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Foreword

The Congenital Malformations Registry (CMR) of the New York State Department of Health has prepared this handbook to provide hospitals and other healthcare facilities with complete information for submitting case reports to the Registry. This handbook contains documents on policy issues within the Department and reporting information to ensure completeness and accuracy in the preparation of reports.

New materials and updated information will be sent as needed in order to assist those responsible for submitting reports to the Congenital Malformations Registry and to improve the quality of Registry data. This handbook is provided for your convenience in keeping Registry information together as a handy reference.

We are interested in your comments and suggestions concerning this handbook and information you would like to receive in the future. Please email any comments or suggestions to us at cmr@health.ny.gov.
The Congenital Malformations Registry (also known as the Birth Defects Registry) of the New York State Department of Health is located in the Bureau of Environmental and Occupational Epidemiology, which is in the Department of Health’s Center for Environmental Health.

**Bureau Director:** Neil Muscatiello, PhD, MPH

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**Website:**

Further information can also be found on the NYS Department of Health’s website at [http://www.health.ny.gov/birthdefects](http://www.health.ny.gov/birthdefects).
General Information

About Birth Defects

Every 4.5 minutes, a baby is born with a birth defect. Major birth defects are conditions present at birth. They include structural changes in one or more parts of the body and biochemical abnormalities that lead to illness. They can have a serious, adverse effect on health, development, or functional ability. The possible association between environmental contaminants and human health problems is an important concern.

- In the U.S., 3% (one in 33) live births have a major structural or genetic birth defect.
- In New York State, close to 12,000 infants are reported to the CMR every year with birth defects.
- Hospitalization costs due to birth defects are disproportionately high, accounting for 3% of all hospitalizations and 5.2% of total hospital costs. In 2013, hospital costs in the U.S. for birth defects totaled $22.9 billion.
- Birth defects are responsible for 20% of infant deaths in children less than one year of age - causing one in every five deaths.
- Effects of birth defects can range from mild to severe and can result in debilitating illness, long-term disability or death.
- Defects of the heart are the most common kind of birth defect and cause most of the hospitalizations.
- Causes of most birth defects are unknown.
- New Yorkers are concerned about the possible association between birth defects and environmental contamination.

Why the Registry is Important for Public Health

The New York State Congenital Malformations Registry (NYS CMR) is the best statewide source of information about congenital malformations in children born or residing in NYS, and it is the second largest statewide population-based birth defects registries in the nation. By monitoring routinely collected reports, public health staff are able to identify and investigate unusual patterns of congenital malformations throughout NYS and study suspected causes of certain conditions. Analysis of CMR information helps public health scientists understand the frequency, variety and pattern of congenital malformations in NYS. This information is used to:

- Identify changes in malformation rates over time that may signal a change in women’s health, environmental conditions, and other factors.
- Identify geographical areas with consistently high rates.
- Provide summaries and tables to the public, health providers, local health departments, and others, upon request.
- Efficiently investigate reports of unusual numbers of malformations.
- Ensure that families of children identified in the Registry locate available resources so that each child can maximize his or her development.
- Identify families of children with specific malformations who may be invited to participate in research studies.

On the New York State Department of Health website, the CMR publishes birth cohort reports that summarize malformations by type, organ system and county. The demographics of children with reported malformations are summarized. Comparisons are also made with birth defects prevalence rates in other states. Additional information about the prevalence of birth defects in New York State are available through the Environmental Public Health Tracker or the birth defects section of the
Health Data NY open data repository. These data and reports serve as resources for healthcare programs and professionals providing preventive healthcare and delivering services to affected children and their families. A number of health research studies using registry data have been published. A bibliography and copies of articles that use CMR data are available. In addition, information about causes and prevention of birth defects, as well as resources for families and professionals, is available on the CMR's webpage.

The CMR partners with patient advocacy organizations, such as Spina Bifida Association, Cleft Palate Foundation, and Little Hearts, to connect families of affected children to services and resources. We also collaborate with NYS Perinatal Association, NY Chapter of American College of Obstetrics and Gynecology and American Academy of Pediatrics on the topic of birth defects prevention.

**How the Registry Obtains Information**

Hospitals (as defined in Article 28 of Public Health Law, see below), physicians, nurse practitioners qualified to diagnose birth defects, physician assistants qualified to diagnose birth defects and midwives throughout NYS are required by law to report children born or living in NYS who have been diagnosed before two years of age with major congenital malformations. For certain birth defects, reporting is required for children diagnosed before ten years of age. In 2016, birth defects diagnosed in a fetus also became reportable. The majority of reports in the Registry are currently submitted by hospitals, from whom we request both inpatient and outpatient information. In the near future, changes will be made to the CMR application on the Health Commerce System which will allow physicians and other healthcare providers to report electronically as well, and to accommodate reporting of non-liveborn fetuses with birth defects. Clinical laboratories also report to the DOH when test results confirm diagnosis of a birth defect.

"Hospital" means a facility or institution engaged principally in providing services by or under the supervision of a physician or, in the case of a dental clinic or dental dispensary, of a dentist, for the prevention, diagnosis or treatment of human disease, pain, injury, deformity or physical condition, including, but not limited to, a general hospital, public health center, diagnostic center, treatment center, dental clinic, dental dispensary, rehabilitation center, nursing home, chronic disease hospital, maternity hospital, out-patient department, out-patient lodge, dispensary and a laboratory or central service facility serving one or more such institutions.

**How Information is Kept Confidential**

DOH staff rigorously secure and protect all Registry information in order to maintain and uphold a high level of privacy and confidentiality. Access to Registry information is restricted and carefully monitored so that the identity of children and families is not disclosed. The NYS Department of Health’s Institutional Review Board for the Protection of Human Subjects must approve any research projects for which families are contacted. If a child is adopted, neither the birth parents nor the adoptive parents are contacted. When information is provided to communities to help them plan for services, no names are attached to the information.

