

POLICY INSIGHTS

Profiled from Birth, Vol. 1

Not Just a Birth Certificate

How states use birth certificates to collect data, conduct research and warehouse electronic health information

By Twila Brase*

Overview

A child's birth certificate is considered part of what state government calls "vital records," which are government records of life events such as birth, death, marriage and divorce. In the United States, most vital records are public documents, available for viewing by anyone.

In the past, a child's birth certificate was relatively simple, with basic data such as name and sex of child, name of mother and/or father, home address, name of hospital, city of birth, and date of birth. Today, however, the birth certificate is used to collect a significant amount of data on the child and the mother.

Our report discusses the history and purpose of the birth certificate, the process of registering births, the data collection forms, the data elements, and the research and analysis rationale used to justify collecting a broader set of data than the basic birth data necessary for simple registration of the birth.

We include comments from mothers concerned about the intrusive nature of the worksheets, as well as segments of laws and rules. We attach a state-by-state spreadsheet of the data fields we found on forms typically

Key Points:

- Parents don't know more data is being collected by the state than is necessary to register the birth of the child.
- Using the child's birth as an opportunity, states collect a wide array of data on children, mothers and families, such as education levels, race, behaviors, last employment and income.
- Data is used to conduct research and analysis without parent consent.
- "Birth Certificate Worksheets," labor, delivery, prenatal and mother's medical records are used to gather the data.
- One state allows parents to refuse to provide data not required for registration, but parents may not be told.
- Included in this report are suggested actions, and attached is a spreadsheet of data collected in 28 states and D.C.

Because it is unclear if parents have any right to restrict state data collection, tracking and research at the time of their child's birth, we include a list of actions...

called birth certificate “worksheets” and one state birth certificate worksheet. We limited our data collection to a state registration handbook, birth certificate worksheets from 27 states, the Centers for Disease Control and Prevention (CDC), and the District of Columbia.

As most of the public is unaware of the extensive data collection facilitated by the birth of a child, and because it is unclear if parents have any right to restrict state data collection, tracking and research at the time of their child's birth, we include suggested actions (p. 12) that parents can take to try to protect the child's and family's personal, medical and genetic privacy.

Same Certificate; Different Data

Using the vital registration handbook from Florida, and the birth certificate worksheets from 27 different states, the District of Columbia (D.C.) and the Centers for Disease Control and Prevention (CDC), we have accumulated at least 300 data fields.

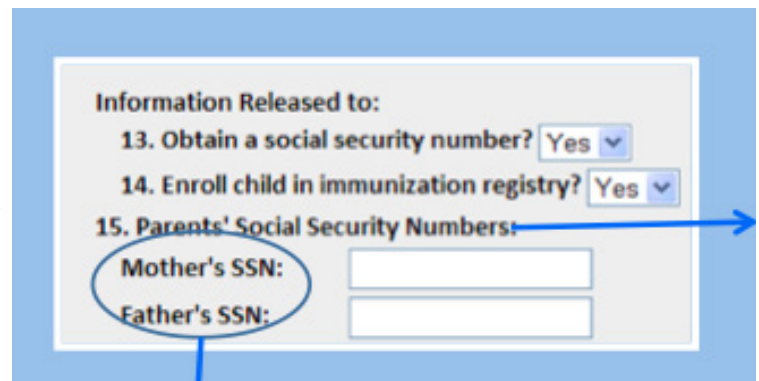
The state in which the birth occurs greatly determines the detail and type of data collected on each newborn, the birth mother, and other family members.

For example, the CDC worksheet suggests 166 data elements for collection, and 24 of the 28 states, plus D.C., record a “Mother's prepregnancy weight” for collection on the birth certificate following the CDC's recommendation. The same 24 states also record the “Mother's height” as suggested by the CDC. This likely means that these 24 states are using the mother's height and weight to record the mother's Body Mass Index (BMI) -- her level of obesity as defined by the CDC¹ -- before her pregnancy began. Although we did not secure a worksheet from Wyoming, the Wyoming Department of Health website explains the following regarding collection of “Mother's

Height”:

In combination with prepregnancy weight, mother's height is used to calculate the body mass index (BMI). Maternal BMI is associated with maternal morbidity and mortality. Maternal weight gain data are of little value without knowledge of maternal BMI.²

Wyoming, Idaho, Montana, New Mexico and Texas even use the birth certificate worksheet as a mechanism to enroll the child in the state's **immunization registry**. The following is a screenshot of one slide from the Wyoming health department's PowerPoint explaining how to fill out the worksheet:³



Some CDC suggestions are ignored. For example, of the 28 states and D.C., only 13 states are recording “Congenital Anomalies of the Newborn” on the birth certificate worksheet. Only seven of the 28 states are collecting data on whether the Home Birth was planned. And despite the CDC's recommendations, only 13 states collect data on whether the baby is still living and only 15 states record whether the baby was being breastfed at discharge.

