HHS Public Access

Author manuscript

Matern Child Health J. Author manuscript; available in PMC 2015 August 13.

Published in final edited form as:

Matern Child Health J. 2012 December ; 16(0 2): 353–359. doi:10.1007/s10995-012-1186-5.

Louisiana Implementation of the National Fetal and Infant Mortality Review (NFIMR) Program Model: Successes and Opportunities

Lyn Kieltyka,

Division of Reproductive Health, Centers for Disease Control and Prevention, Atlanta, GA, USA

Mary Craig,

Louisiana Department of Health and Hospitals, Office of Public Health, Maternal and Child Health Program, New Orleans, LA, USA

David A. Goodman, and

Division of Reproductive Health, Centers for Disease Control and Prevention, Atlanta, GA, USA

Rodney Wise

Louisiana Department of Health and Hospitals, Office of Management and Finance, Bureau of Health Services Financing, Baton Rouge, LA, USA

Lyn Kieltyka: lyn.kieltyka@la.gov

Abstract

Common features of successful, local-level, Fetal Infant Mortality Review (FIMR) Programs are identified by the National Fetal and Infant Mortality Review (NFIMR) Program, including medical records abstraction and home interviews, case reviews by a case review team (CRT), and community systems action recommendations implemented by a community action team (CAT). This paper presents Louisiana's FIMR program, an adaptation of NFIMR recommendations. In 2001, the Louisiana Maternal and Child Health Program began a statewide FIMR Network (LaFIMR) based on the NFIMR model. Geographic areas of focus, case identification, staffing, data collection methods, and CRT and CAT membership and activities include modifications of the NFIMR recommendations unique to LaFIMR implementation. Adaptations made to the NFIMR model were advantageous to LaFIMR's success. Specifically, LaFIMR geographic areas of interest cover multiple natural communities. Compared with independent FIMR programs elsewhere, LaFIMR represents a Title V Program-based coordinated network of regional LaFIMR teams offering opportunities for expanded partnerships. Primary sources for LaFIMR case identification include obituaries and hospital logs, with secondary identification available through vital records. Improvements in vital records data systems are expected to enhance future LaFIMR case identification. LaFIMR-identified records that are linked with vital event certificates provide enhanced contextual findings for reviews and support continuous quality improvement processes. These differences in the LaFIMR implementation reinforce the NFIMR-supported uniqueness of

Correspondence to: Lyn Kieltyka, lyn.kieltyka@la.govrkieltyka@cdc.gov.

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FIMR programs across the United States, and may encourage other FIMR programs to consider how adaptations to NFIMR recommendations could benefit their programs.

Keywords

Infant mortality; Fetal and Infant Mortality Review; Pregnancy outcomes review; Program implementation

Purpose

The infant mortality rate (deaths per 1,000 live births) is a valuable indicator of a community's overall health [1], relating to both social [2] and economic [3] development. The U.S. infant mortality rate decreased from 40.7 infant deaths per 1,000 live births in 1940, to 6.4 per 1,000 live births in 2009 [4], due to a combination of significant advances in medical care and increased access to medical services through Medicaid and regionalization of perinatal services [5]. Dramatic improvements to reduce infant mortality rates are no longer being realized [6], suggesting considerable challenges to further affecting the complex, multifactorial pathways currently contributing to infant deaths. The number of fetal deaths that occur are similar to the number of infant deaths, but fetal deaths are less frequently reported or examined than infant deaths. In 2006, the most recent year for which national fetal mortality rates have been published, both Louisiana and the U.S. reported 6.1 fetal deaths per 1,000 live births and fetal deaths [7]. However, Louisiana's perinatal mortality rate is higher than the U.S. rate, at 12.2 versus 10.5 per 1,000 fetal and infant deaths [7]. Fetal and infant deaths during the perinatal period are a reflection of both the health of women and their communities. One method to advance perinatal mortality assessment for identifying opportunities to develop community actions within complex systems of care is through Fetal and Infant Mortality Review (FIMR) Programs. FIMR is an action-oriented, community process that leads to improvement in services and resources for families. A full description of the National Fetal and Infant Mortality Review (NFIMR) Program is available at www.nfimr.org [8].

In 1988, the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) began an Infant Mortality Review Program. In 1990, a public–private partnership between the MCHB and the American College of Obstetricians and Gynecologists (ACOG) founded the NFIMR program, providing a resource of FIMR program best practices [8].

