Checking the pregnancy checkbox: Evaluation of a four-state quality assurance pilot

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Abstract

Background: The 2003 revision of the standard United States death certificate included a set of "pregnancy checkboxes" to ascertain whether a woman was pregnant at the time of her death or within the preceding year. Studies validating the pregnancy checkbox have indicated a potentially high number of errors, resulting in inflated maternal mortality rates. In response to concerns about pregnancy checkbox data quality, four state health departments implemented a quality assurance pilot project examining the accuracy of the pregnancy checkbox for 2016 deaths.

Methods: State staff conducted searches for birth or fetal death reports that matched a death certificate, within a year of death. If a pregnancy checkbox was marked, but no match was found between certificates, confirmation of the pregnancy was attempted through active follow-up with the death certifier. From December 2017 to January 2018, the quality assurance pilot was evaluated through three focus groups with key stakeholders. The evaluation aimed to describe opportunities and challenges to implementation, sustainability, and lessons learned.

Results: Opportunities for implementing the pilot included written documentation of the quality assurance process, improved certifier response, improved data quality, and increased data timeliness for Maternal Mortality Review Committees. Challenges included initial delays in certifier response, staff turnover, high caseloads in relation to resources, and lack of pilot prioritization in the health department. All four pilot states plan to sustain the pregnancy checkbox quality assurance process in some capacity.

Conclusions: Implementing quality assurance processes for the pregnancy checkbox may ultimately improve state and national maternal death data quality.

Keywords

data quality; evaluation; maternal mortality; pregnancy checkbox; vital records

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1 | INTRODUCTION

In the United States (US), the National Center for Health Statistics (NCHS) calculates the maternal mortality ratio (MMR) using a specific set of International Classification of Disease (ICD) codes.[1,2] These codes (A34, O00-O95, O98-O99) are based on the World Health Organization definition of the death of a woman while pregnant or within 42 days of pregnancy that cannot be attributed to incidental or accidental causes.[3,4] All death certificates indicating pregnancy at time of death, pregnancy within 42 days of death, or obstetric-related cause of death are ascribed one of these codes, except for deaths due to external causes.[5] Historically, changes in maternal death identification have led to increased success in capturing these deaths. Implementation of the 10th revision of the ICD accounted for a 13% increase in the number of maternal deaths counted from 1998 to 1999.[5]

Before 2003, 16 states included questions on their death certificates ascertaining whether a woman had been pregnant at the time of her death or within the preceding year.[1,2] These "pregnancy checkbox questions" were developed to improve identification of maternal deaths. A study among states using pregnancy checkboxes on their death certificates in 1991 and 1992 highlights the benefits of the checkbox in capturing maternal deaths.[2] Investigators found an additional 5%-40% of maternal deaths were identified by checkboxes, compared with only using pregnancy-related terms documented on death certificates.[2] Pregnancy checkboxes were added to the 2003 revision of the standard United States death certificate (Figure 1), which all states adopted in some form between 2003 and 2017.[6,7] The pregnancy checkboxes were expected to improve identification of maternal deaths and accuracy of the MMR.[2]

Although the addition of the pregnancy checkbox to the standard death certificate resulted in increased identification of maternal deaths, many researchers have raised questions about its accuracy.[6,8-10] The staggered adoption of the revised death certificate by states resulted in a lack of nationally comparable data, and NCHS has not released an official United States MMR since 2007.[7] Instead, calculations of the MMR by researchers and others are based on the publicly available National Vital Statistics Systems data.[11]

A 2017 report from four state Maternal Mortality Review Committees found that pregnancy checkboxes identified an additional 50% of deaths during pregnancy, 11% of deaths within 42 days of delivery, and 8% of deaths from 43 to 365 days postdelivery, compared with only using pregnancy-related terms found on the death certificate.[12] However, approximately 15% of checkbox-identified deaths had no verifiable evidence of pregnancy.[12] A Texas study found an 87% increase in maternal deaths comparing 2006-2010 to 2011-2015 data.[13] A subsequent Texas study found that 50% of obstetric-coded deaths in 2012 showed no evidence of pregnancy within 42 days of death after data-matching—suggesting that the reported increase in maternal deaths was inflated by pregnancy checkbox errors.[14] These studies question the accuracy of United States maternal death data, highlighting the necessity of data quality improvement measures.[6,8-10,13,15,16,18]

