

A Report on the Status of  
Fetal and Infant Mortality  
Review in the United States  
2017



## Source of Information:

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



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# Introduction

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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 Case 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.

For many years, HRSA funded a National Center for Child Death Review (CDR) as a resource center for fatality review programs. In 2015, HRSA released a Funding Opportunity Announcement for a new Center that would combine FIMR and CDR 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. The Center continues to provide leadership, training, and technical support to FIMR programs, to standardize fatality review data collection and streamline the quality improvement process, to coordinate and disseminate information and findings related to fatality review, and to facilitate the translation of recommendations from review teams into action and practice for prevention.

In late 2017, the National Center surveyed 183 FIMR teams in 28 states were surveyed about their structure, process, and activities during 2017. Figure 1 is a map showing the states and number of FIMR programs in each state. One hundred and sixty-three programs in 26 states, DC, and Puerto Rico responded to the survey. Both local and state programs were surveyed and their responses are represented together in aggregate. Table 1 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 their health department (whether state, county, or city) is the lead agency for FIMR. 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 74.4% of programs, the primary sources of funding are state and federal Maternal Child Health/Title V block grant and other state funding. Federal funding, including federal Healthy Start funding, accounts for 24.8% of programs; and local foundations and charities such as United Way fund 6.0% of programs, with 28.2% of respondents indicating "other" sources of funding (Fig. 3).

The authority to access medical records and conduct FIMR reviews varies across state and local jurisdictions. Approximately half of responding FIMR programs (42.1%) operate under state statute or language in the Public Health Code enabling or permitting local FIMR to operate. In 34.3% 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 of the community and its services and resources overall. Of the respondents, 62.7% report 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 (2.7%) or residents of certain zip codes (4.7%). In more rural settings, a FIMR program may include multiple counties for case selection and review (21.3%). State and local FIMR teams (n=147) reported reviewing an estimated total of 2,111 infant deaths (babies born alive who did not survive until their first birthday) and 2,019 stillborn infants in 2017.

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**

While there may be some overlap in membership between the case review and community action teams, 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 (63.2%) 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. Common members of case review teams include: representatives from local health departments, social workers, obstetric/pediatric nurses; pediatricians; obstetricians; nurse home visitors; mental health professionals; child welfare workers; and educators. Community Actions Teams are better suited for community members with influence and political will such as agency directors; board members of service-delivery organizations; and hospital administrators. This type of representation enables them to more easily and effectively implement FIMR recommendations and changes that effect mothers and babies.

## **MATERNAL INTERVIEWS**

A core element of FIMR is its focus on obtaining a family interview as part of the review process, providing the family's perspective of their baby's death and allowing 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 the father of the infant, grandparent, or other caregiver may be included. The interviews yield information not captured in routinely-collected health records. More than three quarters of responding teams (70%) report they typically include information from an interview with a family member as part of their reviews. On average, FIMR teams reported 29.4% of their reviewed cases included a maternal interview. Of the respondents, 11.9% report that they get completed interviews for 76 – 100% of their cases, 3.4% report having interviews for 51 – 75% of their cases,

17.8% report having interviews for 26 – 50% of their cases, and 66.9% of respondents report that they have maternal interviews for less than 26% of their reviewed cases.

There are many barriers 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. More than half of FIMR teams (59.6%) 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 52.5% of respondents, and a significant number of programs (11.1%) identify lack of staff training/comfort level with grief as a barrier to obtaining maternal interviews. An additional 11.1% 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 Healthy Start programs in 37 states funded by the HRSA. One third of respondents (30.8%) indicated 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 (CAT); FIMR may ask a Healthy Start Community Action Network (CAN) to act as its FIMR CAT. Frequently, Healthy Start may be the vehicle through which FIMR recommendations are implemented in communities. In 58% of the FIMR communities there is no federally-funded Healthy Start, and an additional 11.3% of FIMR respondents described that there is a Healthy Start in the community but there is no documented collaboration.

FIMRs were also 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, 72.0% reported collaboration with state-level MCH or Title V.

## **DATA**

In the past, FIMR teams used 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 American College of Obstetrics and Gynecology (ACOG) 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 worked with the National Center to develop a FIMR module to be integrated with the existing CDR-CRS system.

## **PREVENTION INITIATIVES**

A hallmark of FIMR is the way team and communities use their findings by translating them into meaningful actions. Teams are 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 Mobile Alabama, FIMR reviews found that in many cases of infant deaths due to prematurity mothers were not referred to existing interconception care programs and services, resulting in poor maternal

health prior to pregnancy. The team targeted Medicaid recipients and enhanced the efforts of the care coordinators to refer patients with a previous fetal or infant loss to interconception care programs and services. Engaging pamphlets were developed to promote overall good health prior to pregnancy during annual well-woman and other gynecological visits, and the materials were included in maternal intake packets and posted in waiting areas and exam rooms where women frequently sought care.

