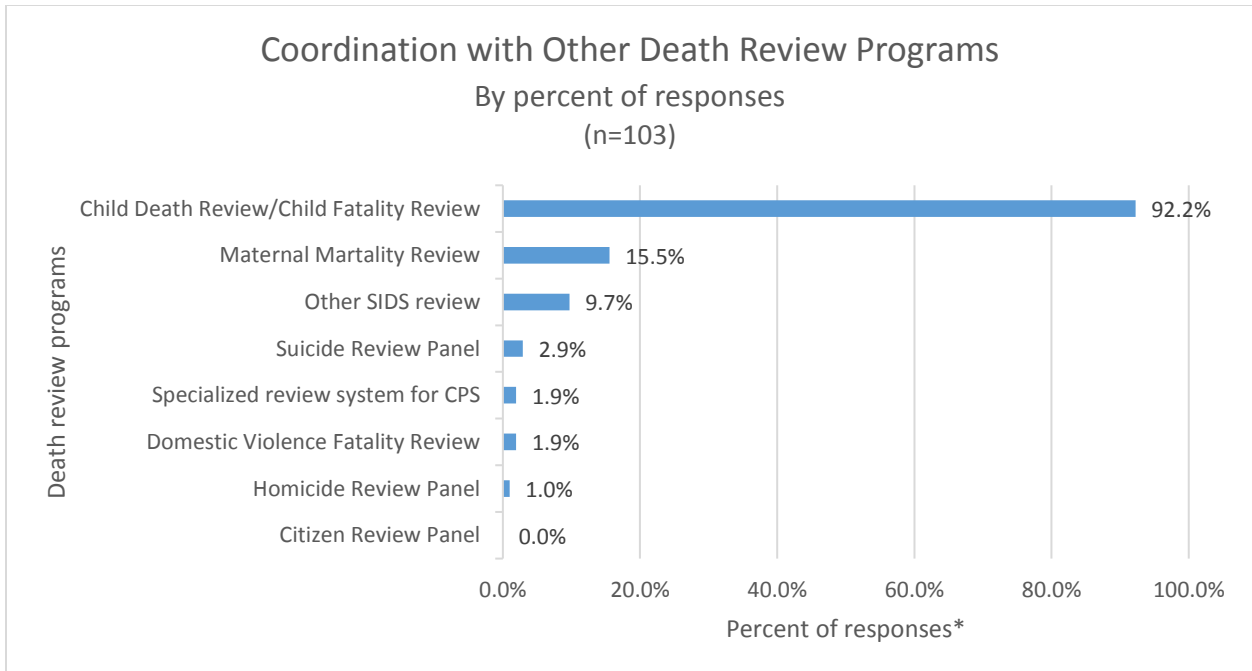
SECTION C

Collaboration with Other Maternal and Child Health Initiatives

11. Coordination with Federal Healthy Start (HS)