Given concerns over the quality of the data collected by the pregnancy checkbox, four state health departments (Georgia, Louisiana, Michigan, and Ohio) implemented a quality

assurance pilot in collaboration with Vital Records offices, Maternal and Child Health (MCH) programs, and technical assistance from staff at the Centers for Disease Control and Prevention (CDC). From January 2016 to March 2017, states reviewed all 2016 death certificates with a pregnancy checkbox marked—with the goal to amend vital statistics files sent to NCHS. States conducted monthly to bimonthly searches for birth or fetal death reports that matched death certificates to women of reproductive age, within a year of death. If no match was found, but a pregnancy checkbox was marked, an attempt was made to confirm the pregnancy by contacting the certifier or reviewing the decedent's medical records. Participants from each state developed their own specific quality assurance processes based on existing practices, policies, and structures. CDC provided technical assistance at the states' requests, including organizing quarterly calls to share updates and best practices, assisting in designing a template to track death certificates, and communicating findings to other stakeholders.

Throughout the quality assurance pilot, participants evaluated a total of 467 death certificates with a pregnancy checkbox marked. Of these deaths, 55% (n = 255) linked to a birth or fetal death certificate. After following up with the death certifiers of the remaining 212 records, 38% (n = 80) were confirmed to be pregnant, 17% (n = 35) were unable to be confirmed, and 46% (n = 97) were confirmed to not be pregnant (manuscript under review).

The purpose of this study is to describe opportunities and challenges to pilot implementation, project sustainability, and lessons learned—as identified by stakeholders who participated in the pilot.

2 | METHODS

From December 2017 to January 2018, the CDC project led identified key stakeholders to participate in an evaluation of the quality assurance pilot through focus groups. These group discussions provided a robust opportunity for analyzing the experiences, perspectives, and learnings of pilot participants. Participants had already established rapport with one another through the pilot's quarterly calls, which facilitated rich and in-depth focus group discussions.

The researcher, who was not involved in the pilot, conducted three focus groups by means of teleconference. Each focus group was stratified by pilot role (Active Follow-up, MCH program, or Vital Records leadership) with typically one representative per state. Ten staff members across four states participated. Active Follow-up staff (n = 4) in the Vital Records Department performed linkages of vital records and case follow-up to verify pregnancy status, MCH program staff (n = 3) facilitated communication between offices, and Vital Records leadership staff (n = 3) designed and adapted the pilot process for their offices. These group compositions supported comparing experiences across shared roles and obtaining detailed information related to each unique state context. Discussion guides were developed with input from CDC staff to facilitate dialogue with respect to the pilot implementation, outcomes, and future quality assurance work. Institutional Review Board approval was obtained from Emory University, and all participants consented to focus group participation.

All focus group discussions were transcribed verbatim and analyzed using MAXQDA software (VERBI Software, Berlin, Germany). A codebook was developed with both deductive codes of expected themes and inductive codes derived from the data. Key themes were identified and compared across focus groups. All coded data were assessed using thematic analysis to discern consistent and unique themes across responses. Exemplar quotes were chosen to demonstrate source data.

3 | RESULTS

Themes were identified across focus groups (Table 1) and explained in-depth with exemplar quotes for the following topics: pilot process, pilot outcomes, and future quality assurance.