On the other hand, many states collect data on the birth certificate that is not suggested by the CDC. For example, fourteen states record **alcohol use** during pregnancy. Worksheets from California, Georgia, Indiana, New Hampshire, New Jersey and New York capture the **last day the mother worked**. Fourteen states record whether the mother has **syphilis** or was treated for it during the pregnancy. New York does

fitness, depression, and “how did you feel about becoming pregnant?” assessments.

Vermont asks about **hearing loss** in the family of the mother or father. Georgia and Texas record whether mothers receive **vaccinations** during pregnancy. And Colorado is the only state of the 28 to record **household income**.

Data Used for Analysis and Research

Various state websites explain that they collect certain data at birth for research and analysis. For example, many states record a mother’s use of **tobacco**. The State of Wyoming explains why they collect this information:

Smoking during pregnancy has been determined to have an adverse affect [sic] on pregnancy outcome. This information is used to evaluate the relationship between certain lifestyle factors and pregnancy outcome and to determine at what levels these factors clearly being [sic] to affect pregnancy outcome.⁴

Wyoming also clarifies why the state requires hospitals to include data on the **education level** of the parents:

Education is highly related to fertility, health practices and pregnancy outcome. It is also used as an indicator of socioeconomic status.⁵

In addition, the State of Wyoming’s PowerPoint explains the rationale for requiring parents to pick a **race** for themselves and their child:

Race is essential in producing data for minority groups and is an important variable in planning for and evaluating the effectiveness of health programs. It is also used to study racial variations in childbearing, access to health care, and

pregnancy outcomes (perinatal mortality and birth weight).⁶

Meanwhile, although Iowa law states, “The state registrar may share information from birth certificates for the sole purpose of identifying those children in need of immunizations,”⁷ the Iowa Department of Public Health is using data from the birth certificate for the state **Environmental Public Health Tracking Program**, an initiative funded by the CDC:

Vital statistics data are used to estimate reproductive and birth outcome measures. Provisional data from the annual birth certificate is available within four to six months after the close of the file. Reporting may be delayed when a state resident gives birth out of state.⁸

Iowa also uses the birth certificate to conduct surveillance on mothers of newborns through a CDC-funded system called the **Pregnancy Risk Assessment Monitoring System (PRAMS)**:

The PRAMS sample of women who have had a recent live birth is drawn from the state’s birth certificate file. Iowa samples about 1,800 women per year. ... Data collection procedures and instruments are standardized to allow comparisons between states. One strength of the PRAMS surveillance system is the standardized data collection methodology. ...⁹

In many cases parents may feel they have little recourse but to submit to the data collection process. Wyoming, which rationalizes the data collection for **monitoring and analysis** purposes, claims the following to data submitters in their push to collect all the data listed on the birth certificate worksheet:

It is very important this worksheet is completed and signed, it provides all of the information to establish a birth record. If there are any questions unanswered you should get a response so the worksheet is complete.¹⁰

Wyoming requires hospitals to include the education level of the parents: “Education is highly related to fertility, health practices and pregnancy outcome.”

Its not really for the hospital, its for the state...kinda like the census they just gather data...so they can compile stats about births and people...

Unhappy Mothers

Some mothers have discovered and openly questioned the State's intrusion into their personal lives. The website BabyCenter.com includes a question from a mother who calls herself "babyeden2014," and the responses from more than two dozen other mothers. The following mother's question and responses were recorded on February 1, 2012:¹¹

babyeden2046:

Hi there, I know lots of you have brought your LO's [little ones?] home already so I wanted to ask your experiences on filling out LO's birth certificate. I was filling out the "Birth Certificate Worksheet" that my hospital sent home with me to bring in when I deliver, and aside from the usual questions on names, social #, place of birth etc, there were many questions that I thought were odd and fairly personal and were not important for filling out a birth certificate. Some of these questions include: date of last menstrual period, date of first and last OB appointments, if you recived [sic]WIC or any other forms of welfare, how many abortions you've had, how many living and deceased children you've had, how many miscarriages you've had and at how many weeks you had them, if you smoke or drank before and during pregnancy, if you've had various medical conditions like hep B, gestational diabetes[sic], group B strep, etc, race and education level of both parents and the list just goes on and on...

