Stillbirth Data & Privacy

Jill Wieber Lens

About one in 170 births in the United States each year is a stillbirth, meaning the death of a baby after twenty weeks of pregnancy. The general risk of stillbirth is low, but it still translates to over 20,000 stillbirths each year. The stillbirth rate in the U.S. is higher than most other high-income countries, and this already-high rate is not decreasing as it is in other high-income countries. Moreover, the racial disparity in the U.S.'s stillbirth rate is stark, with Black women facing double the risk of stillbirth compared to white women. The number of stillbirths, especially due to fetal abnormalities, is only likely to increase with legal abortion now inaccessible in many states after *Dobbs*.

Stillbirth is not often coined a public health crisis, but it is. And the first step in alleviating any public health crisis is data.[1] Quality and comprehensive data is needed to recognize (and then hopefully alleviate) this public health crisis. Some data is already gathered in the form of state issued fetal death certificates, but that data source has known problems making it increasingly unhelpful to for researchers. This is why advocates have recently pushed for Congress to pass the Stillbirth Health Improvement and Education ("SHINE") for Autumn Act, which aims to improve data and data collection by providing grants to states for projects.

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[1] *See* Jill Wieber Lens, *Counting Stillbirths*, 56 U.C. DAVIS L. REV. 525, 541–44 (2022) [hereinafter Lens, *Counting*].

Increased data on stillbirths, however, is currently a scary proposition. Even when *Roe* was still good law, women had been arrested for allegedly causing their child's stillbirths, including Rennie Gibbs, Regina McKnight, Chelsea Becker, and Adora Perez.[2] Interest in blaming women has only increased post *Dobbs*.

The concerns are real and legitimate, but the answer does not have to be to further neglect stillbirth. The answer can be efforts to improve data and corresponding serious efforts to protect the data.

Recognizing the dangers of stillbirth data, the 2023 SHINE Act included language attempting to mandate privacy protections for data collected. This Essay applauds the recognition of need for privacy protections but argues that the 2023 SHINE Act contained a privacy loophole. The advocates behind the SHINE Act are about to try again to push this legislation through Congress, and should take this opportunity to close that privacy loophole ensuring that stillbirth data is used not to blame, but instead to prevent stillbirth.[3]

I. CLARIFYING THE PRIVACY CONCERN

It's first important to clarify the privacy concern inherent in stillbirth data *collection*. The concern is that collected data could enable a fishing expedition by an eager police officer or prosecutor. That concern is different than the concern about the data itself; that some data could exist allegedly showing that the pregnant person caused their child's stillbirth, usually a finding that the pregnant person used drugs. That is certainly a concern. But data collection does not create that concern. The data itself creates the concern and the data and concern will exist regardless of whether the data is collected.

To explain further, this data will first exist in medical records. At least according to the American College of Obstetricians and Gynecologists and the Society for Maternal Fetal Medicine's Management of Stillbirth guideline, detailing the care to provide during stillbirth. The guideline states that part of an evaluation of the stillbirth should include taking a patient history, including "[t]obacco, alcohol, drug or medication use."[4] The guideline also states to do a toxicology screen "[i]n cases of placental abruption or when drug use is suspected."[5] The guideline separately explains risk factors for stillbirth, including "[m]aternal cocaine, methamphetamine, other illicit drug use, and

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[2] *See* JILL WIEBER LENS, STILLBIRTH & THE LAW 182–87 (2025).

[3] Lens, *Counting*, *supra* note 1, at 74–79; *see also* LENS, *supra* note 2, at 202 (arguing that criminalization of stillbirth distracts from effective prevention efforts).

[4] *Management of Stillbirth*, 135 AMERICAN COLL. OF OBSTETRICIANS & GYNECOLOGISTS 110, 120 (Mar. 2020); *see also* LENS, *supra* note 2, 187–92 (discussing the marked contrast between the usual inevitability sentiment surrounding stillbirth versus the belief drug use causes stillbirth).

[5] *Management of Stillbirth*, *supra* note 4, at 121.

smoking tobacco," describing all as "significant contributors to abruption and stillbirth,"[6] and separately mentions cocaine and drug use as a cause of placental abruption.[7]

If the doctor tests the pregnant person for drug use at time of delivery or before, that possible positive test result would be in the pregnant person's medical records. This is the first written record of drug use during pregnancy and the stillbirth.

That positive drug test is protected health information, protected under the federal Health Insurance Portability and Accountability Act (HIPAA) from doctor disclosure of it. But the police can get it. HIPAA contains an exception allowing disclosure if police have a search warrant,[8] which should be ordered only if the police have demonstrated probable cause that evidence of a crime is present in those medical records. This is important to keep in mind within concerns about stillbirth data. The data already exists, and cops can get to it with a court ordered search warrant.

The (supposed) danger of data *collection*, then, is that the data on all stillbirths is in one repository. And curious cops or prosecutors might want to peruse the data, essentially a fishing expedition.

Note, however, that some repositories already exist. As will be discussed more later, for over a century, states have issued fetal death certificates for stillbirths in their states.[9] Some states also have created fetal and infant mortality review teams that can review stillbirths, also creating a repository but on a much smaller scale.[10] The data collected, whether it be FDCs or FIMR reports, is also mandated confidential by the same state laws created the repositories.[11] The lesson here is that repositories can exist, collecting the data to address stillbirth as the public health crisis that it is but also still protecting the privacy of individuals experiencing stillbirth.