- The Placer County, California FIMR Program reviewed a sentinel case of a newborn less than 4 months of age who died due to pertussis, with the dual findings that a Tdap (the vaccine to protect infants from tetanus, diphtheria, and pertussis) was not offered to the mother during her last trimester of pregnancy, and family members and other caregivers were not current on their immunization for pertussis. The program surveyed all OB provider offices to determine whether Tdap was being offered and administered in 3rd trimester, then offered support and assistance to providers to increase the number of women vaccinated in pregnancy. The program secured funding to provide in-home vaccines to anyone not current for Tdap living in a home with a pregnant woman or newborn.
- An ongoing concern in the Delaware FIMR program is need to expand access to and reimbursement for long-acting reversible contraceptives (LARCs) in both the public and private clinics statewide. Due to the efforts of the FIMR CAT team, Delaware Medicaid has approved the reimbursement of postpartum LARC insertion outside the bundled services for delivery admission, making the procedure more economically feasible for providers and hospitals. This provides more options to women for making family planning choices that fit their preferences and lives.
- St. Lucie County Florida's FIMR discovered that lack of transportation was a significant barrier to women attempting to access prenatal care. A two year grant was received by St. Lucie County to provide free bus transportation, insuring that the OB offices are all reachable by public transportation.
- The Region 6 FIMR in Louisiana, serving the Parishes of Vernon, Sabine, Natchitoches, Winn, Grant, Rapides, and LaSalle, has been experiencing a high number of infant deaths in unsafe sleep environments. After FIMR staff did a safe sleep presentation at a local Kiwanis Club, the group offered to provide funding for a safe sleep community project. Partnering with the local hospital, they created a safe sleep display for the hospital lobby with additional donations from the Kiwanis Club. The hospital marketing department created an attractive AAP recommended safe sleep messaging for the display. This project was cited by the Joint Commission as a great example of best practices. Finally, the local coroner's office funded a 30-second safe sleep PSA featuring the well-known coroner sharing points for safe sleep. The MCH Coordinator collaborated with the Communication, Innovation and Action Department within the Bureau of Family Health to target the script to parents with young families (primarily African-American parents in their 20s).

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 16.

## Looking Forward

### DATA

In 2018, the National Child Death Review Case Reporting System (NCDR-CRS) was updated to Version 5.0—an integrated FIMR and CDR case reporting system re-named the National Fatality Review Case Reporting system (NFR-CRS)—making the National Center the data center for both CDR and FIMR. Efforts will continue over the next four years of the grant funding cycle to bring all FIMR users on board to ensure that FIMR teams have access to and avail of a web-based national reporting system for FIMR that is free and easy to use, allowing local collection of FIMR data, and the download and analysis of this de-identified data, at the local, state and national level. The

features of the NFR-CRS currently include: individual case data entry, search, print, data download and creation of standardized reports; a data dictionary (which is linked to every individual question via a help icon); data code book; and user manual. Thirty-two standardized reports are available for downloading and/or printing at the local and state level. These reports are created using real-time data and cover all major causes of deaths and serious injuries.

The purpose of the NFR-CRS is to learn from the data to prevent further deaths. In the coming year, The National Center will begin publishing a series of reports summarizing and analyzing the data relevant to 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 be working to enhance our existing website with a portal where FIMR (and CDR) programs will be encouraged to post their prevention activities and outcomes. While a sampling of prevention initiatives was provided above in this report, and fuller addendum will detail case studies of teams moving from reviews to action.

### **PREVENTION AND COLLABORATION**

In 2017, the Center will also continue its focus on prevention activities, and use of fatality review to identify and address disparities. FIMR teams are working hard to craft better recommendations and implement evidence-based and promising practices that can prevent fetal and infant deaths. The Center 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, including the March of Dimes Prematurity Campaign Collaborative, launched in March of 2017. National 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.

# Tables/Figures Describing the Status of FIMR in the U.S.

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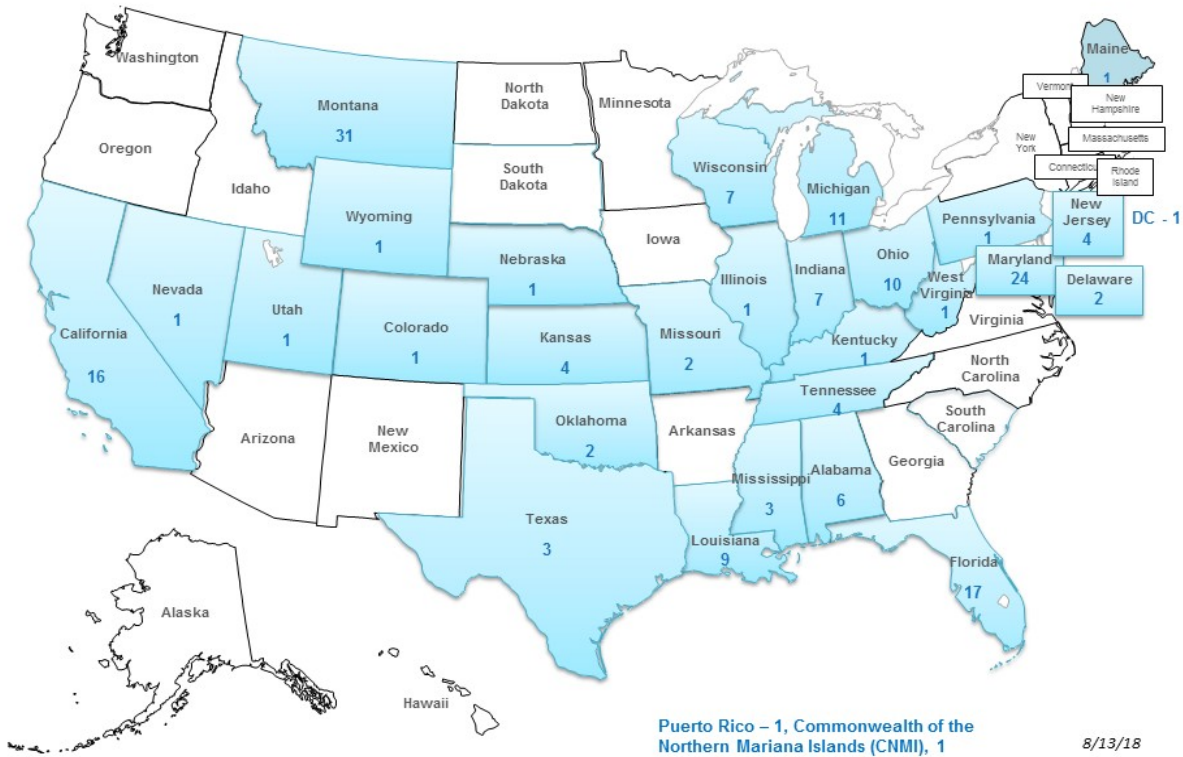