Some of this information would certainly be important for your Dr to know, but why does the hospital need to know it for my baby's birth certificate? I am planning on discussing this with the hospital staff of course, but I was wondering if this [is] common, as I've never had a baby before and am not familiar at all with hospitals. I live in California, if that makes any difference. Thank you in advance for your responses :)

IleaW:

Its not really for the hospital, its for the state..kinda like the census they just gather data...so they can compile stats about births and people living in that state. You dont have to fill out that stuff either

lillilanda:

I didnt give any of that info for my baby...

ab1212:

I live in Ohio and all of those questions were on mine too. Although we aren't married yet my boyfriend and I have been together for 8 yrs so all of the marital questions were somewhat comical for our situation, not to mention we had to sign an affidavit before we could list the baby's last name as his...at any rate I know how you feel the application requires too many details for something that should be simple.

luv2bean:

I have to agree those are really not needed.

I remember having to answer a question like - Do you own guns, and are they locked up at my OBGYN office, and I questioned how that was relevant to my baby.

krr4:

I'm in Florida. Didn't have to do that form, thank God! That's ridiculous!

sweetlovingmama:

I am in Kansas and none of that was asked.

8Dobsaya (in Michigan):

I have never in 8 deliveries been asked those personal questions.

veggieveg:

Same type of personal questions in Washington State. I think the state uses the info for statistics. [sic]

Luv2bean-the pediatricians office asked me about guns at least three separate times!

AgeofAquarius33 (in Oklahoma):

This was the first time (out of five children) that they had weird questions on the birth certificate form... They asked if I'm a smoker, and I forget what else. Then, they asked for permission to use the form for something... Don't think I filled it all out, but it was annoying.

Violet'sMoMMY (Labor/Delivery RN):

To the people who haven't had to answer those questions, I bet someone else is filling it out. At my hospital, it's the nurses job to fill out the birth certificate statistics sheet. We use the prenatal record to fill it out. It asks: how many children born alive and when the last live birth was, how many children born alive and now deceased, how many miscarriages/abortions and when the last one was, any std's, any pre-e, pih, chronic htn, diabetes, gest. diabetes, on meds for hiv, how many c/s. Then pertaining to this birth: weight, weeks gestation, apgar, any tocolysis, external version, if mom received steroids or antibiotics, epidural or spinal, had thick meconium, if it was an emergency c/s, delivery method, if a vacuum or forceps were used, if baby was admitted to the nicu, any defects, if baby is bf.

I have heard some other hospitals ask a lot of other questions. It is for the states statistics.

westernatheart:

i have had four babies never had to answer any of those questions .don't know if i would its none of their business !

BookWormCarrie:

I thought 14 pages was a bit excessive to get a birth certificate. I'm in NY.

Gathering Data Elements from States

Our research project began in July 2014 with phone calls to each state's Vital Records office, typically located in the state health department. We requested a copy of a blank birth certificate form. Department officials were not responsive to our requests. Staff either transferred our call to a supervisor or recommended that we contact the local hospital. Some asked that we provide our request in writing, which we did, but even then some departments never sent us the requested birth certificate form. In fact, we never got a copy of a blank birth certificate.

In response to these denials, we began calling hospitals in various states. Here the response rate was high. Hospitals were happy to send us what we needed, often sending it within an hour or less of our request. A few asked that we send our request in writing, which we did. But instead of a birth certificate we got what the staff often called the **"hospital birth certificate worksheet form."** This is the form the hospital uses to collect the data, which is then sent to the state's vital statistics office or used to input data online using the state electronic vital records system.

Although we contacted every state, due to time constraints, we limited our data collection to the first 27 states that responded, data from the Florida handbook for vital records registration, the District of Columbia (D.C.) and the Centers for Disease Control and Prevention (CDC). Our telephone requests elicited a variety of interesting responses. Here is a small sample:

- Montana's health department said that each hospital designs a template from the CDC to accommodate the needs of the hospital.
- One hospital told us their worksheet was available online, which is where we then found worksheets from other states as well.
- In a few cases, one hospital would deny

To the people who haven't had to answer those questions, I bet someone else is filling it out...It's the nurse's job.

A Texas hospital cited HIPAA as the reason for refusing to send us a blank form of their birth certificate worksheet.

the request and ask us to call the State Vital Records division, but another hospital in the same state would readily send the form.

- A Texas hospital cited HIPAA as the reason for refusing to send us a blank form.
- Hawaii officials refused to send the birth certificate because it is “property of the Department of Health.”
- An Arizona hospital said they weren’t “comfortable” sharing the form. When asked if there is a law against it, they were sure there was. Although the hospital said they’d send a copy of the law by email, they never did.