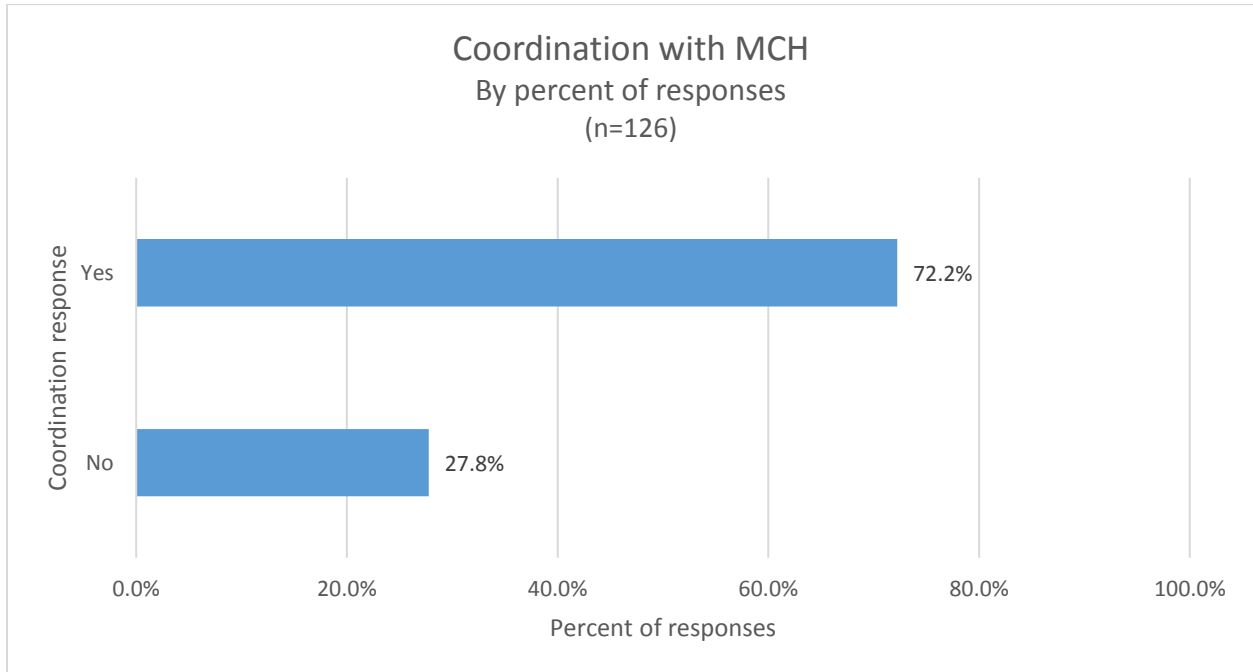


12. Coordination with Other Death Review Programs



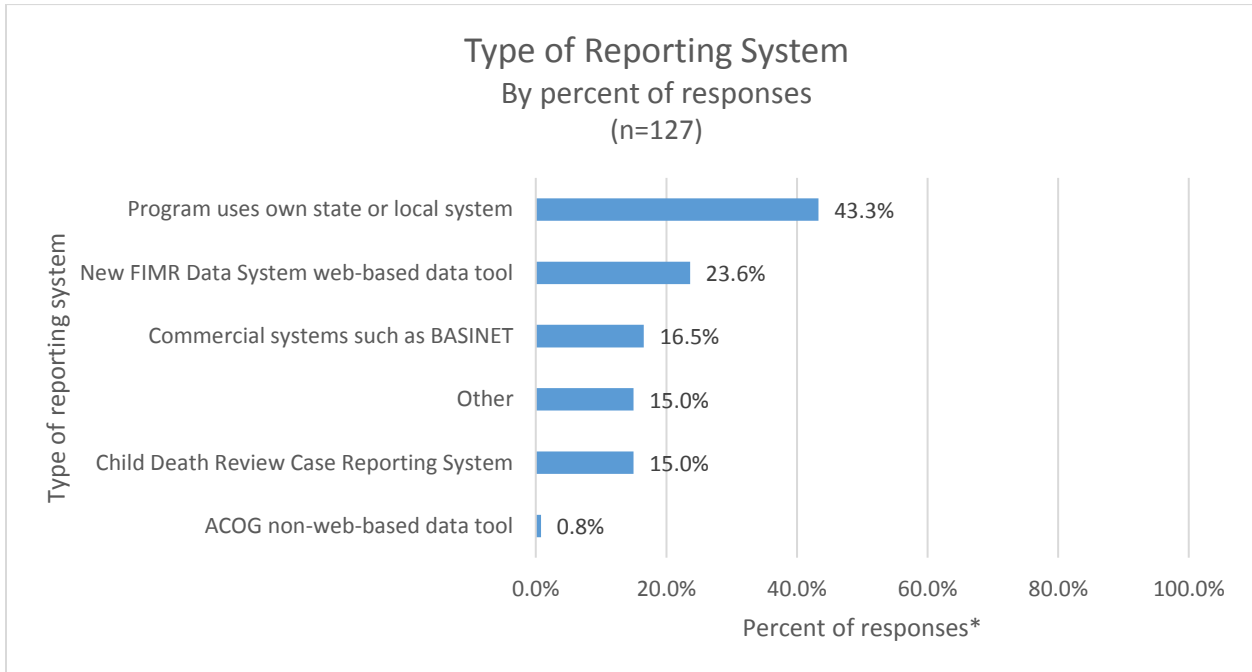
* Responses are not mutually exclusive.