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## SECTION A: FIMR PROGRAMS

**Figure 1: Map of FIMR Programs in the U.S.**

**175 FIMR Programs is 28 States, DC, Puerto Rico, and CNMI**

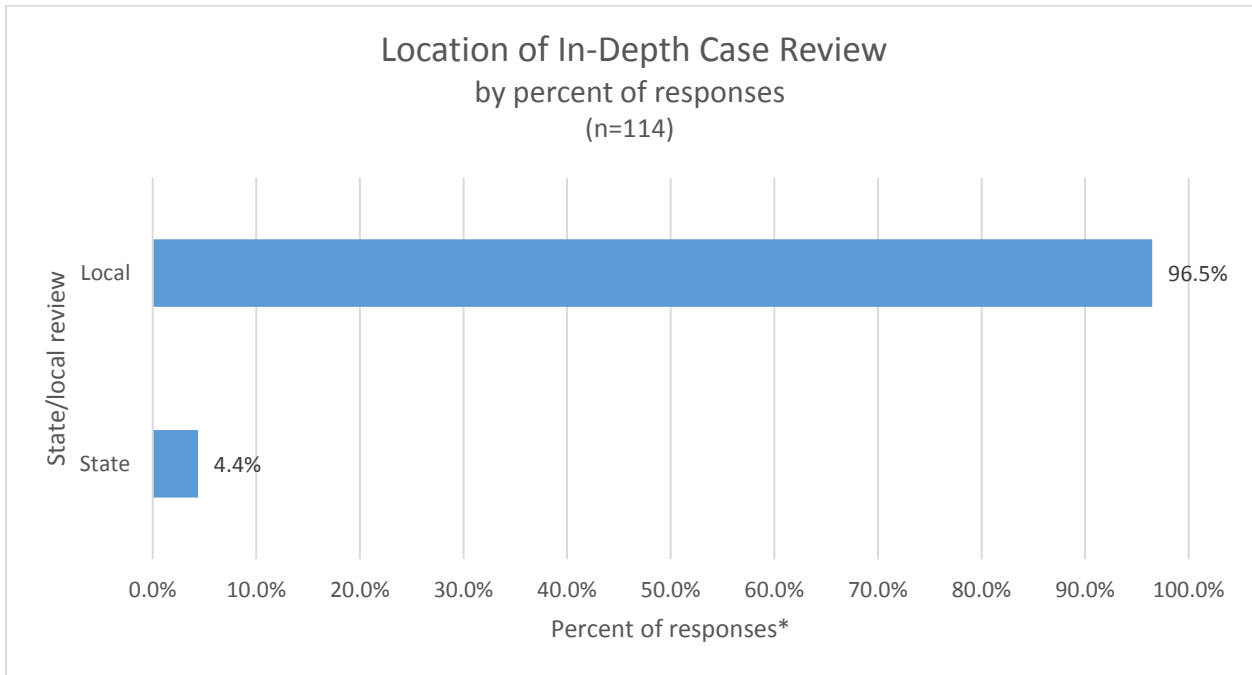


**Table 1: Overview of Survey Respondents**

State	Number of respondents	State	Number of respondents
Alabama*	4	Missouri*	3
California	14	Montana*	28
Colorado	1	Nebraska	1
Delaware*	2	Nevada	1
District of Columbia	1	New Jersey*	3
Florida	15	Ohio*	11
Illinois	1	Oklahoma	2
Indiana	6	Pennsylvania	1
Kansas	3	Tennessee*	6
Kentucky	1	Texas	3
Louisiana*	7	Utah	1
Maryland	24	West Virginia	1
Michigan	12	Wisconsin	7
Mississippi	3	Puerto Rico	1
		<b>Number of states</b>	26, D.C., and Puerto Rico
		<b>Number of respondents</b>	163

\* Indicates that a state coordinator responded to the survey in addition to local program coordinators.

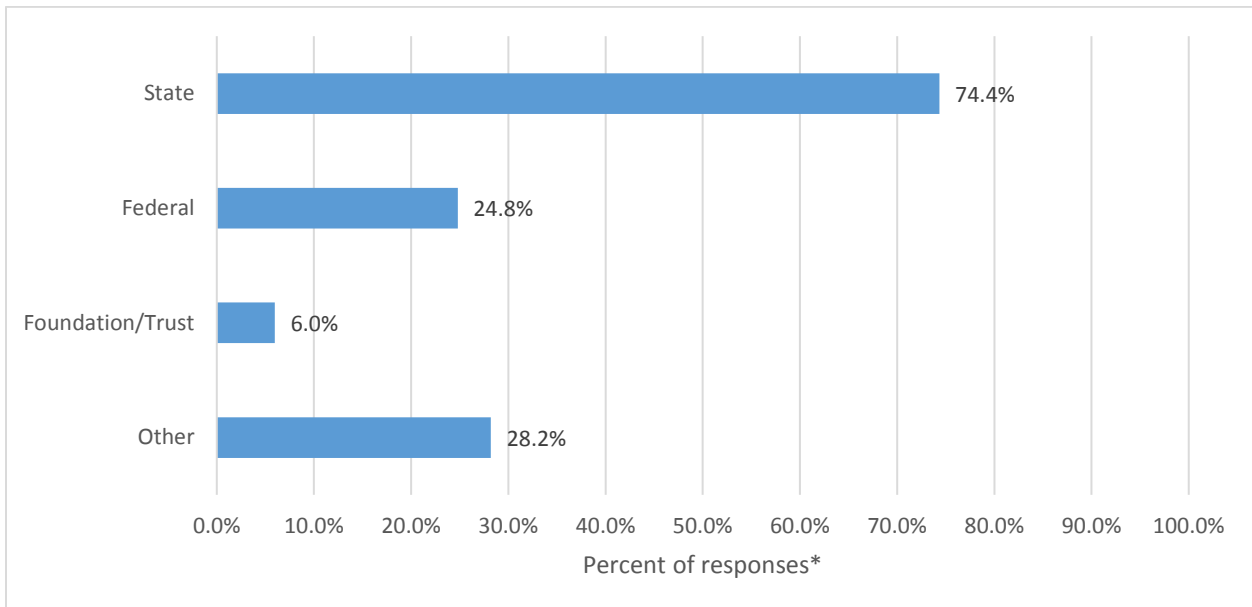
**Figure 2: Location of In-Depth Case Review**



\*Responses are not mutually exclusive.