The National Fetal and Infant Mortality Review Program recognizes and supports local adaptations across programs. Commonalities of successful programs were published in 1998 guide, which was expanded in 2008 [9, 10]. The guide covers elements of the FIMR process, and identifies common elements shared across FIMR programs, including abstraction of medical records and family home interviews, de-identified case reviews through a Case Review Team (CRT), and community systems action recommendations implemented through a Community Action Team (CAT) [10]. This paper presents Louisiana's statewide FIMR program (LaFIMR) implementation using NFIMR recommendations and discusses selected modifications to those recommendations. Other FIMR programs may benefit from

this paper by understanding exact adaptations made in Louisiana and considering the suitability of LaFIMR's implementation for their population.

Description

Infant mortality remains a priority public health concern for Louisiana. Although Louisiana's infant mortality rate decreased from 62.8 in 1940 to 9.8 in 2001 and then to 8.7 in 2009, the nearby states of Georgia, Alabama, Arkansas, and Texas reported lower 2009 infant mortality rates, at 7.4, 7.7, 8.3, and 6.0 per 1,000 live births, respectively [4, 11]. Louisiana ranked 49th in infant mortality in 2009 in the United States, with Mississippi being the only state to report 2009 infant mortality rates higher than Louisiana's, at 10.1 per 1,000 live births [4].

Support for evidence-based programs is needed to prevent future infant deaths in Louisiana. Following a local-level New Orleans area FIMR initiative in the 1990s, the 2000 Title V needs assessment identified FIMR as a recommended statewide strategy to address infant mortality. In 2001, the Louisiana Department of Health and Hospitals, Office of Public Health, Maternal and Child Health (MCH) Program began a statewide LaFIMR Network based on the NFIMR model, including medical record abstraction and home interviews, de-identified case summaries, CRTs, and CATs. The LaFIMR Network is consistent with many of the NFIMR recommendations, but exhibits adaptations related to legislation, geographic areas of focus, staffing, data collection, case identification sources, CRT membership, and CAT membership and activities (Table 1). Although LaFIMR is consistent with NFIMR regarding staffing and data collection/processing methods, the recommendations in NFIMR are necessarily general; therefore, the program was customized for Louisiana. A detailed description of the specific implementation of these recommendations in Louisiana is included in this paper.

Legislative authority to conduct LaFIMR reviews are defined within existing Louisiana state laws, because they were more restrictive than relevant federal legislation; including the Health Insurance Portability and Accountability Act (HIPAA) [12]. Specifically, LaFIMR activities are endorsed as an official activity of the Louisiana Commission on Perinatal Care and Prevention of Infant Mortality (Perinatal Commission), a state-legislated, 16-member, governor-appointed panel [13]. As such, the existing statute covers both the authority to receive and to collect FIMR information, as well as immunity from discovery in legal proceedings. The Perinatal Commission provides additional support for LaFIMR by drafting letters delineating applicable legal authority for distribution to Louisiana hospitals. Maternal interview consent forms were modeled after NFIMR forms. IRB approval was not required because LaFIMR activities are designated as public health practice.

Louisiana's geographic areas of focus were identified through intensive review of epidemiologic data by the MCH Title V Director, epidemiologists, and other program staff. Results showed significant variation in both rates and causes of infant deaths in each of the nine predefined state Public Health Regions (Fig. 1). Therefore, a unique LaFIMR program was implemented in each region, with coordinated oversight provided by state-level MCH

staff. The nine regional programs of LaFIMR differ from the NFIMR recommendation because they each contain multiple natural communities.

Cases available for review depend on complete and timely case identification [10]. When all cases in a geographic area cannot be reviewed, NFIMR provides no additional recommendations for prioritizing cases according to birth weight, gestational age, or other characteristics.

In Louisiana, local Vital Records staff do not directly interface with LaFIMR programs, and the state Vital Records Office has not been able to provide as timely case identification as local hospitals and newspaper obituaries. Therefore, cases represent a convenience sample of death occurrence. Limitations of this method include the lack of ability for LaFIMR teams to know whether they are identifying cases representative of the totality of circumstances and causes of death across their region or if cases that would reveal health care systems issues in their communities are inadvertently missed. However, the relationship between the state FIMR program and Vital Records Office supports the sharing of death records, an invaluable resource for case reconciliation with FIMR-identified cases.