13. Coordination with Maternal Child Health (MCH)



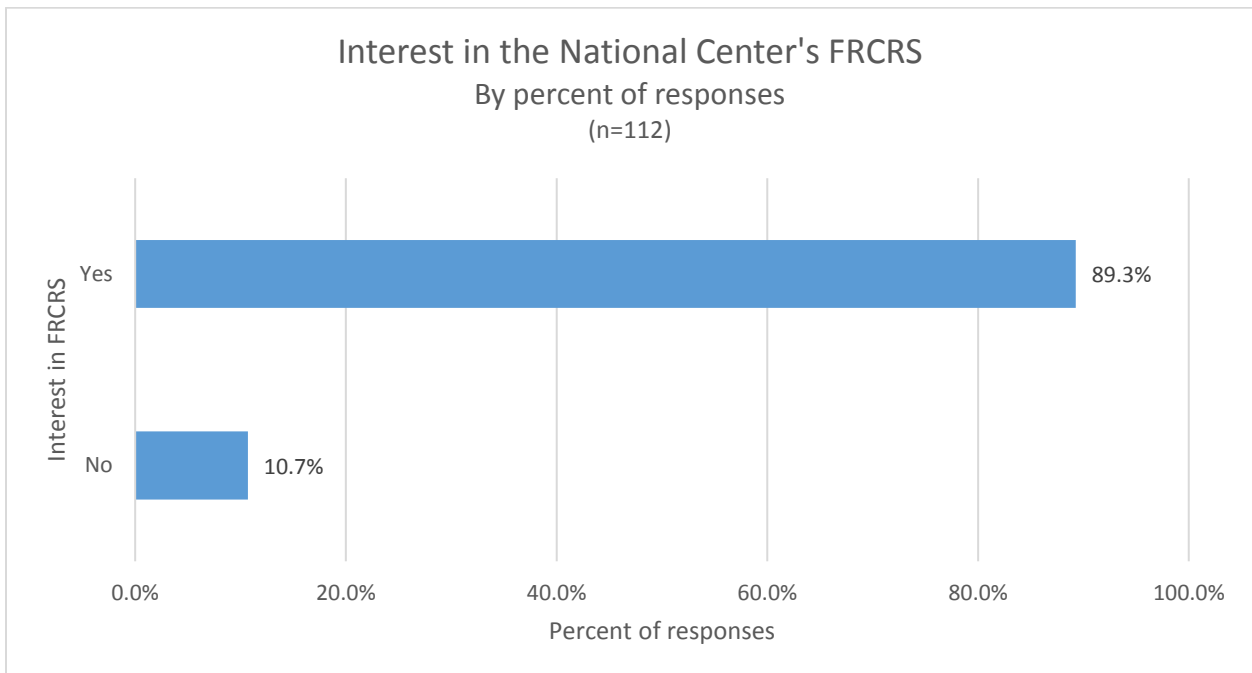
SECTION D
FIMR REPORTING

14. Type of Reporting System



*Responses are not mutually exclusive.