**Why the Registry Collects Stillbirth Reports**

A stillbirth is defined as a spontaneous intrauterine fetal death occurring at 20 or more weeks gestation or 350 or more grams delivery weight with unknown gestational age. Stillbirth is a much understudied outcome and results in considerable emotional and psychological impact for affected families. There is very limited population-based surveillance data. Birth defects surveillance systems
are in a good position to include stillbirth surveillance because: 1) they have an established surveillance system and 2) many stillbirths have birth defects. Reporting of stillbirths will thus provide more complete information on the occurrence of birth defects.

**Pertinent Public Health Laws and Regulations**

The Congenital Malformations Registry (CMR) was established as part of the Environmental Disease Surveillance Program in 1981, by enactment of Part 22 of the New York Sanitary Code. Part 22.1 stipulates that every hospital and physician shall submit a supplemental report of spontaneous fetal death. Part 22.3 stipulates that every physician and hospital in attendance on an individual diagnosed within two years of birth as having one or more congenital anomalies, shall file a supplementary report with the State Commissioner of Health within 10 days of diagnosis.

Data collected by the CMR are, by law, to be used for surveillance and to facilitate epidemiologic research into the prevention of environmental diseases, as prescribed by Public Health Law 225(5)(t). provides for scientific research and surveillance to reduce morbidity and mortality. Confidentiality of all data reported to the Registry is strictly maintained by Department of Health staff and rigorously safeguarded by Section 206(1)(j), which specifically prohibits the release of personal identifiers. Families of children reported to the CMR are never contacted for research without prior consent of the Departments of Health’s Institutional Review Board. If a child is adopted, the family is not contacted.

**Public Health Law: Article 2; Title 1:**

**Section 206 – Commissioner’s General Powers and Duties**

1. The Commissioner shall:

   (j) cause to be made such scientific studies and research the furnishing of such information to the commissioner, or his authorized representatives, shall not subject any person, hospital, sanitarium, rest home, nursing home, or other person or agency furnishing such information to any action for damages or other relief. Such information when received by the commissioner, or his authorized representatives, shall be kept confidential and shall be used solely for the purposes of medical or scientific research or the improvement of the quality of medical care through the conduction of medical audits. Such information shall not be admissible as evidence in any action of any kind in any court or before any other tribunal, board, agency or person.

The statutory authority for Part 22 is Section 225(5)(t) of the Public Health Law.

5. The Sanitary code may:

   (t) facilitate epidemiological research into the prevention of environmental diseases, when such research is conducted pursuant to paragraph (j) of subdivision one of section two hundred six of this chapter, by establishing regulations designating as environmentally related diseases those pathological conditions of the body or mind resulting from contact with toxins, or teratogens in solid, liquid or gaseous form, or in the form of ionizing radiation or nonionizing electromagnetic radiation, and by requiring the reporting of such diseases or suspected cases in such diseases to the department by physicians, medical facilities and clinical laboratories. Any information provided to the department pursuant to such regulations shall be in the form required by the department and shall be kept
confidential and used by the commissioner pursuant to the provisions of paragraph (j) of subdivision one of section two hundred six of this chapter, and other applicable laws relating to the confidential treatment of patient and medical data.

**Codes, Rules and Regulations: Chapter 1**

State Sanitary Code: 10 NYCRR Part 22 – Environmental Diseases

§ 22.1 Supplementary reports of spontaneous abortions and fetal deaths for epidemiologic surveillance; filing. Every physician and hospital shall file a supplemental report with the State Commissioner of Health of each spontaneous abortion or other fetal death occurring naturally. Such report shall be filed within 10 days of the occurrence of such event on such forms as may be prescribed by the commissioner to facilitate epidemiologic investigation and surveillance.

*Revisions below took effect on May 25, 2016:*

§ 22.3 Supplementary reports of certain birth defects for epidemiological surveillance; filing.

(a) Every physician, nurse practitioner authorized to diagnose birth defects, physician assistant authorized to diagnose birth defects, midwife, and hospital as defined in Article 28 of the Public Health Law, providing health care to a pregnant woman or a child under two years of age, who diagnoses an embryo, fetus or child as having one or more of the birth defects listed in Table 1* of this section shall file a supplementary report with the State Commissioner of Health within 10 days of diagnosis thereof.

(b) Every physician, nurse practitioner authorized to diagnose birth defects, physician assistant authorized to diagnose birth defects, midwife, and hospital as defined in Article 28 of the Public Health Law, providing health care to a pregnant woman or a child under ten years of age, who diagnoses an embryo, fetus or child as having one or more of the birth defects listed in Table 2* of this section shall file a supplementary report with the State Commissioner of Health within 10 days of diagnosis thereof.

(c) Every clinical laboratory that conducts diagnostic testing on New York State residents to detect or confirm the diagnosis of genetic or chromosomal anomalies listed in Tables 1* and 2* shall, upon detecting or confirming such a genetic anomaly, file a supplementary report with the State Commissioner of Health within 30 days of detection or confirmation.

(d) Such report shall be on such forms, which may include electronic forms, as may be prescribed by the commissioner to facilitate epidemiological investigation and surveillance.

*The ICD-10 Reportable Congenital Malformations Coding Manual should be referenced for the most up to date tables of reportable congenital malformations.*
Section 2733 of the Public Health Law

1. Birth defects and genetic and allied diseases shall be reported by physicians, hospitals, and persons in attendance at birth in the manner on and such forms as may be prescribed by the commissioner.