Consistently, even though repositories have long existed, the arrests for stillbirth that have occurred did not start with cops perusing FDCs or FIMR reports (nor should they as such a fishing expedition would be illegal). Instead, arrests start with someone calling the cops. Pregnancy Justice has worked for years to document (and defend against) the criminalization of pregnancy. They report that "[r]eports made by medical professionals (e.g., doctors, nurses, or medical assistants) or hospital-based social workers were

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[6] *Id.* at 115.

[7] *Id.* at 116.

[8] 45 C.F.R. § 164.512(e)(1)(i).

[9] Lens, *Counting*, *supra* note 1, at 555–57.

[10] *See infra* note 29.

[11] *See infra* notes 43–45.

the most common basis for an arrest."[12] So a health care provider calls the cops,[13] and the cops start to investigate a little and then get a search warrant, a court order requiring disclosure of the medical records, a HIPAA exception.

In short, the data exists in the patient's medical records, and cops can get to it. That danger already exists. Opposing efforts to improve data collection won't erase that danger (but it will preclude public health uses of stillbirth data that can help prevent stillbirth in the first place).

II. FETAL DEATH CERTIFICATES

As concerns about reproductive surveillance increase post *Dobbs*, it may surprise many to learn that the U.S. has gathered data on stillbirths for over a century.[14] State laws have long mandated issuance of fetal death certificates ("FDCs"). Those same state laws also mandate confidentiality of data gathered. Unfortunately, however, FDCs, have numerous documented data problems.

A. Data Collected

Stillbirth data collection, like with all vital statistics is decentralized, meaning state laws control the standards for issuance of FDCs and federal

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[12] *The Rise of Pregnancy Criminalization*, PREGNANCY JUST. 25 (Sept. 2023).

[13] Whether this call violates HIPAA is a complicated question and the answer varies depending on the state. This is because HIPAA recognizes an exception if the doctor disclosure of medical information is required by state law. 45 C.F.R. § 164.512(a)(1) (2018). And some state laws arguably require this call to the police, assuming a fetus is considered a person. Georgia law, for example, requires a doctor to call the police if they have "cause to believe that a patient has had physical injury or injuries inflicted upon him other than by accidental means." GA. CODE ANN. § 31-7-9 (West 2009). Hawaii law similarly requires a health care provider to call the police is they "attend[ ] or treat[ ] . . . any injury that would . . . produce death . . . sustained in a suspicious or unusual manner . . . ." HAW. REV. STAT. ANN. § 453-14 (West 2009). Idaho law requires a health care provider to call the police if they have "reason to believe that the person treated or requesting treatment has received . . . [a]ny injury indicating that the person may be a victim of a criminal offense." IDAHO CODE ANN. § 39-1390 (West 2019). State laws similarly can require health care provider referral to the coroner or medical examiner. *See* LENS, *supra* note 2, at 16. Regardless, health care providers are likely not too worried about violating HIPAA as the penalties are minimal. The California Attorney General believed the hospital who called the police on both Becker and Perez violated HIPAA. He pursued enforcement, and the case ended with a settlement in which the hospital paid $10,000 in civil fines and agreed to improve its employee training on HIPAA. Steve Adler, *Adventist Health Settles Alleged HIPAA Violations with California Attorney General*, THE HIPAA J. (Jun. 20, 2024), https://www.hipaajournal.com/adventist-health-hipaa-settlement-california (on file with author).

[14] Historically, states gathered data through the issuance of birth and death certificates, then stillbirth certificates, and now fetal death certificates. Technically, it is a "fetal death report" but everyone in the stillbirth community still calls the certificates. *See* Lens, *Counting supra* note 1, at 554–56 (discussing the history of stillbirth registration in the U.S.).

laws mandate national gathering and reporting.[15] The federal government has, however, created a Model Vital Statistics Act and a model FDC to hopefully improve uniformity.[16]

Image A: Question 18 on Standard Fetal Death Certificate

18. CAUSE/CONDITIONS CONTRIBUTING TO FETAL DEATH

18a. INITIATING CAUSE/CONDITION (AMONG THE CHOICES BELOW, PLEASE SELECT THE ONE WHICH MOST LIKELY BEGAN THE SEQUENCE OF EVENTS RESULTING IN THE DEATH OF THE FETUS)	18b. OTHER SIGNIFICANT CAUSES OR CONDITIONS (SELECT OR SPECIFY ALL OTHER CONDITIONS CONTRIBUTING TO DEATH IN ITEM 18b)
Maternal Conditions/Diseases (Specify) _____	Maternal Conditions/Diseases (Specify) _____
Complications of Placenta, Cord, or Membranes	Complications of Placenta, Cord, or Membranes
□ Rupture of membranes prior to onset of labor	□ Rupture of membranes prior to onset of labor
□ Abruptio placenta	□ Abruptio placenta
□ Placental insufficiency	□ Placental insufficiency
□ Prolapsed cord	□ Prolapsed cord
□ Chorioamnionitis	□ Chorioamnionitis
□ Other Specify)_____	□ Other Specify)_____
Other Obstetrical or Pregnancy Complications (Specify) _____	Other Obstetrical or Pregnancy Complications (Specify) _____
Fetal Anomaly (Specify) _____	Fetal Anomaly (Specify) _____
Fetal Injury (Specify) _____	Fetal Injury (Specify) _____
Fetal Infection (Specify) _____	Fetal Infection (Specify) _____
Other Fetal Conditions/Disorders (Specify) _____	Other Fetal Conditions/Disorders (Specify) _____
□ Unknown	□ Unknown