3.1 | Pilot process: multi-state connection/CDC support

All focus group participants expressed that CDC staff provided instrumental technical assistance and support in quality assurance process development and adaptation. The common pilot goal and data templates helped states build a comprehensive quality assurance process. Active Follow-up staff described key ways that the multi-state effort improved the approach for certificate identification and follow-up. For example, one participant shared a draft of a certifier query letter requesting confirmation of pregnancy. Members from other states developed their own letters, which they described as an effective approach for pregnancy confirmation in addition to phone calls. According to one MCH program staff person, the CDC's involvement gave them the "teeth needed to go to leadership" and prioritize the project in the state health department. Active Follow-up staff noted that CDC staff provided inclusion criteria for positive checkbox cases, assisted with especially difficult cases, and informed staff about how relevant ICD codes are applied to death certificates.

> I think for [STATE C] it was more the structure of the multistate process and having a common goal and meeting from time to time and the expectation to have tables filled out and be able to discuss those, and having that platform for sharing what we're doing and thinking critically about what we're doing and why—that was helpful in moving it along.
>
> (MCH, State C)

3.2 | Pilot process: death certificate certifiers

Participants across all states and role types identified that contacting certifiers to confirm pregnancies was the greatest challenge in successful implementation of the quality assurance pilot. The majority of staff time commitment was dedicated to contacting death certifiers through phone calls and query letters. Participants raised the following issues: high numbers of death certifiers across the state, limited standard education in correctly completing death certificates, lack of medical training among coroners, and high certifier turnover. States adjusted their certifier contacting strategies as the pilot progressed, for example using rural health department coordinators familiar with the local community. One state used Vital Records staff with strong preexisting relationships with certifiers to perform follow-up, and other states engaged Maternal Mortality Review Committee abstractors in certifier

follow-up. Active Follow-up staff in two states experienced improvement in the timeliness of certifier responses after that relationship developed.

> Then there are lots of variables that determine how much time was spent, like sometimes they would get someone—or the certifier of the death the first time. Sometimes it took ten times, sometimes we had to employ letters, or you know get creative trying to find someone to verify whether it was a true maternal death or not.
>
> (MCH, State D)

3.3 | Pilot process: prioritization of pregnancy checkbox quality assurance pilot

Perceived priority of the quality assurance pilot varied depending on the role of each participant. Vital Records leadership acknowledged that despite having a high volume of responsibilities, Vital Records staff prioritized the quality assurance pilot within their scope of work. MCH staff, conversely, reported that vital records did not always have quality assurance "on the top of the radar" due to competing priorities. MCH staff described scenarios where changes in staff turnover affected buy-in from Vital Records leadership, requiring MCH staff to reestablish the quality assurance process as a priority with new leadership. MCH staff also explained that state health departments focused more on maternal mortality activities directly related to prevention (such as Maternal Mortality Review Committees) than on the quality assurance pilot, which was perceived as a data quality initiative. The state which most consistently identified the quality assurance pilot as a priority received commitment and funding from their leadership.

> You kind of go into this, and the people that are in it they find a way and find the time and they just get it done. We all have 15 things on our plate at one time, and you just get them taken care of. And that's what it was, the people that were in it and the work they did.
>
> (Vital Records, State B)

3.4 | Pilot process: time burden on staff

Participants agreed that caseload and certifier responsiveness affected time burden on staff, which varied by participant role. Vital Records leadership spent the shortest time (estimated as a few hours per month) and Active Follow-up spent the longest time (estimated as 20-40 total hours per month) on implementing the quality assurance processes. The state with the lowest time commitment of 3.3 hours per month explained that they already had a system of record linkage, so most time was dedicated to contacting certifiers. Another state described total time commitment for Active Follow-up at approximately 10-15 hours per month, and about 5 hours per month for MCH program staff (epidemiologist). In the other two states with the highest number of identified maternal deaths, staff time amounted to 30-40 total hours per month, largely completed by Active Follow-up staff in vital records. One participant from a state with high time burden attributed the time investment to death certifier "repeat offenders" with multiple erroneous certificates. Overall, states identified the significant time commitment required to conduct the pilot as a major lesson learned.

And it was individual case follow up and it took 30-40 hours a month. And this was on top of their day job. So it was very very laborious…it's people's time. It's frustrating with not being able to get ahold of someone that you know could give you a quick answer. It's repeat offenders, it's follow-up. It's laborious, it's not fun.