To balance the desire for statewide geographic coverage with limited resources, priority was given to abstraction of fetal and infant death records with birth weights of at least 500 g and fetal deaths of at least 24 weeks gestation, consistent with Perinatal Periods of Risk (PPOR) methodology [14]. Approximately 60–65 % of all Louisiana-resident fetal and infant deaths meet eligibility criteria for FIMR review annually, with the highest number of eligible cases in 2004 (N = 743) and the lowest number in 2007 (N = 607). LaFIMR CRTs reviewed 214 (33.4 %) of the 186 fetal and 455 infant deaths eligible for case review in 2008. In 2010, the state LaFIMR team made recommendations to narrow the scope of reviews to deaths among preterm deliveries (i.e., fetal deaths of 28–36 weeks gestation and births of 24–36 weeks gestation), consistent with MCH priority needs and the state's priority to improve birth outcomes. This focused approach is expected to provide LaFIMR teams with greater opportunities to take meaningful action because 100 % of the expected 300 annual eligible cases can be reviewed based on current staffing capacity. In order to assure that important other factors are not overlooked longer-term, updated epidemiologic data that includes PPOR and race and cause specific rates will be reviewed in 2012 to determine if a shift in priority is warranted. In addition, the existing infrastructure provides a foundation for monitoring and investigating emerging issues in Louisiana, such as the prevention of perinatal human immunodeficiency virus (HIV) and congenital syphilis.

Each regional LaFIMR team is led by a local LaFIMR registered nurse (RN) coordinator who links hospitals, physicians, community members, and public health workers to address infant mortality. These regional RN coordinators, most of whom have perinatal experience, raise MCH awareness in their communities and provide a strong infrastructure to promote Louisiana Title V activities, including conducting MCH needs assessments. LaFIMR expanded the NFIMR recommendations for team leadership by including state-level oversight and coordination of the regional teams. MCH Title V staff support communications, technical assistance, and partnership development. Mechanisms used by MCH staff include statewide conferences that offer continuing education to physicians,

nurses, and social workers; individual calls, conference calls, and in-person meetings; and periodic attendance of state LaFIMR staff at regional meetings. In addition to their clinical expertise, which enables advanced understanding of medical records during abstraction, during their first year of employment and as needed thereafter, LaFIMR RN abstractors work with a board-certified obstetrician. These board-certified obstetricians volunteer as LaFIMR champions for each regional team and review all cases prior to CRT presentation. When a board-certified obstetrician is not available at the regional level, the state-funded MCH medical director assists with case reviews. This process helps identify anticipated questions and clarify case information before CRT presentation.

Standardized data collection forms have been used since inception of the LaFIMR program. Initially, standardized paper NFIMR data abstraction forms, available at no cost to FIMR programs, were used by the LaFIMR Network. Beginning in 2007, funding was made available from the Louisiana Chapter of ACOG and the Louisiana Title V MCH Program to purchase licenses for a web-based data system, BASINET [15]. The BASINET program offered the best solution for LaFIMR to create an integrated, electronic, statewide data system at a time when state resources were insufficient to build a comparable system. LaFIMR information is used to support CRTs and provide aggregate regional analyses of death causes and risk factors. Each regional CRT team uses de-identified narrative case summaries, including information from maternal interviews, to identify opportunities to reduce fetal-infant mortality. Separate from the de-identified review process, Louisiana state legal staff and information technology and security staff granted permission for LaFIMR to store identified case information in BASINET. Each regional LaFIMR abstractor maintains one unique login and password-protected account for that regional team. One state-level LaFIMR/MCH staff person maintains a master account to access all regional records for monthly review, quality assurance, and data analysis, providing accessible aggregate analyses that are desired by most LaFIMR teams and state LaFIMR/MCH program staff.

The electronic BASINET system is used to retain case-level information of eligible deaths, including identifying information that can be used to link records with their corresponding death certificate. This system meets strict security standards, and all LaFIMR staff who access identified information sign a Louisiana vital records con-fidentiality form. BASINET automatically strips identifying information from case summaries, and de-identified case summaries are distributed on colored paper to assist FIMR staff in easily identifying confidential records to be collected from CRT participants. The summaries are then shredded at the end of each meeting. Each of the nine LaFIMR regional staff and CRT members are required to sign confidentiality forms that are kept on file with the regional LaFIMR coordinator, and they are prohibited from discussing cases outside of CRT meetings.