The Birth Registration Worksheet

The worksheet used to gather data after the birth comes in various forms and formats. For example, the worksheet given to parents from Memorial Hospital West in the state of **Florida** has only 34 data elements, including categories for information on the baby, the father, and the mother. Such data includes baby’s name, time of birth, mother’s last menstrual cycle, mailing address only for the mother, social security numbers for both parents, method of delivery, and educational level and race for both parents.

The Memorial Hospital West form, which we discovered online, is a blue-colored document labeled “BABY BOY,” which tells the parents the following: “This is a worksheet only. The information will be transferred to the actual birth certificate. Please complete every section and PRINT CLEARLY. Detailed instructions on how to complete this form are on the reverse side. If you have any questions or need assistance, please dial ext. 7298.”¹²

It asks parents not to leave the hospital without filling out the form. Prior to the signature, the

following is stated:

PATIENT’S ACKNOWLEDGEMENT

I HAVE READ AND UNDERSTAND THE FRONT AND BACK OF THIS WORKSHEET. I CERTIFY THAT THE PERSONAL INFORMATION PROVIDED ON THIS FORM IS CORRECT TO THE BEST OF MY KNOWLEDGE. IF AN ERROR OCCURS DUE TO THE INFORMATION GIVEN ON THIS FORM, THE STATE OF FLORIDA REQUIRES A FEE TO CORRECT THE BIRTH CERTIFICATE. MEMORIAL HOSPITAL WEST IS NOT RESPONSIBLE FOR ANY AMENDMENT FEES.

Sign Here X _____¹³

On the other hand, the **Arizona Certificate of Live Birth Worksheet** (4/23/2014) is six pages long with 76 data fields, but there is a signature line only on page one, and it’s only for the field in which the parent is asked, “Do you want a Social Security Number issued for your baby? Yes or No?” Thus, it is entirely possible that this is the only page of the six-page document that the mother or father may ever see.

Notably, if parents exhausted by the birth process noticed the small print disclosure on page one, they would read the following:

The state registrar may provide information contained in vital records to persons, including federal, state, local and other agencies, as required by law and for statistical or research purposes.

More Forms Than the Worksheet

It is quite possible that the data fields on the worksheet are not the only data collected at the

time of birth. It also appears that some states have a form they give to parents to complete and another form they use to gather data on the mother and child from other sources.

For example a **Washington** hospital sent us two forms. The *Birth Certificate Information Form* appeared to be the form given to parents to complete. It has only 44 data elements, including the question, “Would you like us to publish this birth?” in which a parent’s signature is required. The other form, called the *Washington State Birth Filing Form* (with the logo of the Washington Department of Health), has two pages. All data elements from the *Information Form*, except “Race of Infant,” were also on the Department’s form. Page 1 of the *Filing Form* has 33 elements, an “Optional Signature” and this statement: “*Only these items will be displayed on Legal Certificate. However all items are required by law (RCW 70.58.080).” Meanwhile page 2 has 35 additional data elements (34 – 69).

We also received a different state *Filing Form* from another Washington hospital. Page one was the same, but page two only had data elements 34 – 56 and 66 – 69. On the top of page two is the following statement “Medical Records will complete the following information.” And on the bottom of the form was the following:

Insurance: _____
 Verified (DSHS): _____
 Hep B: _____
 ___ given ___ not given ___ refused
 Filed: _____

In another example, **Florida** has a much more extensive data collection regimen than was contained in the Memorial Hospital West form we found online. Since we did not secure a worksheet directly from a Florida hospital, it is possible that the Memorial Hospital West worksheet was outdated. Nevertheless, what we discovered in the Florida handbook detailing birth registration was extensive data collection unrelated to the registration of births.

The *Florida Vital Records Registration Handbook* includes a very involved section of data collection for birth registration, administrative use, and medical and health research.

After the birth registration section, in a section called “For Administrative Use Only,” the registration handbook states, “*The following information is for administrative use only and is not part of any certification.*” The handbook then goes on to ask for information on social security numbers (as authorized by federal law), source of payment for delivery of the child (as an indication of socioeconomic status and birth outcomes), use of WIC, the Women, Infants & Children nutrition program (to improve pregnancy outcomes), transfer from another facility (to study transfer patterns), whether the child is still living and more.¹⁴

Florida’s vital records registration also includes a “Medical and Health Use Only” section, which by all appearances is completed without the knowledge or consent of the baby’s parents. The only times the word ‘consent’ is mentioned in the birth certificate section of the Handbook are related to getting consent from parents who are minors and consent for the state’s Healthy Start Program.