(Vital Records, State D)

3.5 | Pilot outcomes: verification process

Participants identified that the quality assurance pilot contributed to improving the process of verifying pregnancies and increasing awareness of the pregnancy checkbox among certifiers. One state posited that certifiers mark the pregnancy checkboxes indiscriminately "because it's there." All states reported that following the pilot, certifiers paid greater attention to marking the checkboxes accurately. As a result, one state plans to implement a pop-up question in their electronic death registration system to ask certifiers to verify pregnancy checkbox information, thereby increasing intentional checkbox completion. Additional achievements of the pilot included raising awareness of the pregnancy checkbox problem with state agency leadership and improving communication between Vital Records offices and MCH programs.

I think just from a process standpoint one of the take-aways that I at least saw was a little more communication around deaths around pregnancy between the MCH epidemiologists and Vital Records themselves, so it really was a helping stepping stone for the maternal mortality review.

(Active Follow-up, State B)

3.6 | Pilot outcomes: data quality

Focus group participants unanimously identified data quality improvements as the most significant outcome of the pilot. Participants found more false positives than expected through certifier follow-up, but also identified false negatives. False positives and negatives resulted from seemingly random errors in marking the pregnancy checkbox. Confirmation of checkbox responses by certifiers was especially valuable in instances where cause of death information on the death certificate was not specific to pregnancy, and there were no matched birth or fetal death records. Focus group participants felt more confident that they could provide quality data to their Maternal Mortality Review Committees. Multiple participants stated that because maternal mortality is a rare event, small mistakes can substantially affect the data. Many participants commented that the national MMR would likely be overestimated because ICD-10 codes are ascribed based on an algorithm that includes the pregnancy checkbox, which was often marked in error in their states.

I think Vital Records in [STATE D] is better off because of the pilot and what we learned.

(Vital Records, State D)

It is not wise to presume reporting of this field [pregnancy checkbox] is error free. Given the thousands of deaths to women in child bearing years and the rarity of maternal death, a very small false positive rate will significantly inflate the maternal mortality data.

(Active Follow-up, State A)

3.7 | Pilot outcomes: effect on Maternal Mortality Review Committees

Timeliness for providing death certificates to Maternal Mortality Review Committees has improved for two states. The first state has reduced its delay in reviewing deaths by 1 year. Similarly, a second state now identifies deaths for the Maternal Mortality Review Committee immediately instead of waiting 1.5 years. The states that have not yet seen an improvement in timeliness expressed that they expect current data verification efforts to improve the process in the next few years. Staff involved in Active Follow-up claimed that the extra time it takes them as individuals to verify pregnancy status is worthwhile because the Maternal Mortality Review Committee can focus on reviewing true pregnancy-associated deaths.

> Over time it's going to improve the timeliness of our review process for our maternal mortality review team, so you know that's really what we're looking at is improving that and getting that down so that those cases can be reviewed and reviewed thoroughly and timely to improve health outcomes.
>
> (Vital Records, State B)

> And the impact of [removing false positives] is that's 27 less cases—27 less resources that the Maternal Mortality Review Committee has to spend. So you know it—it benefits downstream our MCH team and our MMR team committee because they'll have fewer cases to review.
>
> (Vital Records, State D)

3.8 | Future quality assurance: sustainability

All four states anticipate continuing the quality assurance pilot processes in some capacity. One state has committed to incorporating pregnancy checkbox quality assurance into their routine Maternal Mortality Review Committee process. Another state plans to continue the quality assurance process and has documented a standard procedure to continue the work. A third state expressed intentions for continuing the project but stated that high burden of deaths and changing priorities related to agency leadership turnover presented challenges. Vital Records leadership and Active Follow-up staff in this state suggested that incorporating Pregnancy Risk Assessment Monitoring System (PRAMS) and MCH Epidemiology staff, as well as using CDC Link Plus, might help them continue with the verification process. CDC Link Plus is a probabilistic record linkage program designed by CDC that can be used by researchers to link and maintain public health data.[18] Staff in the fourth pilot state presented differing opinions about sustainability. MCH staff in this state reported that the quality assurance process ended with 2016 data but may be incorporated in quarterly state quality improvement reports, whereas Vital Records leadership expressed that the state would fully integrate and formalize the quality assurance process because of its important public health implications.