The LaFIMR Network Case Review Teams (CRTs) are multidisciplinary; composed of physicians, social service professionals, and other experts from the medical community. Louisiana's CRTs represent a well-functioning public–private partnership grounded in systems improvement. Most CRTs meet quarterly. Differing from NFIMR recommendations of 12–25 members, some LaFIMR CRTs have more than 100 active members. Among the larger CRTs, about 30–40 members attend any one review session. Few members miss more

than one or two meetings per year, and the broadened membership ensures diverse representation from a variety of professional backgrounds. Two of the nine regions hold CRT meetings at more than one site, thus involving additional providers and hospitals. Despite the large number of LaFIMR CRT members, their commitment allows for greater reach into each CRT's broader geographic community and has not negatively affected their ability to reach consensus recommendations. Extensive partnerships and collaboration with Healthy Start programs, local Nurse Family Partnership teams, March of Dimes, and the Louisiana Chapter of ACOG support LaFIMR activities. Although NFIMR recommends annual presentations, LaFIMR coordinators present recommendations to each regional Community Action Team (CAT) on a rolling basis to minimize delays in information sharing and to help maintain CAT engagement.

LaFIMR CATs are diverse groups of community leaders, faith-based groups, hospital and program administrators, legislators, and individuals from other community based organizations involved with issues related to women, infants, and families. Most of the nine regional LaFIMR CATs meet biannually. As with CRTs, LaFIMR CAT sizes vary; ranging between 25 and 111 members, with most exceeding the NFIMR recommended size of 15–35 members. Each LaFIMR CAT reviews CRT recommendations, prioritizes identified system gaps and lapses, then works to design and implement interventions to improve service systems and resources. Historically, sponsorship was through a partnership between health departments and Healthy Start programs. Over the past 2 years, LaFIMR CATs have been integrated into existing community-based public health-oriented leadership organizations, including Healthy Start, whose mission includes working with people, groups, and organizations that provide critical support and services to children and families. The folding of LaFIMR CATs into existing, external, partner coalitions has resulted in a broader network of individuals serving on the LaFIMR CATs, thereby giving the Louisiana FIMR Network new opportunities for affecting change by leveraging partnerships to strengthen FIMR program resources. Each LaFIMR regional coordinator maintains records of CAT activities and submits monthly progress reports to the state LaFIMR program. Although Louisiana CATs began submitting action plans to the state program in 2009, few have the resources to produce annual reports independent from the state LaFIMR report.

Assessment of Louisiana FIMR

Louisiana FIMR is one of more than 200 FIMR programs across the United States. While not legislatively mandated, LaFIMR receives necessary authority and protections to ensure appropriate program activity. Although LaFIMR regional geographic areas are more heterogeneous than the NFIMR recommended "natural" communities, the advantages of statewide geographic coverage and supportive infrastructure through Louisiana's existing regional system have outweighed most drawbacks of large geographic size. In addition, housing the LaFIMRs within a known state administrative unit supports rapid mobilization of communities in response to health outbreaks and in times of emergency. Specifically, the LaFIMR infrastructure has been used to investigate a perceived cluster of anencephaly cases and to guide infant-related supplies to relief locations following the 2005 Louisiana hurricanes Katrina and Rita.

LaFIMR case identification sources include reviews of obituaries and hospital logs provided by labor and delivery nurses. Significant improvements have recently been made in case finding through the Louisiana Vital Events Registry, Louisiana Electronic Event Registration System (LEERS). Implementation of the new web-based Louisiana vital records data system, which began capturing birth records in December 2010, has already proven an invaluable resource for access to timely birth records with improved accuracy from automated system checks prior to registration. Analysis of preliminary birth data around the time of system implementation showed that approximately 75 % of births are registered within 30 days of delivery, and more than 93 % are registered within 2 months. If a similar time frame is found when the new death and fetal death registration systems become active in late 2012, data timeliness will be improved at the population level. MCH epidemiologists will soon be able to perform linkages based on preliminary data to help LaFIMR teams identify cases eligible for review. By the end of 2012, it is expected that MCH epidemiologists will receive a preliminary birth, death, and fetal death file on a monthly basis that will allow for case identification from the population-based registry rather than newspapers and hospital logs.