The current standard FDC asks for relatively detailed medical information on both the mother and the baby,[17] to be completed with information from the medical records and by the medical provider attending the birth.[18] The first medical information asked is about the cause of the baby's death.[19] As can be seen, Questions 18a and 18b include specific medical conditions to check as the initiating or contributing causes of the baby's death, but also include places for the medical provider to write in causes like maternal conditions or pregnancy complications.[20]

The second page of the FDC also asks for more health information,[21] including the first and last dates of prenatal care, and the number of prenatal

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[15] *See* Lens, *Counting supra* note 1, at 554–57.

[16] *Id.*

[17] *Id.*

[18] State laws also sometimes dictate that the FDC be completed by a coroner or medical examiner. LENS, *supra* note 2, at 16–17.

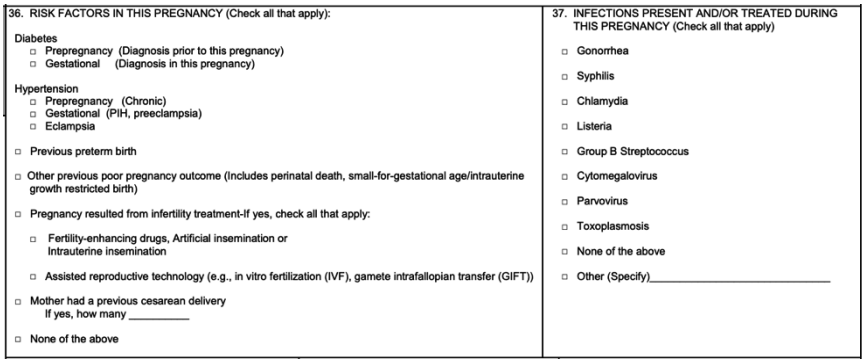
[19] CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. STANDARD REPORT OF FETAL DEATH 1-2 (2003), https://www.cdc.gov/nchs/data/dvs/FDEATH11-03finalACC.pdf [hereinafter STANDARD FDC].

[20] *Id.*

[21] The second page of the FDC asks demographic and social questions regarding the mother (not the father). It asks the woman's level of education, origin, race, marital status. *Id.*

care visits.[22] The FDC also asks the mother's height, weight pre-pregnancy, and weight at delivery, and whether she got "WIC Food" for herself during this pregnancy.[23] It asks for the woman's number of previous live births and number of other pregnancy outcomes ("spontaneous or induced losses or ectopic pregnancies").[24] The second page of the standard FDC also has a specific section titled "Medical and Health Information" (including both the mother and baby). It asks about specified risk factors during pregnancy and infections present and/or treated during pregnancy.[25]

Image B: Question 36–37 on Standard Fetal Death Certificate



36. RISK FACTORS IN THIS PREGNANCY (Check all that apply):

Diabetes
- ☐ Prepregnancy (Diagnosis prior to this pregnancy)
- ☐ Gestational (Diagnosis in this pregnancy)

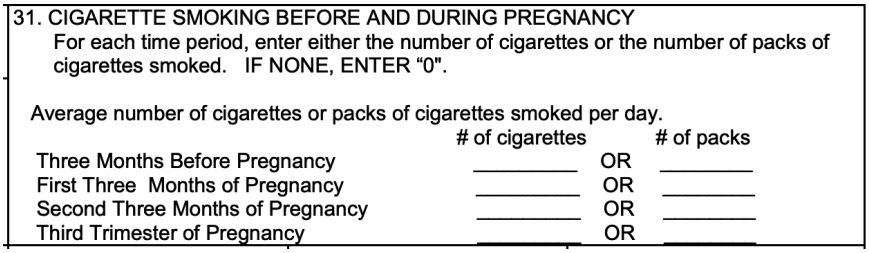
Hypertension
- ☐ Prepregnancy (Chronic)
- ☐ Gestational (PIH, preeclampsia)
- ☐ Eclampsia

- ☐ Previous preterm birth
- ☐ Other previous poor pregnancy outcome (Includes perinatal death, small-for-gestational age/intrauterine growth restricted birth)
- ☐ Pregnancy resulted from infertility treatment-If yes, check all that apply:
  - ☐ Fertility-enhancing drugs, Artificial insemination or Intrauterine insemination
  - ☐ Assisted reproductive technology (e.g., in vitro fertilization (IVF), gamete intrafallopian transfer (GIFT))
- ☐ Mother had a previous cesarean delivery
  If yes, how many _____
- ☐ None of the above

37. INFECTIONS PRESENT AND/OR TREATED DURING THIS PREGNANCY (Check all that apply)
- ☐ Gonorrhea
- ☐ Syphilis
- ☐ Chlamydia
- ☐ Listeria
- ☐ Group B Streptococcus
- ☐ Cytomegalovirus
- ☐ Parvovirus
- ☐ Toxoplasmosis
- ☐ None of the above
- ☐ Other (Specify)_____

The last medical-related questions on the standard FDC focus on the method of delivery; any maternal morbidity issues like admission to ICU or unplanned hysterectomy; and then congenital anomalies of the fetus like anencephaly, cleft lip or palate, or down syndrome.[26]

Image C: Question 31 on Standard Fetal Death Certificate



31. CIGARETTE SMOKING BEFORE AND DURING PREGNANCY
For each time period, enter either the number of cigarettes or the number of packs of cigarettes smoked. IF NONE, ENTER "0".