15. Interest in the National Center's Fatality Review Case Reporting System (FRCRS)

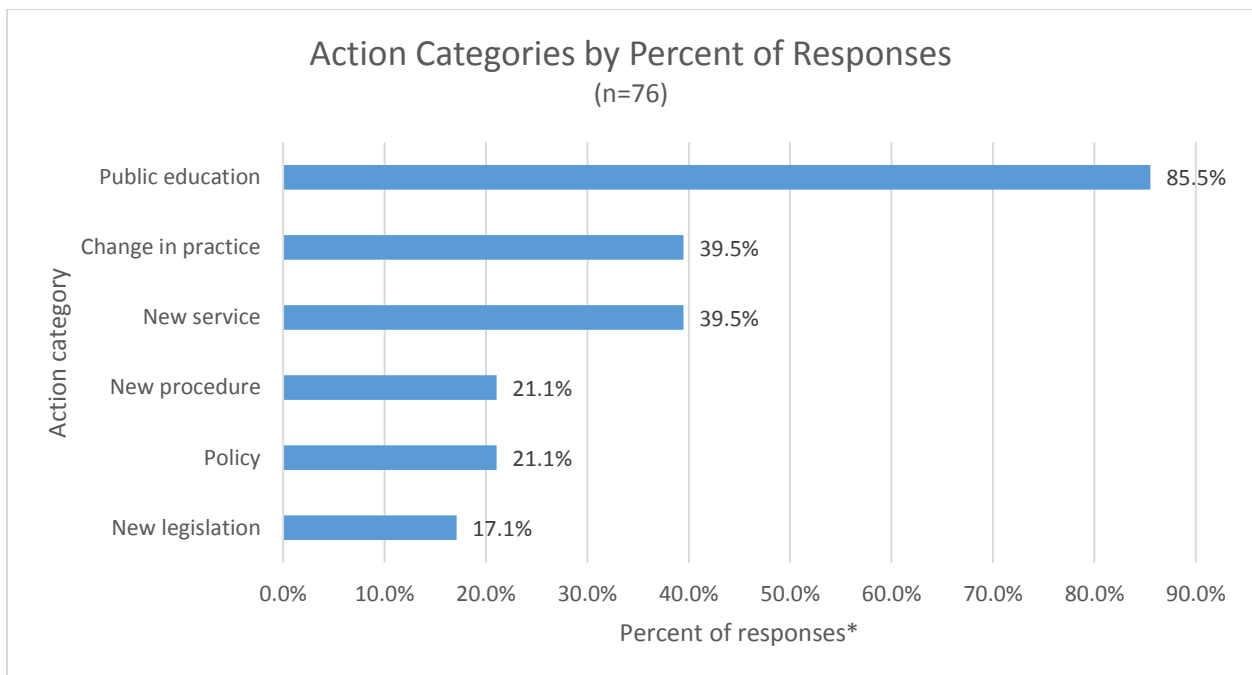


SECTION E
FIMR PROGRAM ACTIVITIES

16. FIMR Action Categories

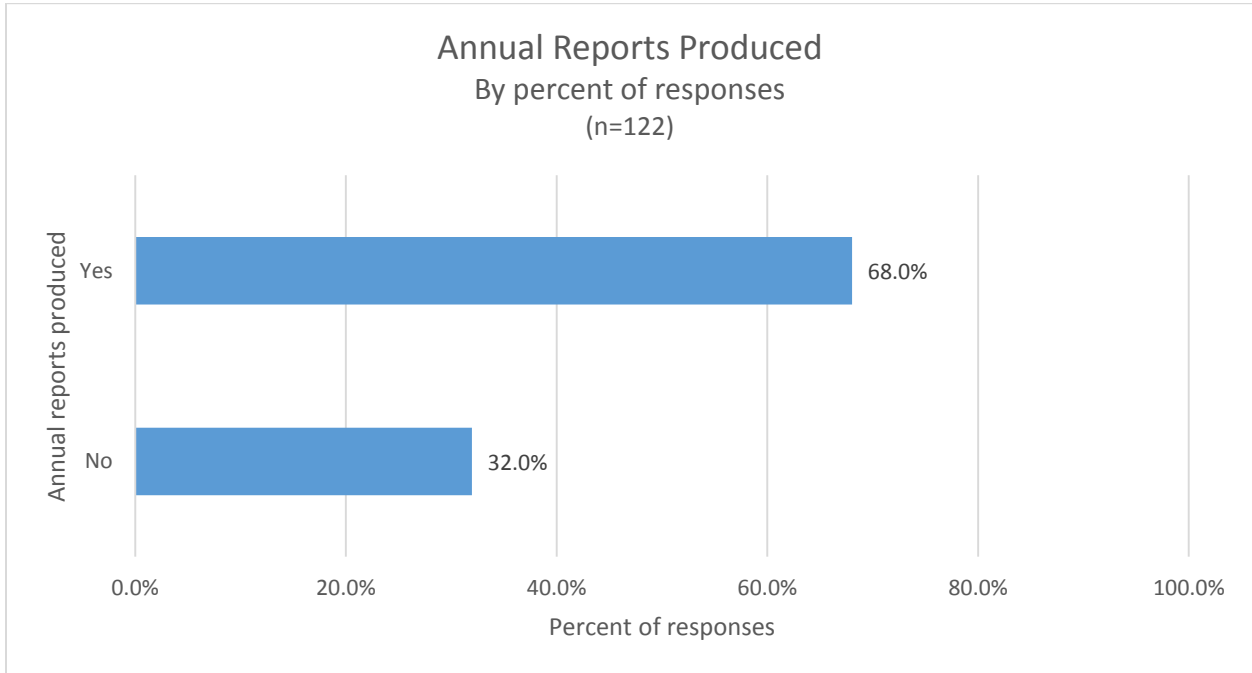
Action Category	Number of Respondents implementing this type of action
Public Education	65
New Service	30
Change in Practice	30
Policy	16
New Procedure	16
Legislation/Policy/Advocacy	13