According to the Handbook, data collection under the medical and health section is specifically for research purposes using data collected on babies, mothers, and fathers despite seemingly no consent from the subjects of the data:

The information for medical and health studies are [sic] separated from the identifying information so that they can be excluded from certified copies of the certificate. They are used for a wide range of research and medical purposes.

Information obtained for this portion of the birth certificate should come from the physician’s prenatal record for the mother, labor and delivery records, neonatal unit records or other hospital medical records.¹⁵

It is quite possible that the data fields on the birth certificate worksheet are not the only data collected at the time of birth.

The government-issued birth certificate was generally a Progressive-era reform designed to generate more precise infant mortality numbers.

History of the State Birth Certificate

Prior to the 20th century there were no official birth certificates in America, although families often registered births with their church. The government-issued birth certificate was “generally a Progressive-era reform designed to generate more precise infant mortality numbers,” according to Shane Landrum’s extensive research on the history of birth certificates.¹⁶ The postwar welfare state made birth certificates “tools of social citizenship for the children of the Baby Boom.”¹⁷ For example, the military required birth certificates of children and a marriage license before dependents could receive health services.

State governments have been issuing birth certificates using a national model since the start of the 20th century. In 1902, Congress established the Bureau of Census as a permanent agency to develop birth certificates for registration of newborn citizens.¹⁸ States made their own decisions about birth registration. In Pennsylvania, the state health department began to issue birth certificates on January 1, 1906. Previously, they “were recorded only sporadically by the counties and some cities such as Philadelphia and Pittsburgh.”¹⁹ In 1914, a compulsory registration law was enacted in Georgia but it didn’t go into effect until 1919. The state supreme court struck it down as unconstitutional. A Georgia birth certificate law that apparently passed muster didn’t go into effect until 1927.²⁰

According to the *Journal of Perinatology* in 2012:

Although all states had birth records by 1919, the use of the standardized version was not uniformly adopted until the 1930’s. In the 1989 US Standard Birth Certificate revision, the format was finally uniformly adopted to include checkboxes to improve data quality and completeness. The

evolution of the 12 federal birth certificate revisions is reflected in the growth of the number of items from 33 in 1900 to more than 60 items in the 2003 birth certificate. As birth registration has moved from paper to electronic, the birth certificate’s potential utility has broadened, yet issues with updating the electronic format and maintaining quality data continue to evolve.²¹

In the early 1940s around 43 million Americans had no birth certificate. Meanwhile the Fair Labor Standard Act of 1938 required young workers to prove their ages before joining the paid labor market. After World War II, U.S. law began requiring birth certificates for certain industries, such as defense, which were prohibited from hiring people unless they could prove they were American. Thus, birth certificates became a standard of identification and proof of citizenship.

During a 1945 national Child Health Day celebration, communities publicized birth registration claiming, “a child’s birth certificate is his first and most valuable citizenship paper.”²² A year later, the task of designing the certificate was given to the U.S. Public Health Service,²³ today known as the U.S. Department of Health & Human Services (HHS).

The history of birth certificates also contains controversial identity politics. Documents from the state of Virginia reveal the 1927 “Act to Preserve Racial Integrity,” in which individuals had to disclose whether they were “white” or “colored.” There were no other categories. So those of indigenous descent – native-born Indians – had to choose one of the categories or go without a certificate of birth and citizenship. They were “vulnerable to the state’s attempts to document them out of existence,” reports Mr. Landrum, who says birth certificates were “powerful tools for government control over the categories of identity.”

Today, many state birth certificate worksheets include an array of race and ethnicity options.

Most of the data fields of the 28 states and D.C. include five Hispanic options and 15 or more race/ethnicity options. Arizona has an additional 21 Indian tribe categories, and South Dakota has another nine tribal options.

The Data Elements

The registration of births is a state function. The U.S. Centers for Disease Control and Prevention (CDC), a division of HHS, offers two templates for birth certificate data collection: the “Standard Certificate”²⁴ and the “Mother’s Worksheet.”²⁵ But the CDC does not require state compliance with either template.

