

# Assessment of Healthy Start Fetal and Infant Mortality Review Recommendations

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*Objectives:* We examine the scope and nature of the recommendations that emerged from the Healthy Start Fetal and Infant Mortality Review (FIMR) projects and explore their use to promote systems change. *Methods:* The FIMR process of 16 of the 22 federal Healthy Start projects was reviewed. We analyzed data from a June 1996 survey developed and administered by the MCH Bureau which gathered information about recommendations produced by the FIMRs. We supplemented these data with information gathered through follow-up telephone interviews and by abstracting information from grant documents. *Results:* The 16 Healthy Start FIMRs reviewed approximately 1300 cases between 1991 and 1996. A total of 303 specific action strategies were recommended, reflecting eighteen specific substantive areas of concern. Overall, 65% of recommendations fell under the rubric of "program" functions, 31% under "practice," and 4% under "policy." Healthy Start itself was most commonly targeted for action. The second most frequent target for action were public and private provider institutions. Public policymaking entities were rarely targeted. *Conclusions:* In the first several years of implementation, with few exceptions these FIMRs sought limited change. They worked almost exclusively within their own span of control to effect important, but limited changes in systems serving women and their infants. As public health professionals seek to monitor population health, the field must strengthen any and all vehicles that draw upon collaborative structures at the community level to not only uncover problems, but to address them as well.

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**KEY WORDS:** FIMR; Healthy Start; mortality review; infant mortality; perinatal health; public health.

## INTRODUCTION

In recent years, efforts have increasingly focused on examining the larger social, economic and environmental context of infant mortality, and on engaging communities in public health problem solving (1-3). One such venue, Fetal and Infant Mortality Review (FIMR), is a process used to determine the community-level factors associated with individual cases of fetal and infant death. FIMR goes beyond

biomedical causes to place infant mortality in the larger context of systems factors, with the ultimate goals of improving community resources and health service delivery systems for women, infants, and families (1-7). FIMR can thus be seen as a vehicle for implementing the public health functions of assessment, quality assurance, and policy development at the community level.

The FIMR process can best be described as a "cycle of improvement" (Fig. 1). The cycle begins with data gathering. For each identified case of fetal or infant death in the community, information is collected from a wide range of sources, and importantly, usually includes an interview with the family. A case review team (CRT), composed of members of the community, representing consumers and professionals, meets on an ongoing basis to review the informa-

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## THE FIMR PROCESS

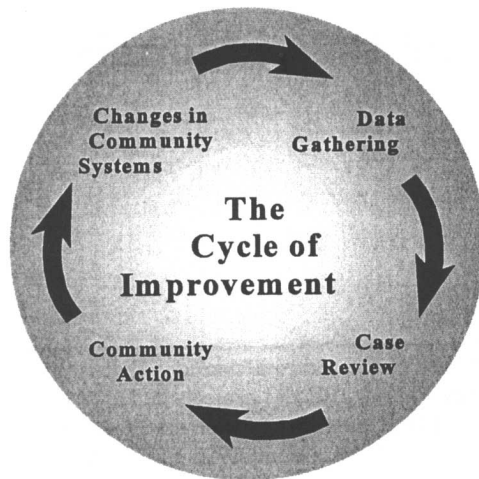


Fig. 1.

tion gathered about cases of fetal and infant deaths. During the review of the cases, the team attempts to identify the factors that contributed to those deaths and determine if these factors represent system problems. The development of recommendations for changing any identified problems in the service system follows. At this step, FIMRs turn to a community action team (CAT: individual FIMRs may utilize different terminology to describe the teams that perform either/both of these sets of functions) for development of recommendations. The CAT includes members of the community (consumers and professionals) as well as key individuals in positions of broad authority who have the leverage to create change in the community. The final step before the cycle is begun anew is the implementation of new policies, practices, and/or programs to effect change in the community systems. Then, as data are again gathered and new cases are reviewed, the FIMR process naturally incorporates a feedback mechanism to examine the effect of these changes in the community systems (8).

The first demonstration projects using FIMR were funded by the federal Maternal and Child Health Bureau (MCHB) in 1988. The number of communities implementing FIMR as a tool for change was expanded in 1990 with the establishment of the National Fetal and Infant Mortality Review (NFIMR) program, a collaborative effort between the American College of Obstetricians and Gynecologists (ACOG) and MCHB. NFIMR funds from

ACOG and MCHB were supplemented with funds from the March of Dimes Birth Defects Foundation, Carnation Nutrition Products, the Centers for Disease Control and Prevention, and the Robert Wood Johnson Foundation (8).