Average number of cigarettes or packs of cigarettes smoked per day.

	# of cigarettes		# of packs
Three Months Before Pregnancy	_____	OR	_____
First Three Months of Pregnancy	_____	OR	_____
Second Three Months of Pregnancy	_____	OR	_____
Third Trimester of Pregnancy	_____	OR	_____

[22] *Id.*

[23] *Id.*

[24] *Id.*

[25] *See generally* STANDARD FDC, *supra* note 19.

[26] *Id.*

Notably, the FDC does not ask any information about alcohol or drug use.[27] It asks for very specific details about cigarette use before and during pregnancy.[28]

But it does not ask about alcohol or drug use. As visible, however, there are places for the doctor to write in whatever they choose. For instance, the doctor could write in drug use as a "maternal condition/disease" or an "obstetrical or pregnancy complication" in the questions about the initiating or significant causes of the stillbirth.

Another system gather data on stillbirths if Fetal and Infant Mortality Review (FIMR). A few states have laws enabling the creation of localized FIMR teams to put simply, review fetal and infant deaths.[29] Unlike FDCs, the goal is much broader than data collection, including investigation and review of stillbirths. Consistently, the data gathered is much broader, including medical records but also interviews with families. The data is broader, but the scale is much smaller as not all stillbirths are reviewed. FIMR is localized review, usually on a county scale.[30] Plus, creation does not also equal sufficient funding, or an equal focus on fetal death as opposed to infant death. If sufficiently funded, which is unfortunately a big if, FIMRs have the capacity to do quality work within stillbirth prevention. FIMR is not, however, a way to gather comprehensive data on all stillbirths.

B. Privacy Protections

FDCs contain possibly extensive medical information,[31] increasing concerns about the privacy and confidentiality of this information. That confidentiality is also governed by state law, just as the issuance of FDCs is. Fortunately, privacy protections exist.

For instance, Massachusetts law dictates: "Fetal death reports shall be confidential and shall be released by the department only upon written request of the parent, his or her guardian, executor, attorney, or any other

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[27] *Id.*

[28] *Id.*

[29] *See, e.g.*, IND. CODE ANN. § 16-49-6-3 (West 2019) (enabling the creation of county or regional FIMRs); OHIO REV. CODE ANN. § 3707.75 (West 2019); DEL. CODE ANN. tit. 31 § 324 (West 2017).

[30] The localized focused on FIMRs mean that FIMRs could not serve the same purpose of FDCs in simply obtaining an accurate count of how many stillbirths are occurring each year either on a state or national scale.

[31] Notably, the patient's medical information input into the FDC is information protected by HIPAA. Except there are applicable HIPAA exceptions, allowing disclosure of that medical information for public health purposes, including reporting deaths, 45 C.F.R. § 164.512 (2018), and if state law requires the disclosure, like would a state law mandating completion of a FDC.

person designated by the parent in writing."[32] Connecticut law lists specific persons eligible to access fetal death records, none of which are police or prosecutors, and states that no one else can "examine or receive a copy of any . . . fetal death record or certificate, access the information contained therein, or disclose any matter contained therein, except upon written order of a court of competent jurisdiction."[33] Michigan law dictates that "a person or governmental entity shall not permit inspection of, disclose information contained in vital records, or copy or issue a copy of all or part of a record except as authorized by this part, by rule, or by order of a court of competent jurisdiction."[34] New York law states that "the disclosure of information filed pursuant" to the law requiring issuance of the FDC "shall be limited to the mother, her lawful representative and to authorized personnel of the department" and the law provides penalties for unauthorized disclosures.[35] Washington law declares that vital records "are not subject to public inspection" and "may permit the inspection of, disclose data or information contained in, or copy or issue a copy of all or part of any vital records, reports, supporting documentation, vital statistics, data, or information contained therein."[36] California law also protects the medical and health information within the FDC, restricting access to identified officials and entities, none of which involve law enforcement,[37] and even lacking any exception for access pursuant to a court order.

California is worth separate motion because it recently passed a new anti-criminalization privacy protection for stillbirth data. In reaction to *Dobbs* and the prosecutions of Chelsea Becker and Adora Perez, California lawmakers created a new prohibition on the use of a coroner-completed FDC "to establish, bring, or support a criminal prosecution or civil cause of action seeking damages" against the person in which the fetal death occurred.[38] The law is not nearly as broad as it seems, however. It applies only to coroner-

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[32] MASS. GEN. LAWS ANN. ch. 111, § 202 (West 2024). The law also authorizes release of information to the

> National Center for Health Statistics in the Department of Health, Education and Welfare, and to persons authorized by said commissioner under section twenty-four A of this chapter to conduct research studies. The department may release copies of such reports, or information contained therein, to other persons only in a manner which does not allow identification of the parents.