A child’s birth certificate is considered part of “vital records,” which are government records of major life events such as birth and death registration, marriage licenses and divorce decrees. These records are often kept on file by the county of record as well as the state health department, typically in a division called “Vital Records” or “Vital Statistics.” The National Archives notes that vital records are “not considered Federal records” and therefore not kept by the federal government.²⁶ The CDC has a list of all state vital records offices.²⁷

The public may reasonably believe that a child’s birth certificate is limited to basic data such as name and sex of child, name of mother and father, home address, name and address of hospital, city and county of birth, and date of birth. That may have been true in the early years, however, as noted in the *New Republic*:

Nowadays, the birth certificate is an opportunity to capture information about prematurity, prenatal care, complications of delivery, obstetrical practices, and maternal risk factors such as obesity and smoking.²⁸

The breadth of data may not be obvious to parents or anyone else reading the state vital records laws. For example, as described above,

the official Washington State *Filing Form* records a total of 69 data elements. But state law in Washington (RCW 70.58) gives no such details:

Within ten days after the birth of any child, the attending physician, midwife, or his or her agent shall...Fill out a certificate of birth, giving **all of the particulars** required, including: (i) The mother’s name and date of birth, and (ii) if the mother and father are married at the time of birth or an acknowledgment of paternity has been signed or one has been filed with the state registrar of vital statistics naming the man as the father, the father’s name and date of birth. ... [Emphasis added.]

If there is no attending physician or midwife, the father or mother of the child, householder or owner of the premises, manager or superintendent of the public or private institution in which the birth occurred, shall notify the local registrar, within ten days after the birth, of the fact of the birth, and the local registrar shall secure the **necessary information** and signature to make a proper certificate of birth.²⁹ [Emphasis added.]

Furthermore, the Washington birth certificate, as in many states includes “public data” – available to the general public – and “confidential data” – available only to the subject of the data, as well as to the government and other entities allowed to receive it as permitted by state law. But if a parent asks for a copy of the child’s birth certificate, the data from the confidential or private section may not be provided.

The **public section** of Washington’s birth certificate (WAC 246-491-149) includes the table of data found on the next page.³⁰

The confidential or **private section** contains numerous data fields into which hospital staff or parents willingly or unwittingly enter substantial data on the child, the mother and the father before their discharge from the hospital

The public may think that a child’s birth certificate data is limited to basic data such as name and sex of child, name of mother and/or father...

Data on both the public and private sections of the birth certificate are sent to the state health department for processing and collection.

Child's name	Child's date of birth	Time of birth	Type of birthplace including if "enroute" to facility and if actual birthplace was different than planned birth place	Child's sex
Name of facility	City, town or location of birth	County of birth	Mother's name before first marriage	Mother's date of birth
Mother's birthplace	Mother's Social Security Number	Mother's current legal last name	Social Security number request for child?	Mother's residence Number, street, and Apt No.
Mother's residence - city or town	Mother's residence - County	Tribal reservation name (if applicable)	Mother's residence-State or foreign country	Mother's residence-Zip code + 4
Mother's residence-Inside city limits?	Telephone number	How long at current residence?	Mother's mailing address, if different	Father's current legal name
Father's date of birth	Father's birthplace	Father's Social Security number	Certifier name and title	Date certified
Attendant name and title	NPI [National Provider ID] of person delivering the baby			

Data Collected for Washington State Birth Certificate - **Public Section** (Table by CCHF)

or birthing center. Data on both the public and private sections of the birth certificate are sent to and stored by the state vital records office.

and fetal death certificates; modifications to the United States standard certificates and report forms

Washington State treats the confidential data according to the following state regulations:³¹

...(3) Tables 1 and 2 list the statistical information contained in the confidential sections of the birth and fetal death certificates that the board requires the department to collect, and the differences

WAC 246-491-029 Information collected on the confidential section of live birth

Is mother married to the father?	If no, was mother married to anyone during the pregnancy? Has the paternity affidavit been signed?	Mother's education, with "Specify" for "8 th Grade or less"	Mother of Hispanic origin?	Mother's race
Mother's occupation	Mother's kind of business/industry	Father's education, with "Specify" for "8 th Grade or less"	Father of Hispanic origin?	Father's race
Mother's medical record number	Mother's pre pregnancy weight	Mother's weight at delivery	Mother's height	Did mother get WIC food for herself during pregnancy?
Cigarette smoking before and during pregnancy	Number of previous live births	Date of last live birth	Number of other pregnancy outcomes	Date of last other pregnancy outcomes
Date of first prenatal care visit	Date of last prenatal care visit	Total number of prenatal visits for this pregnancy	Date last normal menses began	Was mother transferred to higher-level care for maternal medical or fetal indications for delivery?
Newborn medical record number	Birth weight	Infant head circumference	Obstetric estimate of gestation	Apgar score at 5 min; if score is less than 6, score at 10 minutes
Plurality	If not single birth born 1 st , 2 nd , 3 rd , etc.	Was infant transferred within 24 hours of delivery?	Is infant living at time of the report?	Is infant being breastfed?
Risk factors in this pregnancy, including whether Group B Streptococcus culture positive	Method of delivery	Infections present and/or treated during this pregnancy, including HIV infection and "Other: Specify"	Obstetric procedures	Abnormal conditions of the newborn
Characteristics of labor and delivery	Congenital anomalies of the newborn	Maternal morbidity	Onset of labor	

Data Collected for Washington State Birth Certificate - **Confidential Section** (Table by CCHF)

between the state and U.S. Standard. ...