2. Such reports and information shall be kept confidential and shall not be admissible as evidence in an action or proceeding in any court or before any other tribunal, board, agency or person. The commissioner may, however, publish analyses of such information from time to time for scientific and public health purposes, in such manner as to assure that the identities of the individuals concerned cannot be ascertained.

Pertinent Sections of the Health Insurance Portability and Accountability Act of 1996 (HIPAA)

The Congenital Malformations Registry (CMR) is authorized by Public Health Law 225(5)(t) to collect data for the purposes of surveillance and epidemiologic research. Public Health entities are exempt from the HIPAA-related Privacy Rule. Reporting to the CMR, therefore, is included under section 164.512(b) of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Under 45 CFR §164.512(b) of the HIPAA Privacy Rule, covered entities may disclose protected health information without authorization to public health authorities that are authorized by law to collect such information for public health purposes.

§ 164.512 Uses and disclosures for which an authorization or opportunity to agree or object is not required.

(a) Standard: Uses and disclosures required by law. (1) A covered entity may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.

(i) 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, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions; or, at the direction of a public health authority, to an official of a foreign government agency that is acting in collaboration with a public health authority.
Reporting Requirements

**Who must report birth defects diagnosed in a fetus, embryo or child:**

Hospitals, physicians, nurse practitioners qualified to diagnose birth defects, physician assistants qualified to diagnose birth defects and midwives providing health care to a pregnant woman or child are required to submit reports for any birth defects diagnosed in a fetus or embryo of a woman living in New York State or a child under age two years born or living in New York State. For certain birth defects, reporting is required for the child if diagnosed before ten years of age. For purposes of this registry, a congenital malformation is defined as any structural, functional or biochemical abnormality determined genetically or induced during gestation and not due to birthing events. This includes newborns and pediatric patients with a birth defect even if they are transferred to or from another hospital. Any child with a congenital malformation who dies in the hospital (inpatient or emergency room) is included. A stillborn or other non-liveborn fetus diagnosed in either a hospital or outpatient setting is also included.

**What to Report:**

All major malformations in the NYS CMR ICD-10 Coding Manual: List of Reportable Congenital Malformations, a separate document. If a child has one or more major malformation, please also report all minor malformations the child has as well.

The ICD-10 Coding Manual contains a complete list of all conditions reportable to the CMR. The file is accessible through the CMR reporting application on Health Commerce System under the ‘Resources’ tab. It is also located on the CMR web page and may be downloaded by going to https://www.health.ny.gov/diseases/congenital_malformations/docs/icd.pdf. The ICD-10 Coding Manual includes the following information:

1) ICD Code - The ICD-10-CM (effective October 2015) and/or ICD-9-CM code that corresponds to the child’s condition.

2) Description - Lists the standard narrative birth defect description(s) and may provide specific directions (e.g. must specify, female only, male only, birth weight criteria, etc.)
   - All major malformations and stillbirths must be reported
     - Minor anomalies, descriptions with an (m) (e.g. (m) ankyloglossia), are only required to be reported if the child also has one or more major malformations or was stillborn.
   - Some birth defects are only reportable if the child is a certain sex or was born above a certain birth weight. Please only report them if they meet the given criteria or the criteria is unknown. Examples:
     - Only report patent ductus arteriosus (PDA) if the child’s birth weight is 1,500 grams or greater. PDA is normal and necessary as a fetus develops and should close at birth.
     - Only report K40-, inguinal hernia, for female children
   - Please include as much specific detail from the medical record as possible for each defect
     - Indicate the laterality if applicable (e.g. talipes equinovarus, left)
     - Avoid reporting vague descriptions starting with “Other” or those with codes ending in -8 or -9
     - Add more specificity if you see ‘(must specify)’ next to an ICD-10 Description

Narrative descriptions are required for all birth defects!
Detailed information on the birth defect is required: All reported malformations will require a specific narrative description of the birth defect. The reason we require this is because often several different defects with different causes are grouped under the same ICD code. When the Registry receives reports, we recode the information provided in the narrative descriptions into a coding system with more specificity. Thus, a general diagnosis is not sufficient, and the report will be queried because of lack of specificity. Examples of general diagnoses are ICD-10 codes Q24.9 “Congenital malformations of heart, unspecified,” Q35.9 “Cleft palate, NOS,” Q27.2 “Congenital malformation of renal artery, NOS,” as well as all other ICD-10-CM codes with NEC, NOS and “Other” in the description of the malformation. When these diagnoses are received, the reporter will receive a query from Registry staff requesting more information.

Genetic studies: Report results of genetic testing or the name of the genetic laboratory that performed the test.

Anomalies of indeterminate sex: Report these birth defects with results of chromosome/ genetic testing or with the name of the genetic laboratory that performed the test.

Unconfirmed, pending and “rule-out” diagnoses: Please indicate if there is uncertainty surrounding the diagnosis using one of these terms. Include the name and address of the pediatrician or pediatric clinic where the child will be followed.

New diagnoses identified in subsequent inpatient or outpatient admissions/ambulatory surgeries/emergency department visits: Each child needs to be reported only once unless additional anomalies are found.

Syndromes and conditions that usually include several defects together: When conditions such as Fetal Alcohol Syndrome (FAS) and Tetralogy of Fallot (TOF) are reported, all associated anomalies should also be reported. This would include any abnormal facial features associated with FAS. With TOF, ventricular septal defects, pulmonary stenosis or atresia, dextrorotation of aorta, and hypertrophy of right ventricle should all be reported.