The experiences of these early FIMR projects led the MCHB Bureau to promote FIMR as a required component of Healthy Start, an infant mortality prevention program. Federal funds were awarded in 1991 to 15 Healthy Start sites across the country along with the challenge to reduce the infant mortality rates in those communities by 50% in a 5-year period. Several additional communities began Healthy Start activities subsequent to 1991 with private foundation funding, and with federal funds for expansion (1994). In addition to FIMRs, Healthy Start resources support a wide range of interventions including community-wide consortia, media and other outreach campaigns to promote utilization of prenatal care, streamlining eligibility for public services through "one stop shopping," and developing a comprehensive package for perinatal care services which includes home visiting and case management to link health and social support services. The FIMR process, with its structured approach to examining the problem of infant mortality and intent to translate case findings into community action, was considered to be highly congruent with the design of the Healthy Start projects.

Since that time, FIMRs have proliferated nationally. A Maternal and Child Health Bureau grant program initiated in 1997 currently supports efforts in five states to build statewide capacity for FIMR implementation. Instrumental in this regard also are NFIMR's promotional and technical assistance activities. As of June 1999, approximately 150 FIMR initiatives are known to exist, some of which address the infant mortality concerns of a multi-county area (9).

Wanting to learn more about the experiences of FIMRs within the larger picture of the Healthy Start Program, the Division of Healthy Start and the Health Resources and Services Administration (HRSA) Office of Planning, Evaluation, and Legislation requested that the Women's and Children's Health Policy Center (WCHPC) at Johns Hopkins University study selected aspects of implementation of the Healthy Start FIMRs. Our overall aim was to describe the FIMRs' recommendations to address issues uncovered, and their strategies to promote implementation of recommended changes. WCHPC tasks specifically included analysis of substantive topic areas and functional approach identified for promoting change—improve programs, clinical or

administrative practices, or system-wide policies. Our analysis of the recommendations within this schema was developed to assess the congruence of these FIMR recommendations with the current knowledge base regarding infant mortality reduction and to assess the extent to which the HS FIMR projects conceived of, or understood, the intent of the FIMR process to promote broad, system-wide changes potentially affecting significant proportions of the population. FIMR Directors' perspectives about factors relevant to implementation of recommended strategies for change also are examined. In this paper, we report our findings in these regards and identify several strategies that may bolster the practices of newly developing FIMRs.

## METHODS

### Sources of Data

We reviewed the FIMR process of the Healthy Start projects using abstraction of information from grant applications/progress reports, mail surveys, and follow-up telephone interviews. The MCH Bureau provided us with grant applications and progress reports from the Healthy Start sites. We abstracted information on: (1) the year the FIMR began and (2) the number of cases reviewed per year by the FIMR. We also were provided with responses from a mailed survey developed and administered by the MCH Bureau in June of 1996 to gather information about the recommendations produced by the FIMRs. The FIMR director was the designated respondent for this survey. FIMR projects were asked to report their recommendations by year of formulation (1993, 1994, 1995, 1996) within one of three functional categories describing their orientation—policy, program, or practice. Respondents were provided a sample completed matrix survey as guidance for classifying recommendations within these categories. The matrix comprised the entirety of the survey, thereby limiting the scope of the analysis. In follow-up telephone interviews conducted by our center, we gathered additional information on the FIMR process. The interviews consisted of nine questions, closed and open-ended, which were asked of all respondents. Many of the questions were not answered by the respondents. However, all of the FIMR coordinators responded when asked to identify both facilitating factors and barriers to formulation and implementation of recommendations. Some of the

respondents also provided noteworthy examples of strategies to promote action on recommendations.

### Sample

Surveys were mailed to the fifteen original Healthy Start sites and three of the seven special projects that first received funding in 1994. These "original" sites were Baltimore, Birmingham, Boston, Chicago, Cleveland, Detroit, Oakland, New Orleans, New York, Northern Plains, Northwest Indiana, PeeDee, Philadelphia, Pittsburgh, and the District of Columbia. The Northern Plains site is not included in analyses because no completed survey matrix was received by HRSA. The three special projects surveyed were Milwaukee, Panhandle (Florida) and Savannah. However, the Milwaukee FIMR reported that they had not yet made any recommendations and was therefore excluded from our analysis. The other four of the seven special projects were not surveyed as they had either not initiated, or had recently begun their FIMR. Follow-up telephone interviews were conducted with the 16 sites reporting recommendations. Therefore, we limited our sample for analysis to these 16 FIMRs.