WAC 246-491-039 Confidential information on state of Washington live birth and fetal death certificates under chapter 70.58 RCW

1. The confidential sections of the certificate of live birth and the certificate of fetal death are not subject to public inspection and may not be included on certified copies of the record except upon order of a court, or as specified in subsection (2) of this section.

2. An individual who is the subject of the birth certificate may request the confidential information from that individual's birth certificate. ...

(d) The department shall, upon receipt of a request in compliance with (a) through (c) of this subsection, provide to the individual the following items, as available from their birth certificate.

- i. Newborn medical record number;
- ii. Birth weight
- iii. Infant head circumference;
- iv. Obstetric estimate of gestation;
- v. Apgar scores;
- vi. Infant transferred within twenty-four hours of delivery
- vii. Abnormal conditions of the newborn; and
- viii. Congenital anomalies of the newborn

This regulatory list of permitted sharing of an individual's confidential data with the individual who is the subject of the data does not appear to be a complete sharing of the data collected. Our table on page 10 provides the confidential data collected on Washington State's birth certificate

(“Confidential Birth Certificate Items”):³²

Given the wording of the regulation, it's also not clear that the mother of the child is allowed to see any of the data collected on her by the state.

Can Parents Refuse?

This report does not detail state birth certificate laws, however during our research, we discovered a protective option in Minnesota. Mothers can refuse to answer questions.

Under Minnesota law, the commissioner of health (designated as the state registrar) has the authority to determine the data content of the birth certificate. In *Minnesota Rules*, in the section written by the Minnesota Department of Health under the authority of the commissioner, parents are allowed to try to limit data recorded on the Minnesota *Documentation of Birth* form:

Birth Registration - Information Required

...The state registrar may waive a birth information requirement if the person filing the birth record can demonstrate that:

- 1. the information is not available through reasonable inquiries;
- 2. providing the information endangers the safety of the mother or child;
- 3. *the mother of the child refuses to provide the information;* or
- 4. the services of a health care provider were not used for prenatal care or delivery. [Emphasis added.]

The following information must be provided:

- 1. date and county of birth;
- 2. child's sex;
- 3. birth order if multiple birth; and
- 4. first name, middle name, and maiden surname of mother.³³

Given the wording of the regulation, it's also not clear that the mother of the child is allowed to see any of the data collected on her by the state.

Parents may be informed about the collection of data for research, but not given the option to refuse: “Giving wrong information...is against the law.”

In short, if the hospital is unable to find the non-required data elsewhere, mothers of newborns can refuse to divulge that data, preventing it from being filed with the State of Minnesota. But only if the mothers know.

Parents may be informed about the collection of data for research, but not given the option to refuse. For example, Iowa’s *Official Worksheet to Establish Legal Certificate of Live Birth* (dated Oct. 2007) tells parents that data is being collected for health studies by researchers, but then states: “Make sure you answer all the items on this worksheet. Truthful information now means that your baby will not have problems in the future. Giving wrong information on purpose for this legal record is against the law.”

Electronic Birth Registration

Many hospitals today file birth registrations electronically. For example, Florida’s birth registration handbook states, “Although the majority of Florida’s birth and death records are filed electronically, there are a few paper records still being filed.³⁴ Florida’s website provides the following explanation of the electronic process:

Electronic Birth Registration (EBR) is the mechanism by which births are registered via a secure Internet connection. It is designed to allow a hospital birth registrar to electronically enter and register a birth record, and capture and store any required signatures. This innovative technology eliminates the need for hospitals to forward original hard copy birth records to county health departments.

Registered users log on through their local Internet provider and enter the data directly into the state database. There is no cost for the organization and no limitation on the number of concurrent users.

In order to ensure a record is filed for every delivery, and that no fraudulent record is filed, the birth registrar will fax the local county vital statistics office, a labor and delivery log for reconciliation against the records entered into the database.³⁵

Meanwhile, as noted by the *Journal of Perinatology*, state transition to electronic birth certificates has facilitated data collection and other uses of the data. For example, the Minnesota Department of Health’s report and grant request to the Maternal Child Health Bureau under Title V listed a plan to “Implement linking bloodspot³⁶ and hearing data with birth/death certificates.”³⁷ In addition, the state discussed plans to use birth certificates to build research projects:

Supported by the SSDI [Social Security Disability Insurance] grant, the Departments of Health and Human Services are proceeding with linking Pregnancy Risk Assessment Monitoring System (PRAMS) data with matched Medicaid claims and **birth record data** to inform future research in Maternal and Child health outcomes, program/policy evaluation, and data quality. Title V staff have had significant input into the development of study questions, study design and dataset parameters.³⁸ [Emphasis added.]