When to Report:

According to public health regulations, a birth defect diagnosed in a child must be reported within 10 days (of diagnosis) by a hospital or physician. To make reporting less burdensome, for inpatient visits, these defects in a maternal or child’s medical record should be reported within 30 days of discharge from a hospital unless the facility submits cases through the monthly file upload process. For outpatient visits, these defects in a maternal or child’s medical record should be reported within 30 days of visit. When a child with a birth defect has not been reported within these time periods, the hospital is out of compliance.

Failure to Comply with Reporting Requirement:

Failure to comply with requirements to submit data to the CMR as mandated by Section 2733 of the Public Health Law may result in the State issuing your facility a Statement of Deficiency.

How to Report:

Send reports over the Internet using the New York State Department of Health’s (NYSDOH) Health Commerce System (HCS) (see Online Reporting section).
Frequently Asked Questions

Who Should Report/When to Report

Q: My facility no longer delivers babies; do we have to report to the CMR?
A: If your facility continues to treat children 10 years of age or younger, then you must report cases of birth defects to the CMR.

Q: A child was born at our facility, but his parents live in New Jersey, do we have to report his birth defect?
A: If a child is either born or lives in New York State, then they must be reported to the New York State CMR.

Q: A child was not born at our facility, but was born in NYS or resides in NYS, do we have to report his birth defect?
A: Yes, all hospitals in NYS are required to report any new birth defect diagnosis for a child who was either born in NYS or who lived in NYS before they were 2 years of age, regardless of their birth hospital.

Q: This child has had several admissions to our facility; do we need to report the child to the CMR each time s/he is admitted?
A: A child with a specific birth defect must be reported after he/she is diagnosed or first seen at your facility. If, on subsequent admissions, the child is diagnosed with that same defect and no others, then you do not need to report that child again. However, if on subsequent admissions additional birth defects are diagnosed, then the child must be reported again and each time a new diagnosis of a birth defect is made. Previously reported birth defects for the child should not be reported again.

Q: A child was just admitted who was transferred from another facility. That facility reported the case to you, do we have to also?
A: Yes, every facility that treats a child with a birth defect must send in a report for that child regardless of where else the child has been treated.

Q: My hospital/healthcare facility has not reported cases before, but we have cases to report. Can we report?
A: Yes, you can. Please see sections on requesting HCS access and online reporting. If you experience any difficulty, please email cmr@health.ny.gov for assistance.

Q: How long from the date of discharge do I have to report a child to the CMR?
A: According to public health regulations, a child with a birth defect must be reported within 10 days (of diagnosis) by a hospital or physician. To make reporting less burdensome, children should be reported within 30 days of discharge from a hospital. When a child with a birth defect has not been reported within these time periods, the hospital is out of compliance.
Q: Do laboratories have to report to the Registry?
A: Laboratories are required to report positive results indicating presences of a birth defect to the Registry. They report electronically through the NYSDOH’s Electronic Clinical Laboratory Reporting System (ECLRS).

Q: Is a child reportable if there is no real address information and hospital of birth is unknown?
A: Yes, the child is reportable. Enter street address: Unknown; City: Unknown; State: blank; ZIP 99999

How to Report

Q: How does our new employee obtain access to the Health Commerce System to report to the CMR?
A: Refer to the section in this handbook entitled “Obtaining Health Commerce System (HCS) ID and Password.”

Q: How do I report if my hospital merged with another hospital?
A: Each hospital with a permanent facility identification (PFI) number should continue to report under its own PFI number. If you need access to the CMR to report for another hospital, please refer to the requesting HCS access section.

Q: If my healthcare organization is reporting for several different facilities with different PFI numbers, can reporting be done under just one PFI or must the PFI numbers reflect the location where the patient with a birth defect was seen?
A: The PFI number for a respective patient with a birth defect should reflect the facility that provided the care to allow effective monitoring of reporting timeliness and completeness.

Q: I’m having trouble reporting in the HCS, but my colleague’s account works fine. Is it okay if I use his/hers?
A: It is important that you log into the HCS as yourself when reporting to the CMR. Do not report under someone else’s name. Instead, please contact us at cmr@health.ny.gov if you are having issues and if we can’t resolve the problem we will point you to someone who can help.

Filling in the Fields/Correct Information to Use

Q: When submitting a routine confidential case report to the CMR, should we fill out everything or just the fields which are mandatory?
A: We ask that you fill out as many fields as possible. Most of the information can likely be found in the chart. We realize, however, that there are circumstances where you may not have all the information. For example, if the child was not born at your hospital, you may not have the child’s birth weight. Complete reporting is important for quality data.
Q: If a child has a corrected congenital malformation, does the child still need to be reported to the CMR? For example, the child had orchidopexy and urethroscopy for undescended testis Q53.10 and the child’s birth weight was over 2,500 grams.
A: Yes, the child needs to be reported to the CMR. Corrective surgery is often an indication of a major malformation. All major malformations are reportable to the CMR.

Q: I am responding to a SPARCS Comparison Audit or a Hospital Discharge Audit. Can I use the most current address for the patient, or do I have to search for the one related to the date of discharge?
A: You may use the most current address for the child.

Q: I am entering a report in the application and only have father’s phone number, not mother’s phone number. Is it okay to use father’s phone number in place of mother’s phone number?
A: No, it is not. Please only enter the mother’s phone number in the mother’s phone number field.

Q: How do I enter the child’s address if it says, “Child of a Diplomat”?
A: Please make every effort to find and enter the local, temporary address. In the absence of that, a billing address if within the United States. If nothing else is available, Street address: Child of Diplomat; City: Unknown; State: blank; ZIP 99999

Q: How do I enter the child’s address if it is unknown or listed as the hospital’s address?
A: Street address: Unknown; City: Unknown; State: blank; ZIP 99999

Q: How do I enter the child’s address if it says “Homeless”
A: Street address: Homeless; City: Homeless; State: NY; ZIP 99999

Q: Should the address be entered as the current address or address at the time of service?
A: Please enter the current address.