**Figure 3: Current Source of Funding**

(n=117)



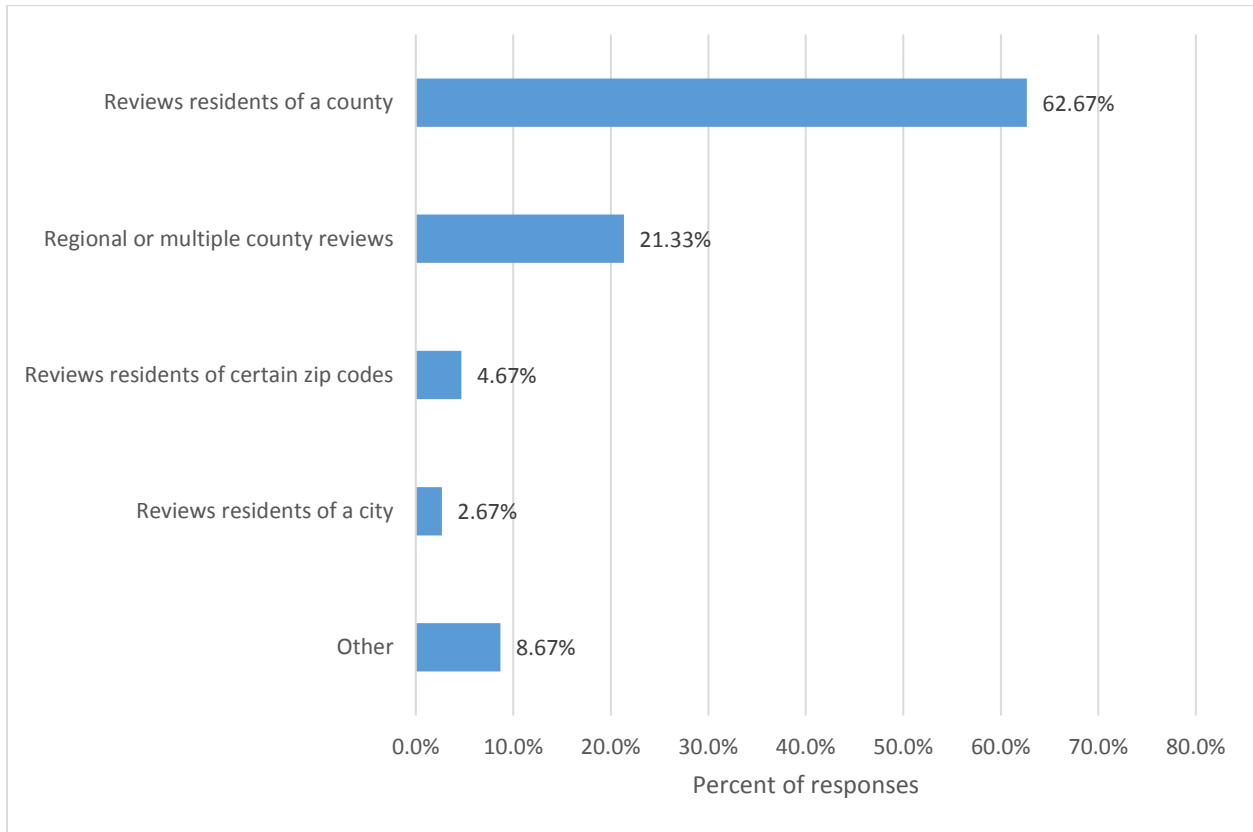
\*Responses are not mutually exclusive.