### Analysis

Based on data abstracted from the grant applications and progress reports, we enumerated the number of cases reviewed by the FIMRs. Using data from the surveys, we examined the recommendations produced by the FIMRs from two perspectives: (1) the substantive topic area (see below) and (2) the functional category (policy, program, practice). Also using survey data, we considered the strategies formulated with a focus on the group targeted to implement the recommendation. Finally, we studied the barriers and facilitating factors for implementation as identified by the FIMR directors in the telephone interviews.

Unable to identify an existing framework into which these recommendations could be readily categorized, we developed our own mutually exclusive list of 18 specific topic areas (recommendations which could not be categorized comprised a "miscellaneous" category). While the list we developed is unique to our analysis, generally our categories represent risk factors (e.g., smoking) and immediate causes

(e.g., congenital malformations) of infant mortality. There are also categories, however, which do not fall under this rubric. For example, as many of the programs developed recommendations which dealt solely with the process of FIMR, we developed "FIMR functions" as a separate category. "Grieving support" was another unusual category not related to the causes of infant mortality. Because the FIMRs usually included an interview with the family of the deceased fetus/infant, issues related to grieving were salient.

After formulating the list of 18 topic areas, we summarized the recommendations across all sites (Table I). However, this analysis had some limitations. Several recommendations might be formulated within one topic area but it may be that just one site contributed most of the recommendations within that area. We therefore also examined which sites formulated recommendations within each topic area and identified the number of sites formulating recommendations for each topic area (Table I).

While respondents identified recommendations by functional category (policy, program, practice), no definitions for the categories were provided to survey respondents and inconsistencies were observed. We therefore developed with MCHB definitions for the categories, and re-coded (done by one of the authors)

**Table I.** Substantive Topic Areas Identified in HS FIMR Recommendations

	Number of recommendations (all sites combined)	Number of sites with $\geq 1$ recommendation
Infant Mortality	242	
Adolescence	9	4
Case management	11	4
Congenital anomalies	4	3
Domestic violence	9	4
Family planning	33	9
High-risk services and follow-up care	19	10
Infection	17	6
Medical care quality	5	5
Medical records and vital records data	21	7
Prenatal care	37	10
Preterm labor & pregnancy complications	19	8
SIDS	16	6
Smoking	9	3
Substance abuse	25	8
Women's health	8	3
Other	61	
FIMR functions	25	7
Grieving support	24	9
Miscellaneous	12	6
Total	303	

them accordingly. For purposes of our analysis, definitions for these categories are as follows:

**Policy:** Focus on groups/populations. Includes legislation, regulation, financing/budget initiatives, and/or governmental guidelines.

**Program:** Focus on a group or subpopulation and/or on a set of activities. Includes the development and implementation of services.

**Practice:** Focus on interventions directed at individuals. Examples would be standards for clinical care, protocols, new treatments.

A small number (17 of 303) could not be classified.

We sought also to examine the "target" of the strategies, the person or entity expected to take action to implement the recommendation. Of particular relevance in this regard are linkages, or potential linkages, with "power brokers" who are routinely involved in government or other public policy bodies or activities (10, 11). Again, as with the substantive topic areas, we found no existing categorization and therefore developed a listing into which the targets could be categorized, which includes the FIMR or Healthy Start projects themselves, provider institutions or individuals, public agencies, specific programs, consumers, and community residents at large.

With respect to barriers and facilitating factors identified in the telephone interviews, we also developed ad hoc categorizations to capture the common themes that emerged and noted examples of structures and processes used to advance action on recommendations.

## RESULTS

The 16 Healthy Start FIMRs reviewed approximately 1300 cases over a five-year period between 1991 and 1996. Given that the first two years of the Healthy Start program involved significant effort for planning and start-up of the overall project activities and direct care services, for the most part, the FIMR component did not become operational until 1993, 1994, and 1995. Over all 16 sites, a total of 303 specific actions (strategies) were recommended between 1993 and July 1996. The FIMRs generated more recommendations each succeeding year.