Using Secure File Transfer
Facilities can use the Secure File Transfer 2.0 (SFT 2.0) Utility on HCS to send files or messages that contain confidential information, such as medical records. The CMR reporting application on HCS should be used to submit Routine Reports, SPARCS Comparison Audit Reports, and other report types upon request. SFT 2.0 should be used for sharing confidential information with CMR staff outside of routine reporting.

Q: If I send a file by Secure File Transfer, does it count as reporting to the CMR?
A: No, Secure File Transfer is used as a troubleshooting tool to share confidential information and is not a means for reporting to the CMR.

Q: Can I submit my routine reports via Secure File Transfer?
A: Routine reports should be submitted via the CMR reporting application on the HCS.
Q: Is sending SPARCS audit reports via the Secure File Transfer the same as reporting them?
A: SPARCS audit reports should be submitted via the CMR reporting application on the HCS under Enter Confidential Case Reports, then SPARCS Audit Reports. If you have a question about specific SPARCS audit reports, please contact a CMR staff person, who will help answer your question.

Q: Who should I send files to when I use Secure File Transfer?
A: Please send your correspondences to a CMR staff person using their User ID to find their name. For example, if you are sending a file to Laura Brady, search for her User ID (lsb04). Other User IDs for CMR staff are: Cindy Link (cmb11), Gwen LaSelva (gdb02), Douglas Done (dhd01), Adrian Michalski (amm24), and Amanda St. Louis (axs39).

To find the name of the person you are sending a file to, click on the address book icon, type in their User ID, and then click the magnifying glass. Select the name of the person you are looking for and then click “Send To…” If you don’t know the User ID, click on the address book icon and type in the first or last name of the person you are sending a file to.

Stillbirth Reporting

Q: What is a stillbirth and what will be done with the reports?
A: A stillbirth is defined as a spontaneous intrauterine fetal death occurring at 20 or more weeks of gestation or 350 or more grams delivery weight with unknown gestational age. The primary purpose is to understand how often stillbirths occur, how frequently they are associated with birth defects, and what the risk factors may be that result in this birth outcome.

Q: If I report a stillbirth under the stillbirth reports tab, do I need to list the ICD10 code and narrative stating ‘stillbirth’ in the Diagnostic Information section?
A: Yes! We need to see the code and description in order to confirm that it was indeed a stillbirth. We will send a query asking for more information if you do not provide this level of detail.

Q: Why has the Registry added stillbirth information?
A: Stillbirth is a much under-studied birth outcome and results in considerable emotional and psychological impact for affected families. There is very limited population-based surveillance data. Birth defects surveillance systems are a useful tool because: 1) they have an established surveillance mechanism; and 2) provide more complete information on the occurrence of birth defects.

Q: Does the Registry have authority to collect stillbirth information?
A: The Bureau of Environmental and Occupational Epidemiology (BEOE) has a mandate to identify environmental risks to the population including those related to adverse reproductive outcomes which include stillbirths. The CMR is part of BEOE. BEOE has regulatory authority (State Sanitary Code Part 22.1) allowing the collection of supplementary reports of fetal deaths for epidemiologic surveillance.

State Sanitary Code Section 22.1 - Supplementary reports of spontaneous abortions and fetal deaths for epidemiologic surveillance; filing. Every physician and hospital shall file a supplemental report with the State Commissioner of Health of each spontaneous
abortion or other fetal death occurring naturally. Such report shall be filed within 10 days of the occurrence of such event on such forms as may be prescribed by the Commissioner to facilitate epidemiologic investigation and surveillance.

About the CMR/CMR Terminology

Q: What is a Statement of Deficiency?

A: It is a legal document issued by the State that describes how the facility was out of compliance with New York State Rules and Regulations. In response to the Statement of Deficiency the facility must submit a Plan of Correction that details the corrective action the facility will implement to prevent such occurrences in the future.

Q: What is a query?

A: A query is a request for additional information on a report. When the CMR does not receive enough detail about a birth defect to adequately code and process the report, a query is sent. Someone from your hospital or healthcare facility must sign into the CMR application on the HCS to securely respond to queries. Responding to queries in a timely manner is extremely important for completing reports and allowing them to be fully processed within the Registry.
Instructions for Completing a Confidential Case Report

PFI Number: This field is automatically populated with hospital’s Permanent Facility Identification (PFI) number.

Date Reported: Current date (mm/dd/yyyy); auto-populated

MRN (Medical Record Number) (required): The number assigned by the hospital or office. This is critical for follow-up. It should not be more than 17 digits. Do not include dashes, spaces or preceding zeroes.

Child’s Information

Child’s Last name (required): The child’s last name as listed on the birth certificate. If reporting a stillbirth, then use the mother’s last name. The last name may be hyphenated and include special characters such as apostrophes or periods.

Suffix: If child has a suffix, select it from the drop-down menu. Otherwise, leave blank.

First name: Do not use “male/female child”, “baby boy/girl”, “B/G / B/B”, or mother's first name. Please leave blank if child is not named.

Middle Name: The child’s middle name or initial. Leave blank if unknown.

AKA/Other Name: Use this field for name(s) different from the child’s last name listed above, for example, the mother’s maiden name. The name may be hyphenated. Do not use special characters such as apostrophes or periods.

Street Address (required): The child’s (or mother’s, if stillbirth) current street address, city, state, and ZIP code. The ZIP code must be a 5 or 9-digit number. If homeless, enter: Street address: Homeless; City: Homeless; State: NY; ZIP 99999.

Street Address 2: Add if floor, apartment, or suite is specified or the address is too big for the first address field. Otherwise, leave blank.