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## SECTION B: CASE SELECTION AND REVIEW STRUCTURE

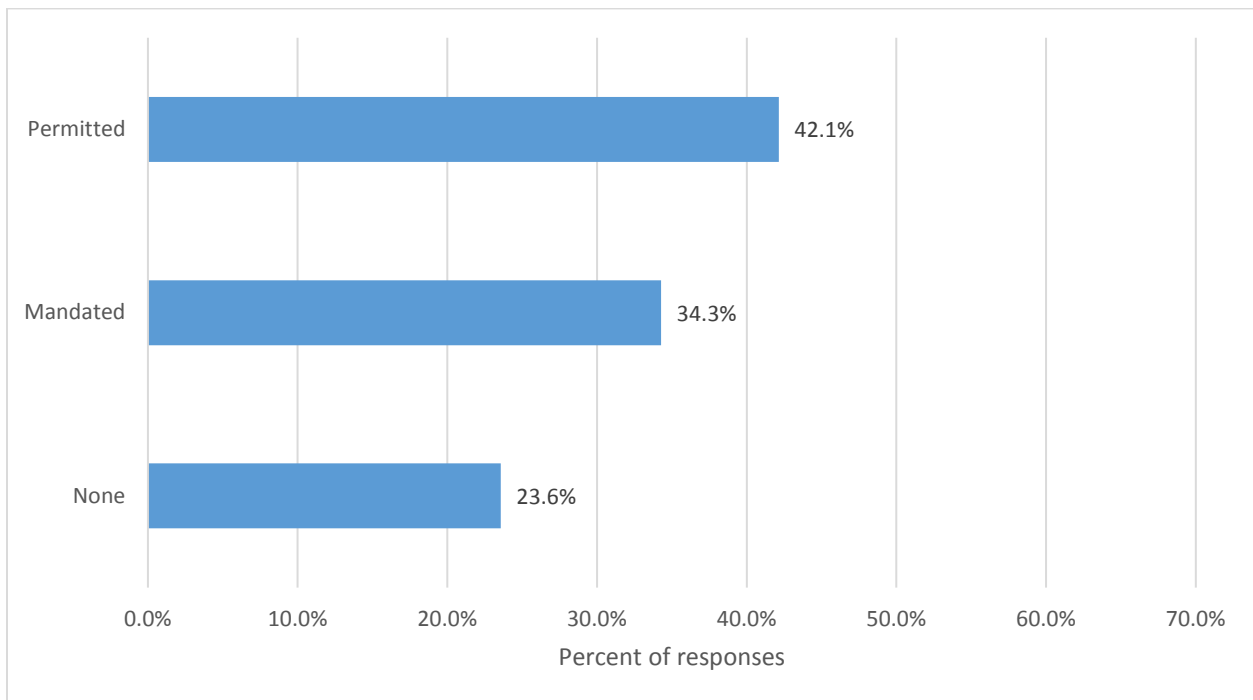
**Figure 4: Area Served**

(n=150)

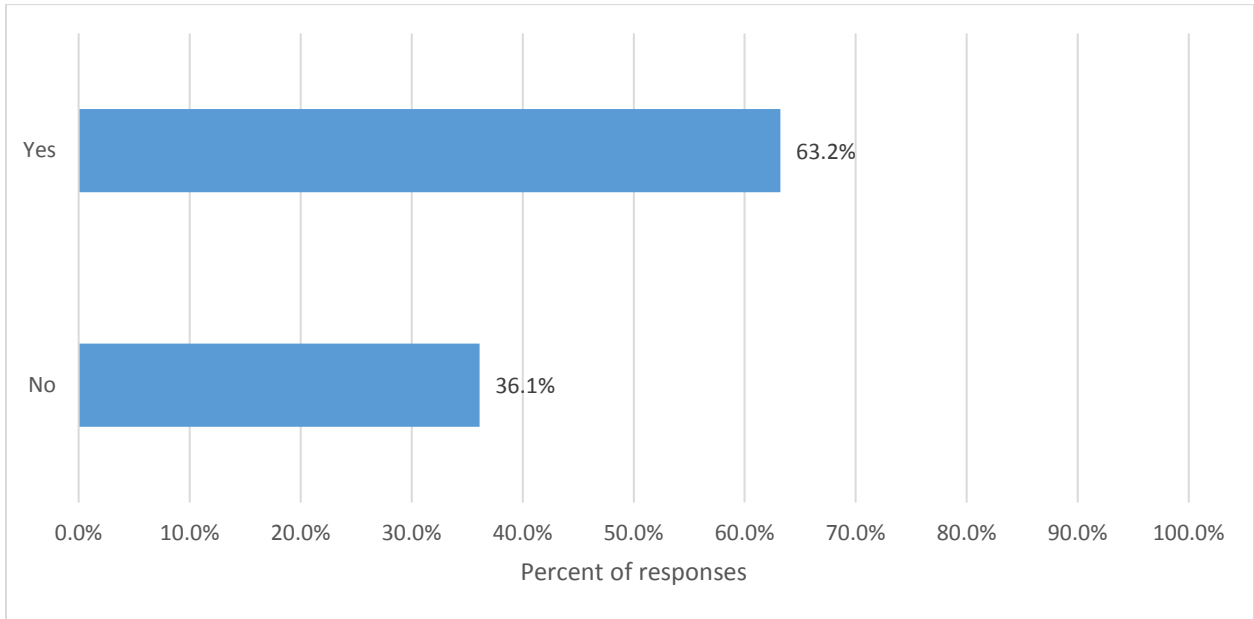


**Figure 5: Types of Legislation Relevant to the FIMR Process**

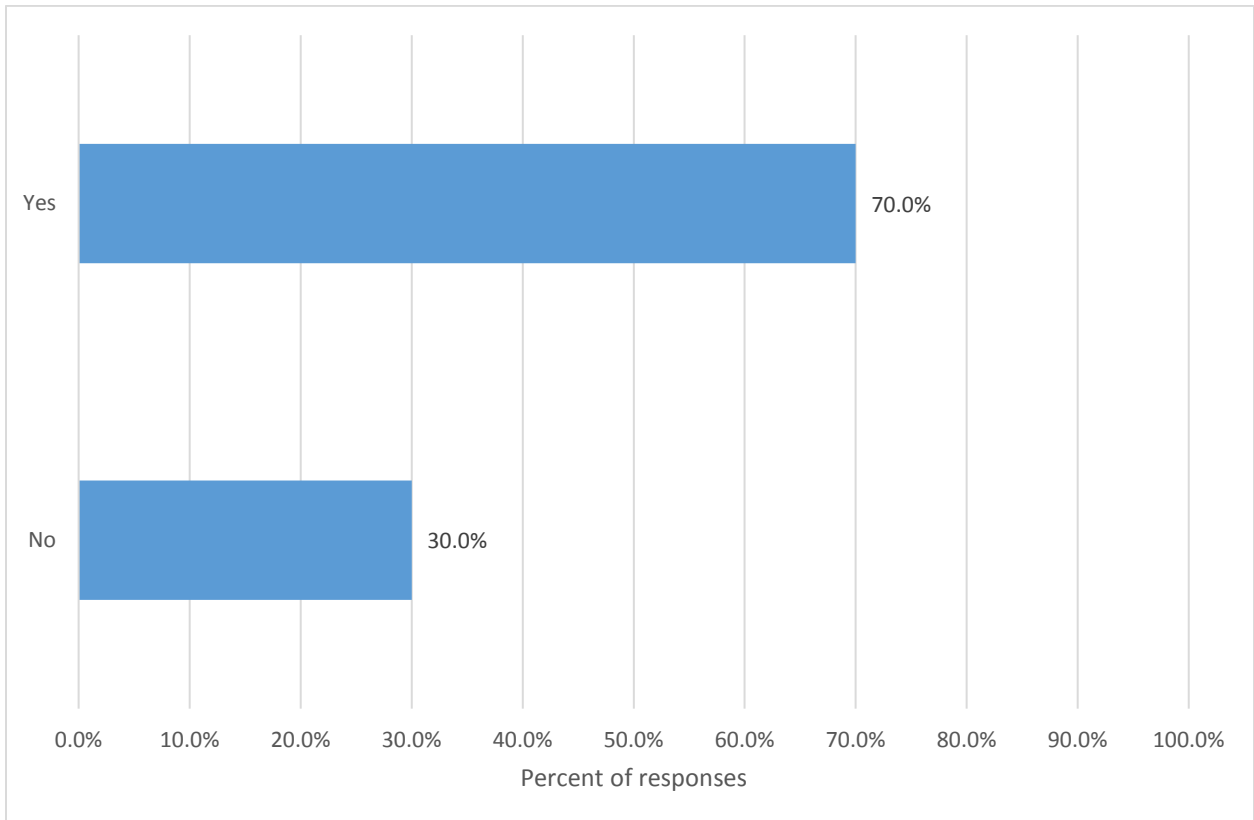
(n=140)