Id.

[33] CONN. GEN. STAT. ANN. § 7-51 (West).

[34] MICH. COMP. LAWS ANN. § 333.2888 (West); *see also id.* § 333.2834 (stating access to fetal death reports same as access to live birth records).

[35] N.Y. PUB. HEALTH LAW § 4160 (McKinney).

[36] WASH. STAT. 70.58A.540.

[37] CAL. HEALTH & SAFETY CODE § 102430.

[38] *Id.* § 103005 (West 2023).

completed FDCs, not attending-medical-professional-completed FDCs.[39] Coroner-completed FDCs is a very small minority of FDCs.[40] But more importantly, this law is a relatively weak anti-criminalization tool because investigations are not starting because of FDCs, coroner completed or otherwise. Criminal investigations begin with health care providers calling the police. This is how the prosecutions of both Becker and Perez started.[41] Thus, the California law passed in response to those prosecutions would not have even prevented them. care providers calling the cops.

Like state laws mandating confidentiality of FDCs, state laws creating FIMR systems also have confidentiality provisions.[42] As examples, under

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[39] Usually, state law mandates that a doctor complete the FDC for in-hospital stillbirths and a coroner or medical examiner complete the FDC for out-of-hospital stillbirths. That was the California law before 2023. *See* CAL. HEALTH & SAFETY CODE § 102975 (West 1995) (mandating doctors complete FDCs for in-hospital stillbirths); *id.* § 103000 (West 2023) (defining out of hospital stillbirths as "unattended deaths" and thus mandating coroners complete FDCs for out of hospital stillbirths). But then the California legislature repealed this statute defining out-of-hospital stillbirths as unattended deaths. Yet the California legislature retained a different provision mandating that coroners complete FDCs. *Id.* § 103005. So California law contemplates that coroners are still supposed to complete FDCs, but there's no law saying *which* FDCS the coroners are supposed to complete. This is also very problematic from a data perspective as there is no longer any legal mandate in California clarifying who is supposed to complete FDCs for stillbirths occurring outside the hospital.

Moreover, media coverage of the changes to California laws was harmfully inaccurate. After the changes were introduced, media coverage noted that California law mandates that coroners investigate stillbirths. Nigel Duara, *Stillbirths and the Law: Bill Would End Required Coroner Investigation of Lost Pregnancies*, CAL MATTERS (Sept. 29, 2022), https://calmatters.org/justice/2022/04/coroner-investigation-stillbirths-anti-abortion [https://perma.cc/Z9KA-437F]. Again, not true. State law mandated that coroners complete FDCs for out-of-hospital stillbirths and investigation was not required, just allowed, the same authority that a coroner has for any unattended death. Now, California law contemplates that coroners will still complete some undefined FDCs, and the repeal of the stillbirths as unattended deaths also eliminated coroner (discretionary) authority to investigate (conduct an inquest) for that unattended stillbirth—once again threatening data quality.

[40] There's no way to determine from publicly available data how many FDCs are completed by medical professionals versus others. I searched in the CDC's Wonder database for 2014–2020 California FDCs where the medical attendant was either "unknown or not stated" or "not reported," and the results were so low that they were suppressed for privacy. The database suppresses data if it is "one through nine (1–9) births or deaths." CTRS. FOR DISEASE CONTROL & PREVENTION WONDER,

Fetal Death Records Data Summary, https://wonder.cdc.gov/wonder/help/fetal-deaths.html [https://perma.cc/2M7W-KM39]. This means only 1–9 California 2014–2020 FDCs had an unknown or not stated, or not reported, medical professional completing it. And even those results would have been overinclusive, including incomplete and/or inaccurate FDCs completed for in-hospital stillbirths.

[41] *See generally* Adler, *supra* note 13 (discussing the hospital's HIPAA violations of Becker's and Perez's medical information).

[42] FIMR has to be set up by state law to enable access to medical data; the state law creates the exception to HIPAA. *See, e.g.*, IND. CODE ANN. 16-49-6-6 (West 2019) (providing FIMR teams access to state department records, local health department records, child services records,

Indiana law, "information and records acquired, and interviews conducted by the local fetal-infant mortality review team in the exercise of the review team's duties . . . are confidential and exempted from disclosure." Similarly, "[r]ecords, information, documents, and reports acquired or produced by the local fetal-infant mortality review team are not" "subject to subpoena or discovery" and are inadmissible as evidence "in any judicial or administrative proceeding."[43] Ohio law similarly mandates confidentiality of all FIMR records, documents, reports, information, work products, etc.[44] Delaware law mandates confidentiality for all FIMR records, clarifies that they are not public records, and makes such records inadmissible "into evidence or otherwise in any civil, criminal, administrative, or judicial proceeding."[45]

C. FDCs' Many Problems

Current data collection systems, especially FDCs, however, fail to serve goals as a public health resource. As I've previously written, those problems include underreporting, data incompleteness and data inaccuracies.[46]

The underreporting results from variations in state law in when fetal death certificates are issued.[47] Medically, a stillbirth is a pregnancy loss after twenty weeks of pregnancy, thus twenty weeks after the last menstrual period. But fetal death certificate issuance does not align with this medical standard in all states. Some states instead base fetal death certificate issuance on a fetal weight of 350 grams, and only if that fetal weight is unknown, the twenty week standard.[48] That aligns roughly with the twenty week standard as 350 grams is the average weight at twenty weeks. But it is not exact. Any stillborn (after twenty weeks) baby weighing under 350 grams would not be registered as a fetal death, an issue that is especially problematic given the increased risk of stillbirth due to fetal growth restriction.[49] The variations in state laws are not as dramatic as they used to be, but some variation still exists, and any variation means underreporting.[50]

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medical records, law enforcement records, coroner records, and "[q]ualitative results of a family or maternal interview").