### Substantive Topic Areas (Tables I and II)

The 18 substantive areas most frequently found to be the focus of recommendations were prenatal

**Table II.** Groups Designated by HS FIMRs to Act on Recommendations<sup>a</sup>

Target group	Number of recommendations
FIMR and its committees	25
Healthy Start project staff	67
Institutions	59
Hospitals	18
Clinics/health centers	20
Local health departments	17
Managed care organizations	4
Agencies	12
Federal	2
State	9
Local (not health department)	1
Clinicians (includes nurses, nutritionists, clergy)	52
Private	3
Public	5
Not otherwise specified	44
Outreach workers	6
Specific programs	23
Public Health System	3
Women	3
Public	8

<sup>a</sup>One recommendation targeted to both federal and state agencies.

care, family planning, and substance abuse. Two areas not directly related to prevention of infant mortality were the subject of a high number of recommendations: “FIMR functions” and “Grieving support”. Recommendations were formulated for an average of seven substantive areas in each site. There were no topic areas for which all sixteen sites formulated recommendations.

### Functional Category (Policy, Program, Practice)

Ninety four percent (286/303) of the recommendations made by the FIMRs could be categorized into one of the three areas: policy, program, or practice. Overall, the majority of recommendations fell under the rubric of “program” functions ( $n = 186$ , 65%). The second most frequently observed functional category of the recommendations was “practice” ( $n = 89$ , 31%). The fewest recommendations ( $n = 11$ , 4%) fell under the category of “policy.”

### Target of Strategies To Address the Recommendation

We summarize this information across sites in Table II. For each target group, we enumerate the

recommendations assigned by the FIMRs. Healthy Start itself was the most common target with 69 recommendations directing action by the program. Half ( $n = 8$ ) of the FIMR sites reported at least one recommendation targeting Healthy Start. The second most frequent target for action (65 recommendations) were institutions which included hospitals, clinics/health centers, the local health department, managed care organizations, and private group practices. Public agencies, whether federal, state or local, were rarely assigned responsibility for promoting action.

### Facilitating Factors and Barriers

The FIMR respondents identified the issues and factors related to the potential effectiveness of the FIMR process for their projects. Several themes emerged related to facilitating factors. These included: (1) sufficient resources (both funds in the system for implementing action, and for staff capacity and competencies for team activities in this regard); (2) a high level of “ownership” and leadership among the members of the committee for the outcomes and impact of the FIMR process; and (3) a track record of positive, long-term working relationships among those participating on the review teams.

The aspect most frequently cited was ownership/leadership. Of specific note in this regard were the comments from two sites which emphasized the potential role of education/ training for the review team members about the FIMR process, including its purpose and potential in the overall scheme of the Healthy Start program for reducing infant mortality.

Barriers cited fell into categories of (1) insufficient staff time to pursue recommendations with the committees (individually or collectively), (2) lack of recognition on the part of the review teams of their ability to influence changes in the system, and limited familiarity with the full range of potential “tools” for policy action, and (3) issues of “politics” in the environment overall, including changes in the system related to managed care generally, as well as to Medicaid managed care (including waivers) specifically. In two sites, some reluctance was noted on the part of the review teams for pursuing recommendations based on small numbers of cases of fetal/infant mortality.

Our telephone interviews with the FIMR project personnel identified some examples of strategies for promoting action on recommendations. We note

these briefly (Table III) as they may have application in other sites seeking to improve their capabilities in effectively implementing FIMR recommendations.

## DISCUSSION

These findings demonstrate that, over a relatively short period of time, the Healthy Start Fetal and Infant Mortality Review efforts progressed despite the inevitable array of technical program implementation challenges and political constraints. Approximately 1300 cases of fetal/infant death were

reviewed in a multi-tiered process of record review, family interviews, and presentation to professional and, in most cases, community teams. Several hundred recommended actions were generated based on these reviews, and the FIMRs and their Healthy Start and professional and community collaborators took steps towards their implementation.

In Table IV we highlight those substantive areas in which all or nearly all of the sites formulated recommendations. We also spotlight a few additional substantive areas that were particularly innovative or relevant for other reasons.