**Figure 6: Two-Tiered Team with a Functioning Community Action Team (CAT)**  
(n=155)

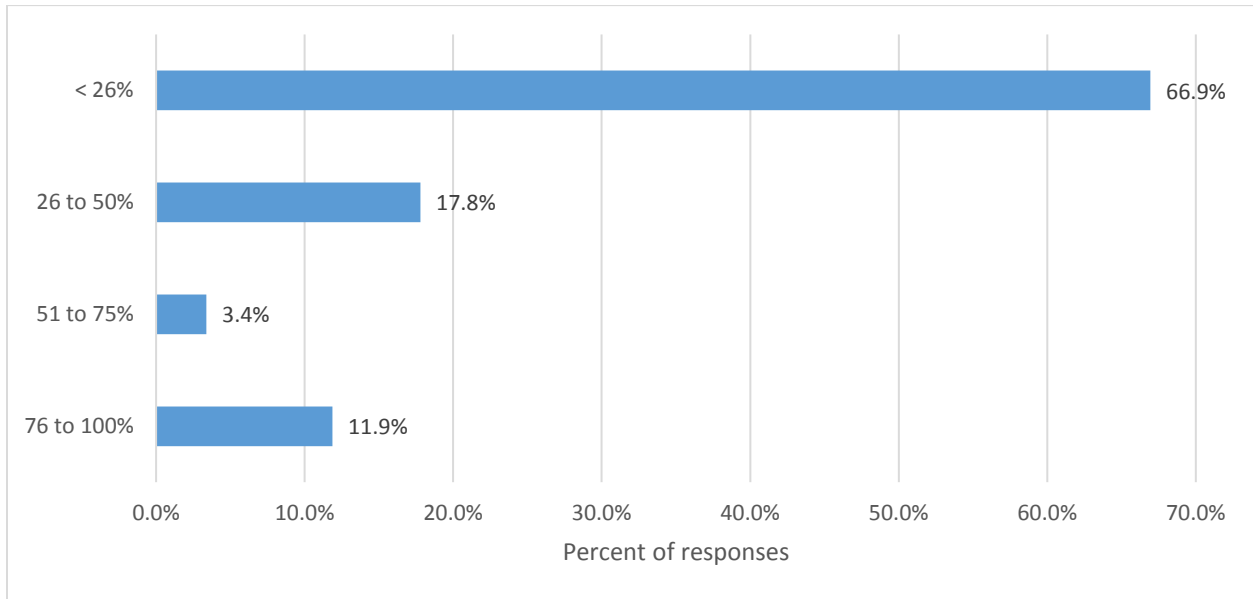


**Figure 7: Maternal Interviews Conducted by Team**  
(n=150)



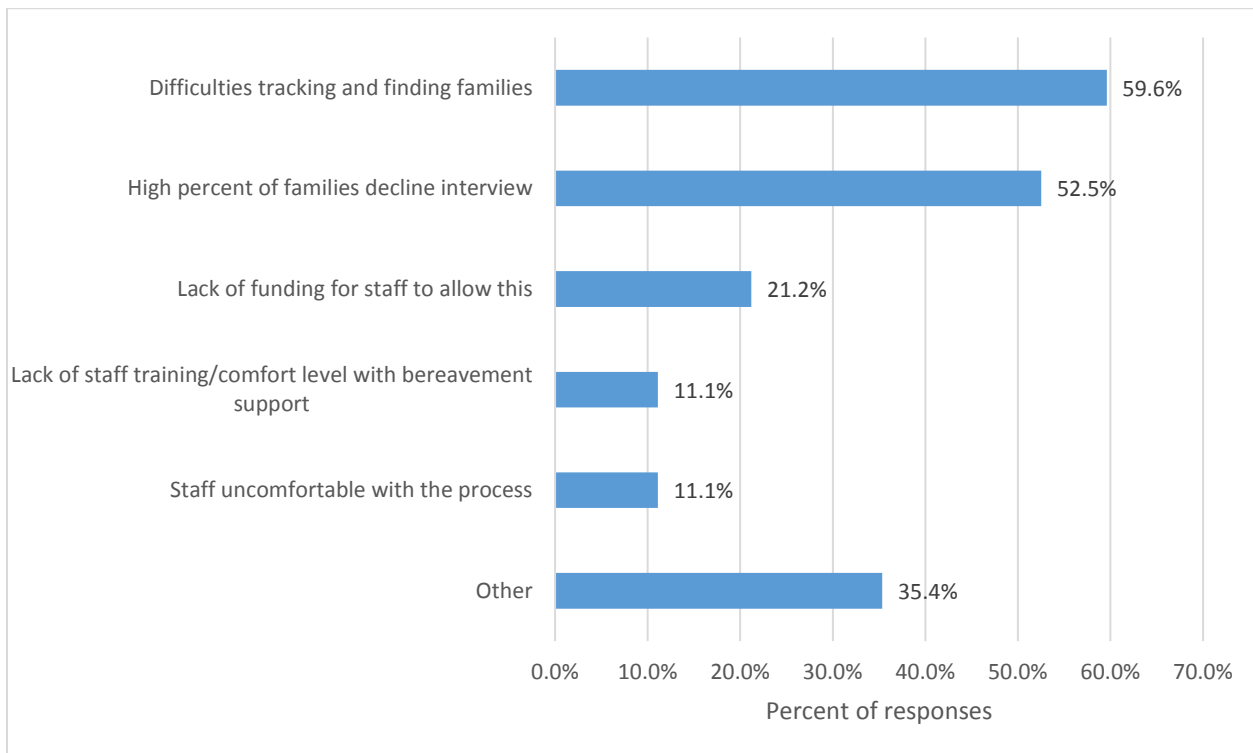
**Figure 8: Cases with a Maternal Interview**