[43] IND. CODE ANN. § 16-49-6-6 (West 2019). FIMR data would have increased concern about admissibility in a criminal case because FIMR teams review a particular stillbirth to try to determine why it occurred, including possibly due to conduct during pregnancy. Pure data gathering systems like FDCs do not have the same concerns about admissibility in a criminal case because the purpose is not to determine cause in a particular stillbirth.

[44] OHIO REV. CODE ANN. § 3707.75 (West 2019).

[45] DEL. CODE ANN. tit. 31 § 324 (West 2017).

[46] *See* Lens, *Counting*, *supra* note 1, at 557–66.

[47] *Id.* at 558–62.

[48] *Id.*

[49] *Id.*

[50] *Id.*

Data incompleteness is an issue with the fetal death certificates that are issued. Studies of fetal death certificates consistently find data incompleteness, meaning questions on the FDC are simply unanswered.[51] The space to list fetal weight is simply blank. The space to list pregnancy history is simply blank. A study of some 2013 fetal death certificates found that over 9% of FDCs were missing the stillborn child's birthweight, compared to only .1% of live birth certificates that lacked information on birthweight.[52] This study also found other important information also missing: "pregnancy weight gain (70% of records with missing values), gravidity (11%), alcohol and tobacco use during pregnancy (18%), paternal age (74%), and cause(s) of death (69%)."[53] If data is missing from FDCs and FDCs are the only source of information for studies on stillbirth, that is a big problem.

Unfortunately, the data that is included on the FDC is often inaccurate.[54] Studies have found inaccuracies in congenital anomaly, birth weight, gestational age, and cause of death information. The inaccuracies in cause-of-death information are not surprising if one knows more about the process of completing an FDC. State law usually mandates that the doctor attending the birth complete the cause of death information; the average obstetrician is not trained to do this.[55] Moreover, state law usually requires the issuance of a FDC within days of the stillbirth, as it also does for death certificates. But most medical tests like placental pathology and especially not a fetal autopsy cannot be completed within those mere days.[56] The model death certificate for a living person accentuates the need for amendment if tests reveal additional information; no such accentuation can be found on the model FDC.[57] Moreover, legal amendment of medical information on an FDC is usually possible only by a medical professional.[58] Does that amendment ever happen? Possibly, but likely not commonly. A recent ProPublica investigation found that only eighteen of nearly 2,000 FDCs issued in

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[51] *Id.* at 62.

[52] *See generally* Lauren Christiansen-Lindquist et al., *Fetal Death Certificate Data Quality: A Tale of Two U.S. Counties*, 27 ANNALS EPIDEMIOLOGY 466 (2017) (finding that fetal death certificate data from two counties suffered from missing and inaccurate data).

[53] *Id.* at 466.

[54] Lens, *Counting*, *supra* note 1, at 562–64.

[55] *See* LENS, *supra* note 2, at 13–18 (discussing the lack of assistance provided to doctors completing cause of death on the FDC).

[56] Lens, *Counting*, *supra* note 1, at 563–64.

[57] *Id.* at 564.

[58] *Id.*

Georgia between 2019 to 2021 with a missing cause of death had been updated.[59]

No studies exist regarding the quality of data gathered by FIMR teams, but the data is likely more accurate given the intensive review of particular stillbirths. But, as already discussed, FIMR data is simply less comprehensive. It's extensive data on the stillbirths reviewed, but it's fewer stillbirths. Plus, FIMR doesn't exist everywhere, increasing the possibility of non-representative data.

III. THE SHINE ACT—AND IMPROVING ITS PRIVACY PROTECTIONS

The stillbirth community has long recognized the problems with relying on current stillbirth data collection systems. Debbie Haines Vijayvergiya has led recent efforts for a new federal law that seeks to improve data collection. That law is the Stillbirth Health Improvement and Education for Autumn Act, named after Haines Vijayvergiya's daughter Autumn, who was stillborn in 2011. It was introduced in the last two Congresses.[60] In 2021, it passed the House resoundingly but never made it to the floor vote in the Senate.[61] The 2023 version never made it to a floor vote in either the House or Senate.[62] At least based on chatter within the stillbirth community, advocates are seeking to get it introduced again in the 2025 Congress.

The 2023 version accurately recognized the need for privacy protections, and included a privacy mandate. That mandate, however, has a loophole that can and should be closed if the Act is introduced again.