Date of Birth (required): The child’s date of birth with month, day, and 4-digit year using format of mmddyyyy or mm/dd/yyyy. If stillborn, indicate delivery date.

Birth Status: Use drop-down button: Live birth or Stillbirth. If a live birth certificate is filed, it is a live birth; if a fetal death certificate is filed, it is a stillbirth.

Gestational Age (in weeks): Enter the completed weeks of gestation (e.g., if child is born at 37 weeks and 6 days, the completed weeks of gestation is 37 weeks).

Birth Weight: Report in grams at birth for live births and stillbirths. Acceptable values are from 250 to 7,500 grams. Do not enter child’s weight at subsequent visits. If unknown, leave blank. Note: some malformations are not reportable if the child is under a certain birth weight.

Sex (required): Use drop-down button: Male, Female or Undesignated. Undesignated is temporary and sex should be determined by chromosome studies. Each case reported with an undesignated sex will be queried if no chromosome studies were reported. Also, a case reported with undesignated
sex should be assigned the ICD-9-CM Code 752.7 or ICD-10-CM Q56 (Indeterminate sex and pseudohermaphroditism).

**Race:** Use drop-down button: White, Black (includes African American), Native American (includes American Indian or Alaskan Eskimo), Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian, or Pacific Islander, Other Race, or Unknown. This is to be answered separately from Hispanic. Race should be reported for Hispanic as well as non-Hispanic children.

**Hispanic:** Use drop-down button: Yes, No, or Unknown. Answer separately from race.

**Plurality:** Use drop-down button: Single birth, Twin, Triplet, Quadruple, Quintuple, Sextuple, or Other. Be sure to count all live and deceased births.

**Birth Order:** Use drop-down button: This field should be completed for multiple births only. Use drop-down screen to specify the order in which this child was born: 1st, 2nd, 3rd, 4th, 5th, or 6th. Be sure to count all live and deceased births.

**Born at this Facility:** Use drop-down button: Yes or No.

**Hospital of Birth:** Use drop-down button: If the child was not born at your facility, choose hospital of birth. If unknown, leave blank.

**Date of Discharge (required):** The date the child was discharged from your hospital. If the child died while a patient, report the date of death here. For stillbirth, enter the date of delivery. For outpatient data, enter the date of the end of the billing period.

**Deceased:** Use drop-down button: Yes or No. For stillbirth, indicate Yes.

**Date of Death:** If child has died, enter the date of death with month, day, and 4-digit year (mmddyyyy or mm/dd/yyyy). For stillbirth, enter date of delivery.

**Foster/Adopted:** Use drop-down button: Foster, Adopted or No. If unknown, leave blank.
Diagnostic Information

Diagnoses and Narratives (required): The valid ICD-10-CM code and narrative description of all birth defects. For each ICD code, the specific diagnosis should be stated, not just the main term from the ICD code list. **Non-specific diagnoses will be queried.** All diagnosed conditions in the CMR ICD-10 Reportable Congenital Malformations Coding Manual should be reported. See examples below:

- Since 2008, we have been asking for specificity for ventricular septal defect codes: muscular, peri-membranous, subarterial, etc. This is indicated in the echocardiogram report or consultant notes.
- Include specificity for hypospadias: degree and location e.g., glandular, coronal, penile, subcoronal, perineal, etc.
- Craniosynostosis should include the particular suture(s) involved: sagittal, metopic, coronal, lambdoidal and basilar.
- Provide laterality if appropriate.
- If a specific syndrome is listed as the child’s condition, list it on the CMR report, along with all the associated anomalies.
- If stillbirth, list any defects noted. If no defects, just list “stillbirth” or “fetal death.”

Genetic Studies: If chromosome studies were done, please report the karyotype in long Paris nomenclature. Also report the results of other genetic testing such as genetic sequencing and chromosomal microarray (CMA) tests. If genetic testing was done, but the results cannot be found in the record, please enter the name of the cytogenetic lab or testing facility. If genetic study results will be available in a short time, delay reporting until they are received.

Newborn Screening ID Number: The 9-digit code listed on the newborn screening blood collection form/report. You will only be able to report this number if this is the birth admission. If unknown, leave blank.
**Pulse Oximetry Screening**: Use drop-down button to indicate if screening was done: Yes, No, Refused, or Unknown.

**Screening Date**: If screening was done, enter the date of screening with month, day, and 4-digit year.

**Screening Results**: If screening was done, enter the screening result: Pass or Fail.

**Saturation Values**: If pass/fail not available, provide the saturation values for the hand and foot for initial and repeated screens. The values should be between 0 and 100%.

<table>
<thead>
<tr>
<th>Pulse Oximetry Screening</th>
<th>If yes, date of Screening (mm/dd/yyyy):</th>
<th>Screening Results: Pass, Fail, Unknown</th>
</tr>
</thead>
</table>

**Saturation Values**: Fill in the saturation values for the hand and foot for initial and repeated screens.

- **Initial Screen**: Enter the saturation values for the hand and foot.
- **Repeat #1**: Enter the saturation values for the hand and foot.
- **Repeat #2**: Enter the saturation values for the hand and foot.
**Parents’ Information**

Note, if adopted, please provide adoptive parents’ information.

**Mother’s information**

**Mother’s Last name**: The last name may be hyphenated and include special characters such as apostrophes or periods.

**First name**: Mother’s first name. Leave blank if unknown.

**Middle Name**: Mother’s middle name or initial. Leave blank if unknown.

**Maiden Name**: If the mother’s present last name has changed since the child was born, note the other last names (maiden name or other previous last name).

**Phone Number**: Provide the mother’s area code and 7-digit phone number (###-###-####). Only enter the mother’s phone number in this field.