Not surprisingly, recommendations were most commonly formulated in topic areas heretofore believed to relate to low birth weight, a leading cause of infant mortality. Areas frequently the focus of recommendations were prenatal care and substance abuse, consistent with the emphasis of Healthy Start. Family planning, recently emphasized by the Institute of Medicine report on unintended pregnancy (12), is sometimes overlooked in efforts to improve infant mortality. However, family planning was frequently the focus of recommendations made by the Healthy Start FIMRs, suggesting either an awareness of its importance or that it emerged in case reviews as an important problem in the system. Few sites (five or less) formulated recommendations in the areas of adolescence, case management, congenital anomalies, smoking, domestic violence, medical care quality, or women's health. The small number of recommendations on women's health were developed primarily by one FIMR site. This is an area that does not often receive attention in infant mortality reduction initiatives. While the health of a woman might be perceived by some as a distal rather than proximate determinant of infant mortality, experts increasingly are understanding it to be an important determinant and worthy of investment.

Grieving support was another area addressed by many of the sites. While recommendations successfully implemented in this area would not be expected to directly affect fetal and infant mortality, the FIMR process likely brought this unmet need in the community to light. Grieving support is part of the larger picture of addressing the needs of Healthy Start communities, which by definition are communities experiencing high rates of fetal/infant loss.

We considered FIMR functions an important area to examine more closely as it may reveal key structural factors that affect successful formulation and implementation of recommendations. Many of the FIMR functions are inherently affected by the

**Table III.** Selected HS FIMR Strategies for Promoting Action on Recommendations

FIMR site	Example
Baltimore	The Baltimore Healthy Start FIMR originally convened only a "case review group." In the third year, they determined the need to establish a "policy review board." This latter review board, composed of individuals with responsibility for community service programming, has been instrumental in bringing key recommendations to the state's process of developing the Medicaid 1115 Waiver program.
Boston	Recommendations developed by the Community Review Team are grouped into topic areas (e.g., prevention of prematurity) and working groups are formed to focus on strategies to address them. One such subgroup is currently preparing a position paper to present to state legislators who might be able to influence the content and process of care provided under Medicaid managed care arrangements.
Cleveland	FIMR recommendations must be reviewed and approved by the Mayor's (Healthy Start) Executive Committee before any dissemination or action is taken. This process has proven effective in promoting action on FIMR recommendations by virtue of the endorsement/power of the Mayor's Office.
Pee Dee	The FIMR Technical Review Team issues "referral sheets" to agencies who, in the opinion of the group, need to be notified about a particular recommendation. Also of note is the professional background/orientation of the FIMR Coordinator, who is experienced in marketing strategies.

**Table IV.** Examples of Recommendations Formulated by the HS FIMRS

Substantive area	Examples
Family Planning	<ul style="list-style-type: none"> <li>—Institute a family planning component in the certification training program for the city’s outreach workers.</li> <li>—Provide 1 hour of contraceptive counseling within the first six months of pregnancy and accompany women to their provider of choice.</li> <li>—Working with the state Medicaid program to fashion provisions in the 1115 Waiver application to eliminate the 10-day waiting period for a family planning visit post delivery.</li> </ul>
Grieving Support	<ul style="list-style-type: none"> <li>—Develop curricula for providers, “When an Infant Dies: A Train the Trainer Program.”</li> <li>—Nurse case managers should contact mothers regarding the need for grief counseling (to be provided by clergy).</li> </ul>
Medical Care Quality Prenatal Care	<ul style="list-style-type: none"> <li>—Inclusion of basic standards of hospital nursery care in statute.</li> <li>—Outline outreach practices for the entire timeframe of a pregnancy.</li> <li>—Establish a hotline for instant referral and appropriate follow-up for women who initiate prenatal care through the emergency room.</li> </ul>
FIMR Functions	<ul style="list-style-type: none"> <li>—Notify hospitals regarding issues of missing records.</li> <li>—Convene meetings with EMS, police, fire department, child welfare personnel, etc., to improve the process (timeliness, quality) of death scene investigations.</li> </ul>
Medical Records & Vital Records Data	<ul style="list-style-type: none"> <li>—Provide in-service training to pediatric residents about the importance of appropriately completed birth and death forms.</li> <li>—Promote passage of City Council Resolution to make any infant death a reportable event.</li> <li>—Adoption of a uniform definition of “preventable death.”</li> </ul>
Infections	<ul style="list-style-type: none"> <li>—Implement clinical protocols whereby all positive screening tests for STDs are followed up within two weeks of diagnosis.</li> <li>—Develop guidelines for more aggressive treatment of bacterial vaginosis during pregnancy.</li> </ul>
Women’s Health	<ul style="list-style-type: none"> <li>—Assess postpartum status and birth control choices during newborn check-up office visits.</li> <li>—Provide training for residents in newborn medicine regarding integration of the mother’s social and medical history and current concerns into pediatric care, beginning at birth.</li> </ul>