(n=118)



**Figure 9: Barriers to Maternal Interviews**

(n=99)



\*Responses are not mutually exclusive.

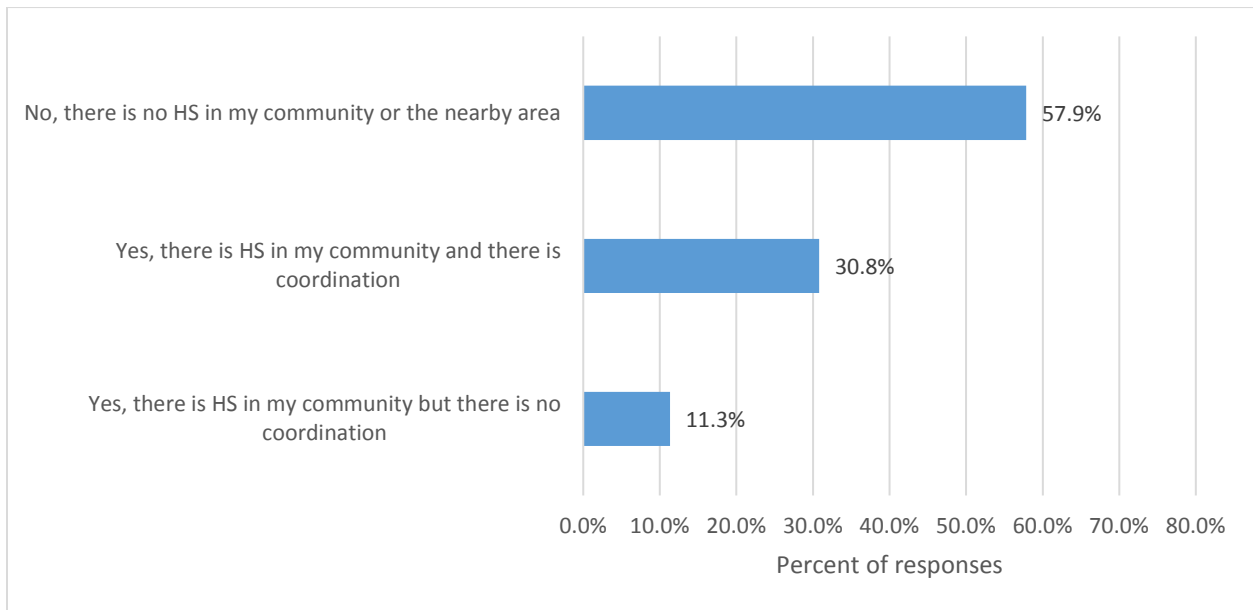
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## SECTION C: COLLABORATION WITH OTHER MATERNAL AND CHILD HEALTH INITIATIVES



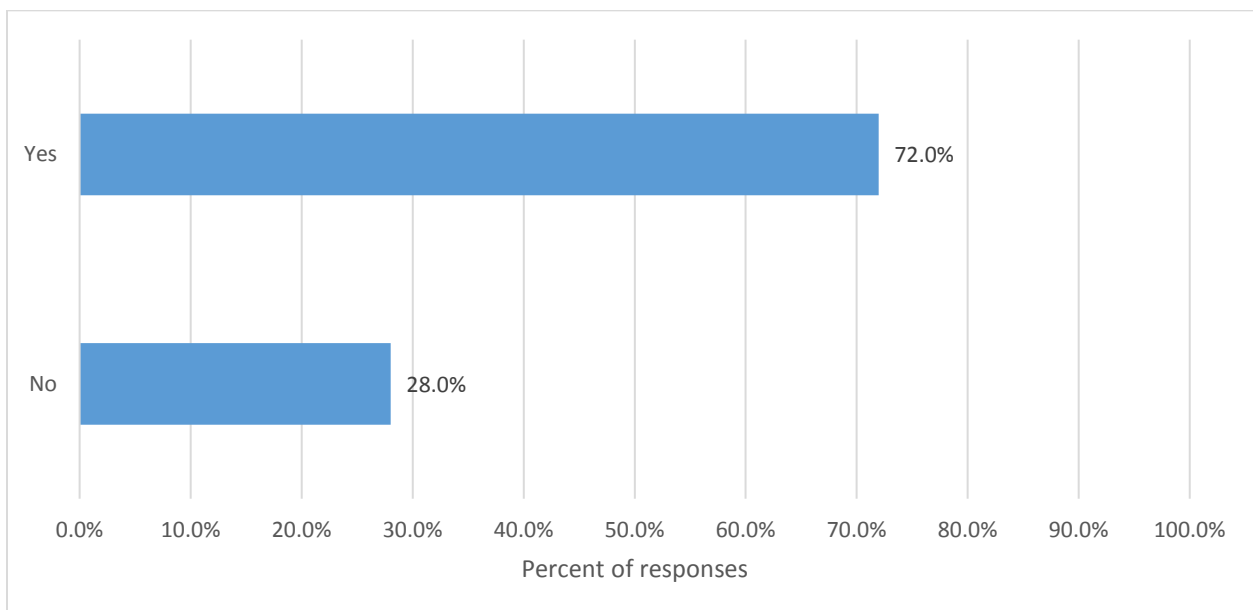
**Figure 10: Coordination with Federal Healthy Start (HS)**