LaFIMR is unique in the coordination of the nine regional teams by a leadership team in the Louisiana Title V MCH Program. Whereas many FIMR programs operate independently within their respective geographic coverage area, LaFIMR operates both independently at the regional level and coordinated at the state level. Active participation in NFIMR activities occurs through LaFIMR participation in NFIMR conference calls and in-person conferences.

Retaining identifiable case-level information and linking FIMR records to vital records data are not consistent with NFIMR recommendations. However, Louisiana has benefitted from maintaining identifiers in a secure data set. Identifiers enable linkages to vital records data, which serves two main purposes. First, LaFIMR supplements abstracted information with data from birth, fetal death, or death certificates to ensure completeness of LaFIMR records. Records are reconciled with state population-based vital records data to better understand the proportion of specific causes of death presented to the CRTs, compared with the total population, thereby preventing bias in the interpretation of results. One example is the regional reporting of a rapid increase in suspected sudden infant death syndrome (SIDS) cases on the basis of the cases identified for review. A comparison with the registry of total population events, however, revealed that the apparent increase was caused by suspected SIDS cases being more likely to be identified as part of the FIMR process relative to other causes of death. Identifying and understanding this detection bias would not have been possible without the reconciliation to the population-based events. It is important to note that without advanced epidemiologic capacity to link, analyze, and translate aggregate FIMR program data, maintaining identified records would not be of sufficient benefit to outweigh the risk of a confidentiality breach.

Second, Vital Records staff benefit from the opportunity to receive reports from the LaFIMR program, which identify vital events not found in the vital records close-out data, reconciling completeness of event registration. Future plans include comparing specific risk factors found on the death certificates with the LaFIMR abstracted data to help Vital Records staff better understand vital event registry data quality, without additional expenses

for resources to either program. Although Louisiana is otherwise consistent with NFIMR recommendations, including de-identified case review summaries, maintaining identified records has provided unique opportunities for LaFIMR data to be useful to Vital Records staff, as well as LaFIMR teams, by providing enhanced contextual findings for reviews and continuous quality improvement opportunities for both systems. Although systems improvements form the underpinnings of all FIMR programs, the additional advantages provided by advanced data analyses and continuous quality improvement further supports maximizing program efficiency in times of budgetary constraints.

Case review team members across Louisiana are committed to quality case reviews resulting in actionable recommendations. As CRTs mature, it has become somewhat difficult to maintain interest in reviews because of the feeling that similar cases are reviewed repeatedly with little opportunity for novel, actionable recommendations. In addition, limited funding of CATs to implement interventions has resulted in frustration among LaFIMR coordinators and CAT members. While NFIMR recommends a local sponsor organization for CATs, the initial LaFIMR model relied on the state health department for primary CAT support. Consistent with NFIMR recommendations, CATs are being relocated within local-level public health-oriented sponsor organizations, with the expectation that this will solidify infrastructure to leverage additional resources for sustainable action and expanded partnerships.

Conclusion

Many similarities are noted between the Louisiana implementation of its LaFIMR Network and NFIMR recommendations. Modifications in Louisiana's implementation of FIMR have increased opportunities for meaningful LaFIMR program impact. Louisiana has infrastructure and supporting resources for all FIMR activities. Expected improvements in case identification suggests revisiting this aspect of LaFIMR after the new death registry is active. Identified, electronic LaFIMR records provide Louisiana MCH epidemiologists with additional opportunities to advance FIMR data. Other FIMRs should weigh potential benefits and risks, including risk of confidentiality breach, before adopting similar adaptations. The State MCH Title V Program and the state MCH epidemiologist may further assist local LaFIMR groups by developing and presenting an annual review of findings, recommendations, and actions to promote the dissemination of information from important FIMR processes. Finally, a comprehensive evaluation of the Louisiana FIMR Network policies and protocols, of and by each of the nine CRTs and CATs across Louisiana, could help ensure positive program effects in the future by guiding actions and redefining program direction.