**Date of Birth**: Mother’s date of birth with month, day and 4-digit year. Please obtain this from the mother’s medical record if it is not in the child’s record. This information is useful for birth certificate matching.

**Social security number (SSN)**: The mother’s social security number is used to facilitate birth certificate matching. Enter either 9 numbers (no hyphens) or the last four digits of the SSN. This is available with all births and should be reported.

**Father’s information**

**Father’s Last Name**: First name alone is not sufficient. The last name may be hyphenated and include special characters such as apostrophes or periods.

**First Name**: Father’s first name.

**Middle Name**: Father’s middle name or initial. Leave blank if unknown.

**Date of Birth**: Father’s date of birth with month, day and 4-digit year (mm/dd/yyyy). Please check admission sheet. This information is useful for birth certificate matching.

**Social security number (SSN)**: The father’s social security number is used to facilitate birth certificate matching. Enter either 9 numbers (no hyphens) or the last four digits of the SSN.
Primary Healthcare Provider’s Information

Provider’s Last Name: The last name of the physician who will follow the child. The last name may be hyphenated and include special characters such as apostrophes or periods. If the pediatrician or the name of the clinic where the child will receive care is unknown, leave blank. Leave blank if stillbirth.

First Name: If unknown, leave blank.

License Number: Provider’s license number

Provider Type: Please enter the type of provider based on the drop-down list (Licensed Practical Nurse (LPN); Medical Physicist, Medical Health; Midwife; Physician; Physician with 3-year limited license; Physician Assistant; Nurse, RN; Nurse-Practitioner, Acute care; Nurse-Practitioner, Family Health; Nurse-Practitioner, Neonatology; Nurse-Practitioner, Obstetrics and Gynecology; Nurse-Practitioner, Perinatology)

Provider’s Address (Address 1, Address 2, City, State, ZIP): The complete address of the provider that will follow the child as an outpatient.

Phone: Provider’s Phone Number
Failed Submissions

When required information is missing such as child’s name, address, date of birth, sex and date of discharge (or date of outpatient visit for healthcare providers), reports (data entered or uploaded) will be rejected and cannot be submitted at all. If you have difficulty with a submission because of missing information, please contact CMR staff at cmr@health.ny.gov.

Incomplete Submissions Must be Updated

Incomplete submissions occur when a file is uploaded as ‘incomplete’, indicating the reports within the file do not have all requested information from the medical record. After an incomplete file submission, hospital staff must do the following as soon as possible:

1. Navigate to ‘Edit/View Unprocessed Case Reports’ and open each incomplete report
2. Add any missing information that is found in the medical record/chart
3. Click ‘Send to CMR’ to mark the incomplete report complete
   a. The column ‘Complete’ will change from ‘No’ to ‘Yes’ under Edit/View Unprocessed Case Reports.

Inadequate Submissions Result in Queries

Submissions are considered inadequate if the file does not have all requested information from the medical record. Inadequate submissions will be queried. You may receive questions (queries) for the following reasons:

1. Submissions lack a specific diagnosis, such as:
   - Description with the terms “NOS” or “NEC.”
   - “Congenital anomaly of …”
   - “Congenital heart disease”
   - “Other congenital malformation of…”
   - Conditions missing laterality (applies to many of the musculoskeletal defects including congenital partial dislocation of hip, split foot, congenital shortening of lower limbs). Left, right or bilateral should be indicated.
   - “Hypospadias” (where the degree should be indicated).
2. Chromosomal results do not accompany the report of a chromosomal anomaly (applies to all chromosomal anomalies).
3. Child’s birthweight is missing and the birthweight is required to determine eligibility of the reported birth defect (e.g., patent ductus arteriosus, Undescended Testicles, etc.)
4. Anything the CMR collects (e.g., parents’ information)

When inadequate reports are received, an electronic query is sent back. Please respond with as much information as available within 10 business days. A continued lack of response or continued inadequate responses will be considered the same as unreported cases.
Auditing and Monitoring

The CMR monitors hospital reports for completeness and accuracy. According to public health regulations, a child with a birth defect must be reported within 10 days (of diagnosis) by a hospital or physician. To make it less burdensome, children should be reported within 10 days of discharge from a hospital unless the facility submits cases through the monthly file upload process. When a child with a birth defect has not been reported within these time periods, the hospital is out of compliance. Reports that are lacking items necessary for processing will be considered incomplete. Queries resulting from incomplete reports must be answered within 10 business days.

Three types of auditing are currently being carried out:

1) **SPARCS Comparison Audits** - Reporting hospitals are audited by comparing the CMR database to the SPARCS inpatient and outpatient databases for children under two years of age with reportable ICD codes. These are routinely conducted for all reporting hospitals.

2) **Hospital discharge summary/validation audits** - CMR staff will periodically request a complete discharge summary for a specific time period for all children under two years of age who were inpatients or outpatients. The discharge summary is compared to the CMR data files already submitted from your facility for the same time period. As a result of this audit, the facility may receive a list of unreported cases that need to be reported. In addition, staff from the CMR may conduct subsequent on-site facility visits to review medical records for accuracy and completeness of reporting. These visits will be announced several weeks beforehand.

3) Copies of medical records may be requested for specific cases reported previously to the CMR to validate accuracy and completeness of reporting.

We also monitor reporting compliance by tracking number of cases submitted by month and year, and observe timeliness of report submission.

Failure to comply with requirements to submit data to the CMR as mandated by Section 2733 of the Public Health Law may result in the State issuing your facility a **Statement of Deficiency**.
Online Reporting through Health Commerce System

The NYSDOH developed the Health Commerce System (HCS) as a secure system for electronically collecting and distributing health related data. CMR and Information Technology (IT) staff developed data entry and file upload applications on the HCS for reporting children diagnosed with a congenital malformation.