A. What the SHINE Act Does

The SHINE Act enables the Secretary of Health and Human Services ("HHS") to "award grants to States for purposes of":

(A) conducting surveillance and collecting data, including from existing datasets like State or sub-State maternal mortality data and Fetal and Infant Mortality Review data, with respect to stillbirths for public health and research purposes;

(B) building State and local public health capacity to assess stillbirth data; and

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[59] Irene Hwang et al., *The Failure to Track Data on Stillbirths Undermines Efforts to Prevent Them*, PROPUBLICA (July 2, 2024, 5:00 AM), https://www.propublica.org/article/stillbirths-prevention-data-pregnancy-parents [https://perma.cc/BGB6-KEGK].

[60] SHINE for Autumn Act of 2021, H.R. 5487, 117th Cong. (2021); SHINE for Autumn Act of 2023, H.R. 5012, 118th Cong. (2023).

[61] *Roll Call 416: Bill Number: H.R. 5487*, CLERK (Dec. 8, 2021, 7:22 PM), https://clerk.house.gov/Votes/2021416?BillNum=5487 [https://perma.cc/5NS4-6TY6].

[62] SHINE for Autumn Act of 2023, H.R. 5012, 118th Cong. (2023).

(C) collecting and reporting data on stillbirth risk factors, including any quantifiable outcomes with respect to such risk factors.[63]

The Act is flexible. Essentially, states can come up with an idea that would improve data collection and receive a grant to fund it. The law could encourage new ideas and allows the state to test whether its idea is effective in improving stillbirth data collection.

B. Privacy Protections and a Loophole

A potential problem with the SHINE Act, however, is privacy protections. The 2021 SHINE Act lacked any language about data privacy and/or confidentiality[64]—an unfortunate error resolved in the 2023 SHINE Act. That 2023 version mandates that "[a]s a condition of receipt of funds under this section, all data collected shall be in a manner that protects personal privacy and in a manner that is consistent with applicable Federal and State privacy law, at a minimum."[65]

A question remains, however, whether this language does enough to protect privacy. The first part of the privacy language is quite vague—that data should be collected "in a manner that protects personal privacy." What does this actually mandate? A manner that protects personal privacy, but protects it how? The language isn't enough to prevent a fishing expedition.

The second part of the privacy language is more specific (and less vague), mandating that the data be collected "in a manner consistent with applicable Federal and State privacy laws, at a minimum." Still, this protection depends on existing applicable Federal and State privacy laws—which may not exist.

There are no applicable federal privacy laws. Stillbirth data is medical data, and federal law, HIPAA does protect the privacy of an individual's medical information. But HIPAA applies only to certain covered entities, mainly health care providers, health (insurance) plans, and health care clearinghouses.[66] Only these covered entities are bound by HIPAA. And thus HIPAA only applies to a recipient of a SHINE grant if that recipient happens to be a covered entity, which is unlikely.

There could be applicable state privacy laws depending on what one is doing with the SHINE grant. For instance, there are existing state laws mandating the confidentiality of FDCs.[67] If the SHINE-funded project to improve data collection still relies on FDCs for data collection—perhaps a grant for a project to improve FDCs—existing FDC confidentiality laws

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[63] *Id.*

[64] SHINE for Autumn Act of 2021, H.R. 5487, 117th Cong. (2021).

[65] SHINE for Autumn Act of 2023, H.R. 5012, 118th Cong. (2023).

[66] 45 C.F.R. § 160.103 (2013).

[67] *See supra* notes 32-37.

would apply. Improved FDCs would still be mandated confidential under (existing) applicable laws and police fishing expeditions would be illegal, at least under current laws.

The same is true if the SHINE-funded project builds on existing state FIMR systems, maybe using a SHINE grant to better fund local FIMR teams. If awarded, existing FIMR data confidentiality laws would apply. And additional data gathered by these FIMR teams would still be mandated confidential under (existing) applicable state laws, and police fishing expeditions would be illegal, at least under current laws.

The same is not true, however, if the SHINE grant is to be used for something independent, something not building off already-existing data collection systems. SHINE only mandates consistency with applicable privacy laws. There are no applicable privacy laws for new systems, nor are there any applicable laws mandating privacy protections if new systems were to be created. Hence, a loophole.

For instance, what if New York wanted to start FIMR systems[68]; it has no such system currently. If New York or a region in New York requested a SHINE grant to fund a FIMR system, the text of SHINE does not require that the FIMR system have any privacy protections. The SHINE Act conditions funding on privacy protections consistent with "applicable Federal or State privacy law." But there are no *applicable* privacy laws. HIPAA doesn't apply, nor do any state FDC confidentiality mandates. And there are no New York laws mandating if New York were to have FIMR teams, the data gathered must be kept confidential.

The same is true if a state believed, as many stillbirth researchers do, that FDCs are relatively hopeless as a data source and instead advocate for the creation of stillbirth surveillance registries. A surveillance registry is the type of data collection system already existing for numerous chronic illness, injuries, and congenital anomalies (former known as birth defects). A registry enables active surveillance, meaning "[t]rained abstractors visit area hospitals, locate medical records for potential cases, and record the relevant information."[69]

A registry has many advantages over FDCs. Trained abstractors looking for stillbirths will likely result in more accurate numbers of stillbirths.[70] Access to medical records also helps cure data incompleteness and

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[68] This would require creation by a state legislature to enable FIMR teams to access medical records; state law is needed to allow disclosure under HIPAA. *See* 45 C.F.R. § 164.512 (HIPAA exception allowing disclosure to a "public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability").