17. Action Categories by Percent of Responses

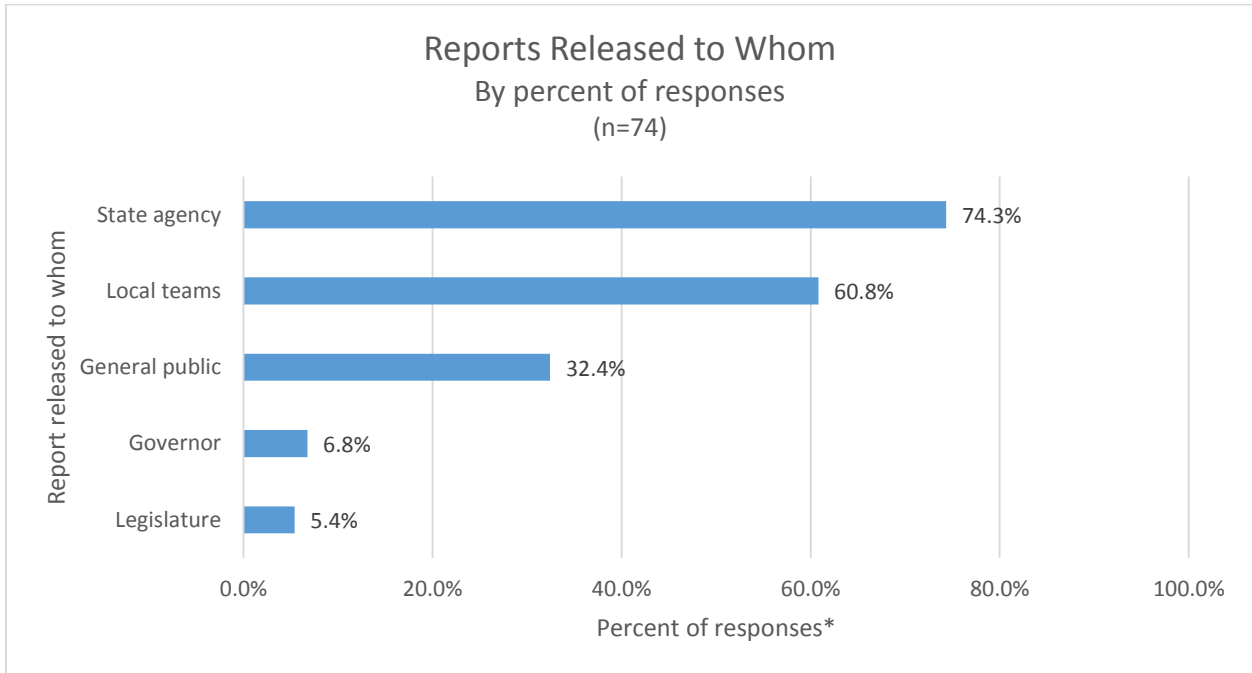


*Responses are not mutually exclusive.

18. Annual Reports Produced



19. Annual Reports Released to Whom



*Responses are not mutually