> We work with vital records to provide a quality assurance report on both births and deaths on a quarterly basis, and I could see including this as part of a quarterly process, but I don't think we would continue it in real time monthly, and I don't think we would continue it in the same way.

(MCH, State B)

For [STATE C] I don't see the project ending, like I said I've done it for years just
in a different aspect of what I'm doing now and will continue for 2017 [deaths].
I'm still using the spreadsheet, still following up with everyone, so I don't see it
coming to an end anytime soon.

(Active Follow-up, State C)

3.9 | Future quality assurance: recommendations moving forward

Overall, pilot participants asserted that conducting a quality assurance process is
instrumental in collecting accurate maternal mortality data. Participants recommended (a)
providing concise, standard training to certifiers about completing the death certificate, (b)
raising awareness of the pregnancy checkbox among certifiers and health departments, (c)
conducting timely follow-up on deaths to preserve certifier memory, and (d) sending clearly
written query letters when requesting information about a death certificate. Vital Records
leadership stated that it is necessary to have collaboration between Vital Records offices and
MCH programs, clearly defined workflows, and devoted resources for the quality assurance
process. One participant recommended that collaborating with Maternal Mortality Review
Committee members and abstractors may streamline the process and increase agency buy-in.
With respect to CDC support, participants suggested that the Division of Reproductive
Health develop internal reports with aggregated state pregnancy checkbox data to engage
state leadership. Another state asked for increased assistance in identifying out-of-state
births and stillbirths through the National Association for Public Health Statistics and
Information Systems State and Territorial Exchange of Vital Events system, which supports
the interstate exchange of vital records.[19] Participants reported a lack of understanding
about the NCHS coding algorithm and stated that education is needed about how the
pregnancy checkbox specifically influences the algorithm. Several states recommended that
NCHS provides routine and accessible information about potential errors with the pregnancy
checkbox and encourages states to implement standard quality assurance processes to work
toward data uniformity.

I would say if [other states are] not doing this, they're not doing a good job.
This is really clearly a problem. Any state that's worried about maternal mortality
and does any maternal mortality review needs to do the linkage to the birth files
and the stillbirth files, I mean that's the only way you're going to get useful and
comparable data on maternal mortality.

(Vital Records, State A)

I would love to see an algorithm from NCHS as to how they use a death certificate
that is filed in order to determine if the corresponding ICD code that will be
assigned to that death certificate will be an O-code or not….in my opinion it
could potentially help bring the importance of the issue full circle to know that the
accuracy of that checkbox is further determining the ICD-10 code that's getting
assigned and if it's incorrect, it can almost be like a vicious process.

(MCH, State B)

4 | DISCUSSION

The evaluation identified many successful outcomes of the quality assurance pilot, namely improved pregnancy checkbox data quality, improved timeliness for Maternal Mortality Review Committees, and increased prioritization of the quality assurance within state departments. Key challenges of pilot implementation included the high number of certifiers in each state, delay in certifier response time, staff turnover, competing priorities for both vital records and MCH departments, and lack of funding. States identified that several strategies assisted in overcoming these barriers: CDC engagement helped prioritize commitment to the pilot among state leadership, the multi-state effort assisted pilot development by sharing lessons learned and strategies, and communication with certifiers improved relationships and reduced certifier response time.