[69] Wes Duke & Suzanne M. Gilboa, *The Utility of Using an Existing Birth Defects Surveillance Program to Enhance Surveillance Data on Stillbirths*, 41 J. REGISTRY MGMT. 13, 13 (2014).

[70] Lens, *Counting*, *supra* note 1, at 568–69.

inaccuracy.[71] Abstractors can simply look to the medical records to fill in any missing pieces data wise.[72] Formal legal amendment is not needed to change and correct information, easily enabling incorporation of additional information learned from a fetal autopsy or other testing.[73]

Stillbirth researchers believe creation of these registries would not be difficult, easily modeled after often already existing congenital anomaly registries.[74] Some do exist. Arkansas has had a "Reproductive Health Monitoring System" since 1985. Its purpose is "collect and analyze data" on "reproductive endpoints" like "congenital anomalies, fetal deaths, stillbirths, and premature births."[75] New Jersey also passed the Autumn Joy Stillbirth Research and Dignity Act in 2015, mandating that the Department of Health create a "fetal death evaluation protocol" and record data from that protocol in a database.[76] With funding from the CDC, Iowa also maintained a stillbirth registry from 2005-2015 using its already-existing congenital abnormalities registry.[77]

If a state wanted to create a stillbirth registry,[78] presumably that's the exact type of thing that could (and should) be funded with grants from SHINE, no different than Iowa's reliance on funding from the CDC. But a registry would fit into SHINE's privacy loophole. HIPAA doesn't apply, FDC confidentiality provisions don't apply, and FIMR confidentiality protections (if FIMRs exist in this state) do not apply. There are simply no laws that require that data gathered via a SHINE-funded registry be kept confidential.

In short, SHINE's privacy protection mandates may be quite effective for improvements to systems already in place, systems like FDCs (in all states) or FIMRs (in certain states) that have existing "applicable" privacy laws. But SHINE contains a privacy loophole for anything new because there are no privacy *laws applicable* to such systems. Without any privacy protections or confidentiality mandates, cops would be free to go on a fishing expedition—immediately endangering stillbirth parents, especially marginalized ones (who had an increased risk of stillbirth in the first place).

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[71] *Id.*

[72] *Id.*

[73] *Id.*

[74] *Id.* at 569.

[75] ARK. CODE ANN. § 20-16-201 (West 2015).

[76] N.J. STAT. ANN. § 26:8-40.29 (West 2018); *id.* at § 26:8-40.30. (West 2015).

[77] Lens, *Counting*, *supra* note 1, at 567.

[78] This would require creation by a state legislature to enable the registry to access medical records; state law is needed to allow disclosure under HIPAA. *See* 45 C.F.R. § 164.512 (HIPAA exception allowing disclosure to a "public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability").

C. Closing the Loophole

Fortunately, this is not necessarily a difficult fix to close this loophole for new data collection systems. The privacy mandates in SHINE are vague, but more specific language is obviously possible.

Fortunately, examples of possible required confidentiality mandates are plentiful. Language could be borrowed from congenital anomaly registries, the same registries that researchers believe stillbirth registries could be easily modeled on, also have possible language. Iowa's congenital abnormalities registry, for example, mandates that "information collected, used, or maintained" by the registry must be kept confidential "unless otherwise ordered by a court."[79] Similarly, Ohio law defines the records within the "birth defects information system" as "confidential medical records" and specifically limits access to specified persons.[80]

Similarly, Arkansas already has a stillbirth registry, named the Arkansas Reproductive Health Monitoring System. Arkansas law mandates that the registry is "expressly exempted and prohibited from supplying any information by individual name or other personal identifier or in a form other than a statistical report or other appropriate form which protects the confidentiality of individuals."[81] The only exception is for disclosure about an individual to a "state agency or department which originally supplied the information to the system unless both the originating agency and the system grant release of this information for a specific purpose."[82]

A new version of the SHINE Act could easily mandate the creation of legal privacy protections and confidentiality mandates, closing the loophole.

IV. CONCLUSION

The need to improve stillbirth data in the U.S. is long overdue, but it is admittedly not an ideal time to push for it. The word "surveillance" applied to anything having to do with reproductive health, right now, is scary.

It is important for those in stillbirth advocacy to recognize the potential harms in gathering data. But it is also important for those in the reproductive rights space to recognize the harm in not improving stillbirth data.

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[79] IOWA CODE ANN. § 136A.7 (West); *id.* § 22.7 (West).

[80] OHIO REV. CODE ANN. § 3705.32 (West).

[81] ARK. CODE ANN. § 20-16-207 (West 1985).

[82] *Id.* Perhaps surprisingly, New Jersey's stillbirth registry laws lack such specific privacy protections. The data gathered is to be kept in a database. The law dictates that the "data shall be made available to the public through the department website, except that no data shall identify any person to whom the data relate." N.J. STAT. ANN. § 26:8-40.30 (West 2015). The registry has never been funded, however, and no such database currently exists.

We can improve stillbirth data yet also ensure that the data does not further endanger those investigated for allegedly causing their child's stillbirth. We do so by ensuring sufficient, specific privacy protections are in place within any stillbirth data collection systems.