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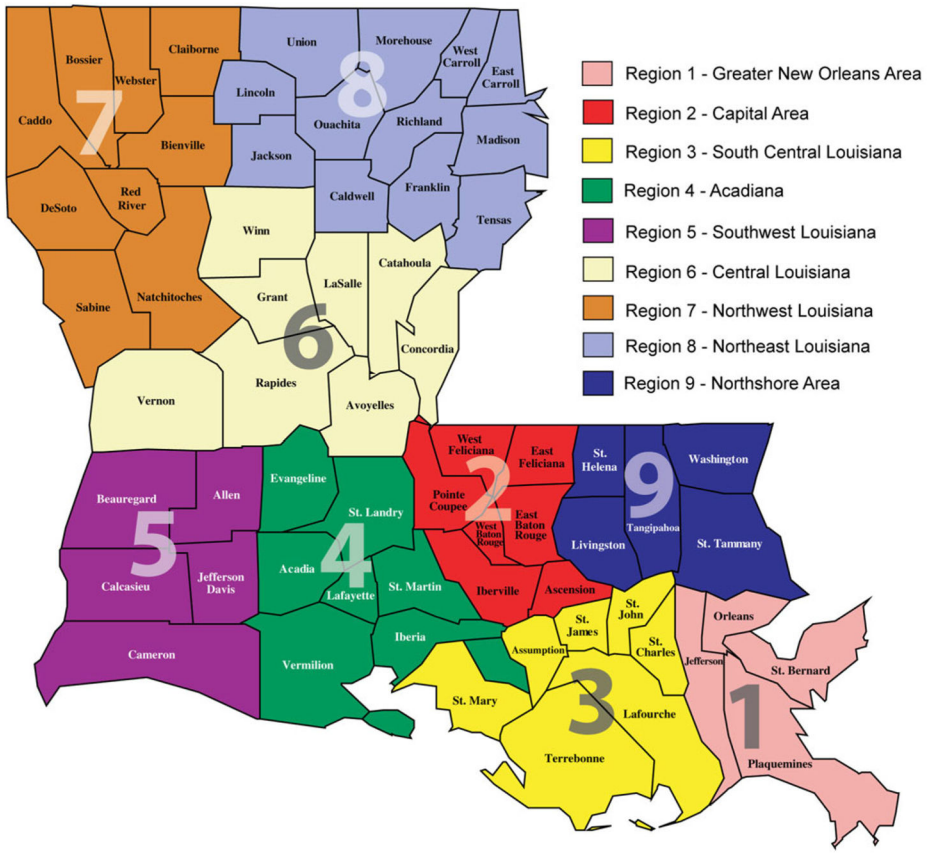

Fig. 1.
Louisiana Department of Health and Hospitals Public Health Regions

Table 1

A comparison of selected NFIMR recommendations to LaFIMR implementation

	NFIMR recommendations	LaFIMR adaptations
Legislation	✓ Immunity from legal proceedings	
	✓ Authority to access records	
	✓ Exclude cases likely to result in litigation	
	• IRB* requirements considered	• IRB *not* required
Geographic areas of focus	✓ Define by reviewing existing data	
	• Communities defined by…	• Communities defined by *state public health region*
	• Review all area cases	• Review a *convenience sample* of cases
Case identification	✓ Hospital logs	
	✓ Obituaries	
	• Vital records	• Vital records - *delayed reconciliation*
	• Notification from other programs	• *No* notification from other programs
	• Within 3 weeks of event	• Within *2 months* of event
Staffing and data collection	✓ Clinical experience (e.g. perinatal nurses)	
	✓ Standardized data collection tools	
	✓ Uses for FIMR information include:	
	✓ supporting case reviews (required)	
	✓ aggregating analyses (optional)	
Confidentiality	✓ Signed confidentiality forms	
	✓ Records secured at all times	
	✓ Case review summaries de-identified	
	• Computer records de-identified	• Computer records *not de-identified*
Case review teams	✓ Meet at least 4 times per year	
	• 12–25 members; professionals and advocates serving the community	• *13–92 members;* professionals and advocates serving the community
	• 3–5 cases per two hour session	• *3–8 cases* per two hour session
	• CRT writes annual report of recommendations	• *State Title V Program* writes annual report of recommendations
Community action teams	• 15–35 members; individuals with the political will, fiscal resources, and community perspective to create change	• *25–111 members;* individuals with the political will, fiscal resources, and community perspective to create change
	• Sponsor organization (usually local health department)	• Sponsor organization is *community-based public health leadership organizations*
	• CAT generates action items with work plan	• *FIMR Coordinator* records action items
	• Write annual report separate from CRT	• Annual report *not separate* from CRT

IRB Institutional Review Board

✓ Indicates consistent with NFIMR recommendations