Participants provided salient recommendations to other states interested in initiating a pregnancy checkbox quality assurance process, including defining workflows, collaborating across departments, and committing time to contact certifiers for pregnancy confirmation. Uncertainty surrounding how NCHS codes the pregnancy checkbox suggests opportunities to increase knowledge of NCHS's maternal death algorithm. In addition, states emphasized the importance of collecting quality data before sending to Maternal Mortality Review Committees for review and NCHS for coding. Lessons learned from this pilot provide guidance to increase collaboration between stakeholders in each state, prevent and/or correct certifier mistakes, improve timeliness of Maternal Mortality Review Committee review, and improve data quality processes at both the state and national level. A primary limitation of this evaluation is the use of focus groups instead of individual interviews, which may have affected how forthcoming participants chose to be in their responses. With 10 participants across the three focus groups, this evaluation may not be generalizable beyond the state agencies that participated.

The results of this pilot suggest that states may be able to achieve improved maternal death data by verifying a decedent's pregnancy status through birth or fetal death linkage and certifier confirmation. The United Kingdom, described by experts as having the "gold standard for maternal health data," implements a similar national vital records process wherein health care practitioners review medical records and additional reports to verify maternal deaths.[6] Pilot participants and previous studies both suggest that additional certifier training, though challenging to deliver to the high number of state certifiers, could enhance efficacy of key pregnancy-related death indicators.[7,20,21] An ideal maternal mortality review process includes usage of the pregnancy checkbox and linkage to birth or fetal death records to capture true maternal deaths.[8,15,21] Vital statistics' investment in providing quality pregnancy-related death data is essential to maternal death prevention efforts, as an accurate list of deaths enables the review committees to spend their limited time and resources on detailed investigations instead of case ascertainment.[14,22]

Ultimately, quality vital records are a critical data source for public health purposes, including state perinatal quality improvement efforts such as perinatal quality collaboratives, fetal and infant mortality reviews, and Maternal Mortality Review Committees.[23] Participants in the pilot stated that conducting a quality assurance process for the

pregnancy checkbox improves reliable state data, which influences state and national maternal mortality rates. As previous studies and pilot participants indicate, MMR data require especially rigorous quality validation because this key indicator of maternal health is calculated based on a small number of death occurrences.[20] Quality maternal health surveillance can improve national maternal health through accurate identification of maternal deaths, thorough maternal death case review, and timely dissemination of findings.[1]

ACKNOWLEDGMENTS

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FIGURE 1.
Pregnancy checkboxes on the United States standard certificate of death, revised November 2003

TABLE 1

Summary of key pilot themes from focus group discussions

Topic	Key themes	Summary
Pilot implementation	*Opportunities:*	Each state developed unique roles for Vital Records and Maternal Child Health staff to maximize timeliness and effectiveness of data linkage and certifier follow-up. Staff roles changed in response to caseload, relationship with certifiers, and staff turnover. States implemented unique strategies for contacting certifiers. Obtaining certification provided the greatest challenge to record pregnancy confirmation and timeliness. Staff commitment varied primarily by state leadership prioritization and caseload.
	• Pregnancy checkbox data quality prioritized	
	• CDC Division of Reproductive Health provided technical assistance	
	• Relationships with certifiers aided follow-up	
	• Clear process documentation	
	• Diverse methods of certifier contact	
	Challenges:	
	• Certifier response delay	
	• High number of certifiers	
	• Staff turnover	
	• Competing leadership priorities	
	• Lack of funding	
Pilot outcomes	• Improved staff coordination	Successes included some states achieving high certifier confirmation rates, identifying false-negative and false-positive cases, and providing timely, high-quality data to Maternal Mortality Review Committees. Additional outcomes included raising awareness of the pregnancy checkbox among certifiers and state leadership.
	• Improved certifier response rate	
	• Improved pregnancy checkbox data quality	
	• Increased timeliness for Maternal Mortality Review Committees	
Future quality assurance	• State commitment to continue	States committed to continuing the quality assurance efforts in various capacities. Recommendations for other states included devoting time and staff to the quality assurance process. CDC Division of Reproductive Health was asked to help with difficult case linkage, and the National Center for Health Statistics was encouraged to be more transparent with death coding.
	• Recommendations for other states and federal agencies	