(n=159)



**Figure 11: Coordination with Maternal Child Health (MCH) Title V**

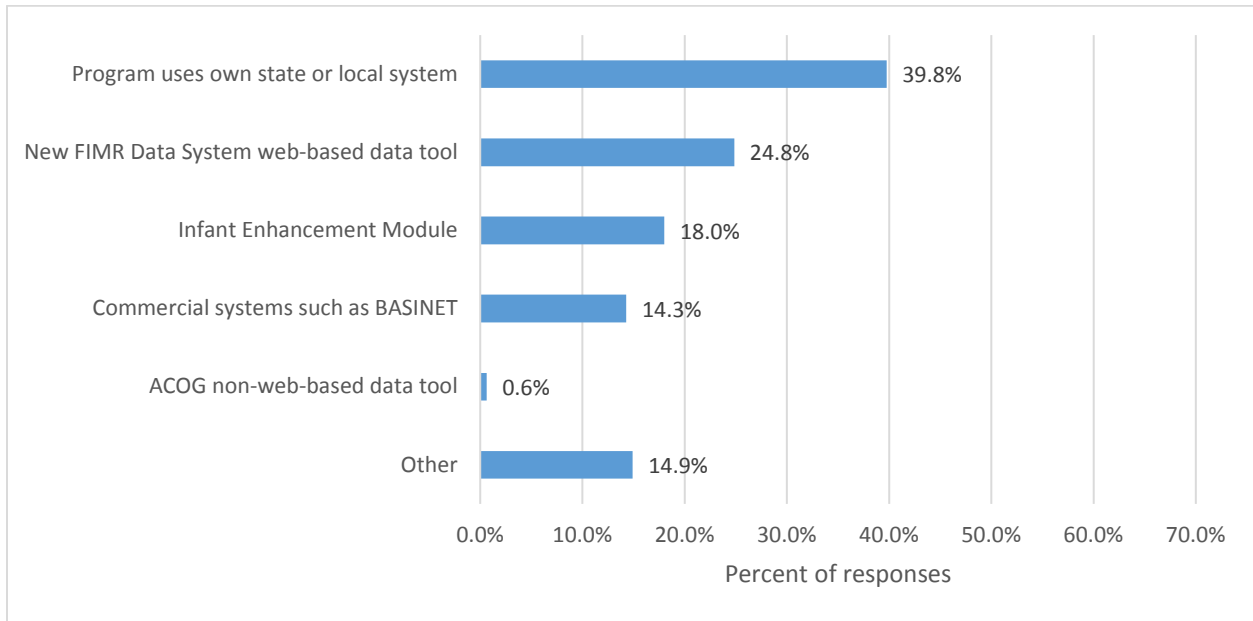
(n=157)



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## SECTION D: FIMR REPORTING

**Figure 12: Type of Reporting System**  
(n=161)



\*Responses are not mutually exclusive.

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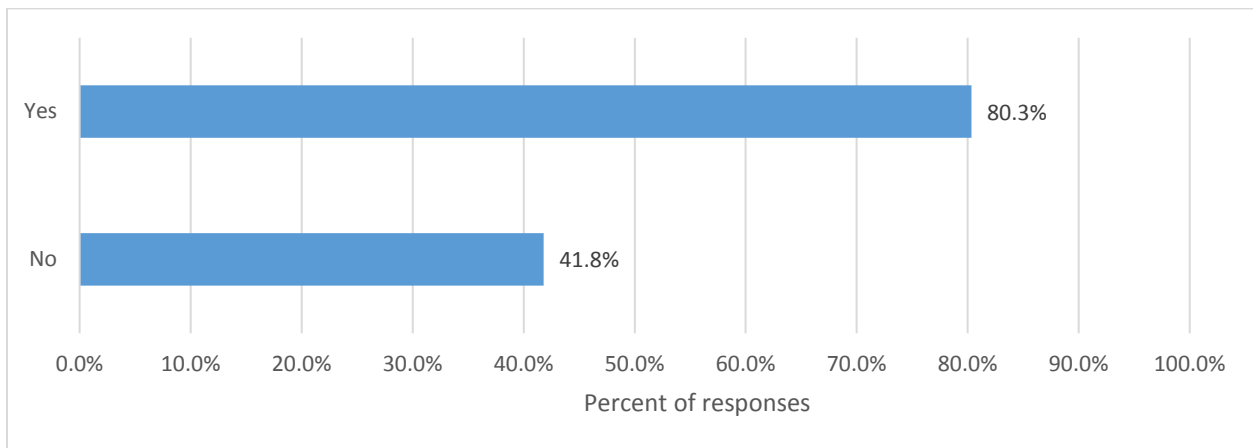
## SECTION E: FIMR PROGRAM ACTIVITIES

**Table 2: 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

**Figure 13: Teams Producing Annual Reports**

(n=149)



\*Responses are not mutually exclusive.

**Figure 14: Annual Reports Released to Whom**

(n=92)