Taking Action

Parents are the primary protectors of their children and their family’s privacy.

Simply knowing that government officials are using the occasion of a child’s birth to collect private data for government research and other analyses without parent consent gives parents an opportunity to take action.

Here are a few options and suggested actions in no particular order of importance:

Limiting Data on the Birth Certificate:

- Check state statutes and regulations for any data requirements for birth certificates (see previous Washington state example).
- Determine whether parents have a right to limit the data collected (see previous Minnesota example).
- Refuse to answer lifestyle and behavior questions at clinic and the hospital.
- Refuse to allow clinics and hospitals to use a health information exchange (HIE) to access other medical records.
- Request that the hospital only include on the birth certificate the basic data necessary to establish a record of the birth (e.g. name, sex, date of birth, mother’s name, address, state and county of birth and name and address of hospital).
- Ask for the hospital’s birth certificate worksheet to review the data fields.
- Ask if the form provided for data collection is the only form or document to be sent to the state to register the child’s birth.
- Politely refuse to answer questions that go beyond data needed to register the birth.
- Once basic registration data is entered on the form and the form is signed, cross out other data fields.
- Refuse to sign the birth certificate if private data other than basic data is included — unless the additional non-registration data is *required by state law* (require the hospital to cite the law or rule) *and* the hospital has the data on file.
- Request a copy of the signed birth certificate form after it has been signed.
- A month after the birth, request a copy of the child’s medical record from the hospital to verify that the form was sent to the state with only the data that was on it when it was signed — and that it was the only form sent to the state.
- Request a complete (public and private) copy of the child’s birth certificate from the State.
- Share birth certificate experiences with us: info@cchfreedom.org.

Legislative Action:

- Share personal birth certificate experiences with state legislators. Most don’t know about the state’s extensive collection of data on parents and children at birth.
- Ask state legislators for a law similar to or better than the Minnesota rule, which allow hospitals to limit birth data collection if parents refuse to share more data than is required simply to register the birth.
- Remember that the HIPAA “privacy” rule does NOT protect privacy. It’s a disclosure rule, potentially allowing 2.2 million entities,³⁹ plus government, to access and share your medical data without consent.
- NOTE: State legislators are allowed under HIPAA to write true privacy laws that actually protect medical privacy.

Birthing Choices:

- Contact birthing centers and hospitals to ask for a list of the data they send to the state.
- Contact midwives to ask for a list of the data they send to the state.
- If choosing to give birth outside of the hospital, consider a private, unaffiliated midwife or doula (not hospital- or health system-based). Request that only basic data be sent to the state for birth registration.
- Refuse newborn hearing screening and choose private testing for newborn (genetic) screening – contract with a laboratory (more info at www.itsmydna.org) instead of using the state newborn screening program which uses hospitals to prick the baby’s heel and send the blood to the state. Some states record the child’s hearing screening on the birth certificate, and some states store, use and share the newborn’s blood (Baby DNA) without parental consent.
- Put data and testing requests in writing. Ask that the signed letter be added to the clinic and hospital record—but do not count on the staff reading or remembering the written requests. Many staff do not understand the privacy implications. Parents must maintain awareness to protect their family’s privacy.

Refuse newborn hearing screening and choose private testing for newborn screening... Some states record the results and some store, use & share the baby’s blood (DNA).

Conclusion

States are using the occasion of a child's birth to collect extensive information on the child, the mother and the family. As required by state law and regulations, hospitals, birthing centers and midwives are collecting personal data for the government through the birth certificate and birth registration process. The data collected goes far beyond the basic information necessary to register the birth of a child. Once collected, this very personal data is being used by states for research, health studies and analysis of babies, mothers and families.

Parents may not know the extent of the data collection or the state's research and analysis initiatives. They may unwittingly assist in the data collection or if they do know, they may feel powerless at this vulnerable time in life to stop the collection of the data.

Now that the extensive data collection and unconsented research initiatives have been exposed by this report, we encourage parents, the public and state legislators to take decisive action to protect children and families from this intrusion, including but not limited to the action suggestions listed in this report.

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We wish to thank the hospitals around the country that graciously responded to our requests for this information.

APPENDICES

- "State of Colorado Birth Certificate Worksheet"
- "Birth Registration Data 2014" spreadsheet

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