availability and quality of medical records and vital records data. Recommendations categorized into this substantive topic area, however, unlike those in the FIMR Functions category, were formulated with regard to affecting system changes which could benefit maternal and infant health rather than function of the FIMR.

Most of the recommendations made relate to infant mortality although an infant mortality prevention framework fails to provide the level of detail needed to describe all the recommendations that emerged from the Healthy Start FIMRs. We do not know whether any of the FIMRs explicitly considered such a framework in conducting the case reviews and/or developing recommendations.

In the first several years of implementation, with few exceptions the Healthy Start FIMRs sought limited change. The vast majority of recommendations, regardless of substantive focus, involved changes in practice or programs. The functional focus of the recommendation has been identified in some studies as an indicator of “comprehensiveness” (a measure of plan quality), ultimately found to be connected with coalition effectiveness (13). As noted by Goodman, Florin and others, many of the coalition initiatives studied to date have tended to focus on “quick fix” problems and actions. While there appears to be some wisdom in this approach in terms of ensuring early success, if that focus is maintained indefinitely, it may be at the expense of missed opportunities to contribute to systems change (14, 15).

Our observations related to the targets of the strategies resonate with others who have examined community coalitions, finding that the success of implementation of a recommendation hinges to a significant, although not exclusive, degree on who is identified as responsible for taking action (10, 16). Success depends as well as on perceptions regarding their own ability to influence systems change or health outcomes (10, 17). Limited outreach to public agencies or legislative bodies whose span of influence can broadly impact and institutionalize system-wide improvements in service delivery, and system resources and capacity was observed. In the vast majority of instances a specific program or project (such as Healthy Start), or institution (such as a hospital) was targeted to take action. In this way, most of the FIMRs worked almost exclusively within their own span of control to effect important, albeit more limited, changes in services to women and their infants.

Clarity around the roles and expectations of the Healthy Start FIMRs continues to be elusive in a

number of sites. As revealed in telephone interviews and discussion with Healthy Start FIMR coordinators at a meeting convened following presentation of our descriptive analysis (18), there was uncertainty related to (1) the intent(s) of the FIMR process, (2) the roles and functions of the FIMR Coordinator, and (3) the relationship of the FIMR to the Healthy Start project team, public health agency, and other key policy initiatives. The various review committees, regardless of their “type”—case review teams (CRTs) composed of health clinicians, or community action teams (CATs) constituted by community leaders and policymakers—were reported by the FIMR coordinators to express somewhat narrow views overall of their roles related to making change happen.

Despite the limited scope of the analysis, these findings point to several possible preventive or ameliorative activities that could be undertaken at the federal or state levels to enhance FIMR processes and extend the reach of their outcomes. First, judicious use of a framework may be a good starting point to ensure the scientific soundness of the case reviews and recommendation development. While existing frameworks may not address newly emerging health issues, and there are topics that FIMRs will need to address that relate to their own infrastructure development, evidence-based strategies should be emphasized. Second, training and technical assistance offerings should be designed to bolster FIMR staff and committee members’ appreciation of the broad scope of possibilities related to systems change strategies. Such training might include enhanced exposure to relevant policy analysis methods and basic information on political processes (10). A third strategy for strengthening the work of FIMRs might entail development of guidance related to the composition and/or competencies important to staffing FIMRs (13, 19). Finally, “promising practices” information related to structure and/or processes (such as in Table III) for promoting action on recommendations is potentially useful to newly developing and/or stagnated FIMRs.

As public health professionals seek to discharge their responsibilities for tracking and monitoring the public’s health within our current environment of rapid and intense change, FIMRs and their counterpart in the field of pediatrics—child fatality reviews—may become even more prevalent and important. As the complexities in the system are magnified it behooves the field to strengthen any and all vehicles that draw upon collaborative structures at the com-

munity level to not only uncover problems, but to address them as well.

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