There are two steps to obtain an HCS account. You must 1) register for an account and 2) enroll your account on the HCS. This second step must be done with your HCS Coordinator. If you don’t know who your HCS Coordinator is, contact the CMR at cmr@health.ny.gov or call the Commerce Accounts Management Unit (CAMU) at 1-866-529-1890 option 1 (M-F 8am - 4:45pm).

Where do I register?

1. Open your web browser and enter this web address in the address bar: https://commerce.health.state.ny.us
2. On the HCS log in page, click Create an HCS Account
3. Respond to pop-up questions
4. Click ‘Register for an account’ and follow the two-step process:
   1) Register for an account
   2) Enroll your account on the HCS. This step must be done with your HCS Coordinator.
   
   Register only once!

How do I register?

1. Complete the Name, Address and Policy Statement sections, and click Continue
   NOTE: Your name must match what is on your Photo ID
2. Create a user ID and password, click Continue
3. Answer at least six of the 27 secret questions, click Register
4. Verify your account information, and click Confirm
5. Print your Account Registration Completion information, click OK
6. Print your confirmation email that your user ID was created
7. See your *HCS Coordinator with your Account Registration Completion email printout and your Photo ID

*If you do not know your HCS Coordinator, please call the Commerce Accounts Management Unit (CAMU) at 1-866-529-1890 option 1 (M-F 8am-4:45pm).
How do I sign on the HCS?

Once your HCS Coordinator completes their steps above, you will be enrolled on the HCS and receive a congratulations email. Complete the following items:

1. Read the ‘Security and Use Policy’ (SAUP) for rules and responsibilities

2. Click the HCS website link, and enter your user ID and password that you created when registering

Note: Newly enrolled users will receive an email. Existing users will not receive an email.

Request Access to the CMR application for a new user (with HCS access)

Two options:

1) Request access through the HCS:
   - Sign into the HCS
   - Click on the My Content Tab at the top right, then select “All Applications”
   - Browse by: select
   - Click the info button next to Congenital Malformations Registry
   - Scroll down and click “Request for Access”
   - Complete that form, hit SEND and wait for an email response stating you have access

2) Email the following information to cmr@health.ny.gov:

   Requestor information:
   1. Name:
   2. E-Mail Address:
   3. Organization:
   4. Phone Number:
   5. HCS account id:
   6. Supervisor/HPN Coordinator:
   7. Supervisor/HPN Coordinator's Phone:
   8. Additional User Info:
   9. Reason for Access Request:
Technical Specifications for HCS Access

Account Information and Tools
Passwords expire every 90 days. You will still be able to access the HCS Portal, but you will be forced to select a new password.

An expired password will be disabled after 24 months. You will not be able to access the portal until your identity has been verified by a Commerce Account Management Unit (CAMU) customer service representative. Customer service representative are available daily at 1-866-529-1890 option 1, from 8:00 a.m. until 4:45 p.m. EST, excluding weekends and holidays.

For any account questions, please contact the Commerce Accounts Management Unit (CAMU) at hinhpn@health.ny.gov.

Browser/Software Help
At more than 20 years old, the Health Commerce System is a mature system providing access to over 250 individual data transaction applications of varying ages. Older applications available through the Health Commerce System may have specific Internet browser requirements that may or may not conflict with the generally supported browsers. In such cases, users are encouraged to check the application profile for specific requirements and should direct any concerns to the application owner.

General Browser Requirements
- TLS 1.1 & 1.2 encryption enabled
- Browser set to accept cookies
- JavaScript must be enabled

Supported Browsers
Due to the volatile nature of rapid release schedules for modern Internet browsers, the Health Commerce System supports the current and previous two versions of the following Internet browsers:

**Desktop:**
- Microsoft Internet Explorer
- Google Chrome
- Safari (Mac OS only)

**Mobile**
- Safari (iOS5.1 or later)
- Google Chrome (iOS5.1/Android 4.0 or later)

**Limited Support:**
- Mozilla Firefox (Desktop/Mobile)
- Most WebKit-based browsers (Android OS 2.3 or later)

**Unsupported Browsers:**
- Microsoft Internet Explorer Mobile (Win 8 Phone)
- Safari for Windows (Desktop)

Mozilla has unfortunately taken a divergent path in developing the Firefox browser and recent changes to Firefox may negatively impact the average person's ability to use many applications and resources found on the HCS. As such, we can only offer limited support for this highly technical browser. You may be asked to choose an alternate if you encounter issues that are not easily resolved by non-technical users. This excludes any legacy applications that may require a specific early version of Mozilla Firefox to operate. We may re-examine full Firefox support in the future.

Due to the flexibility of the WebKit engine customization, we can state that the HCS should work with most WebKit browsers but can only offer limited support. You may be asked to choose an alternate if you encounter issues that are not easily resolved.

Troubleshooting web sites
- Find out about your browser: [http://www.whatsmybrowser.org/](http://www.whatsmybrowser.org/)
- Review your browser's SSL (TLS) support: [https://www.ssllabs.com/ssltest/viewMyClient.html](https://www.ssllabs.com/ssltest/viewMyClient.html)
Not sure which Internet browser you are using? Go to http://www.whatsmybrowser.org/ to find out. Got questions about software? Here are responses to Frequently Asked Questions (FAQs) concerning internet terms, browser (e.g. Firefox, Internet Explorer) setup, pop-ups and navigating the HCS.

Web Browsers
Software needed to view the Commerce web pages and documents is available from the 3rd party web sites listed below.

By clicking on one of the icons you will be directed to the browser download page.

Document viewer software
Windows Media Player | Microsoft Silverlight | Microsoft Office

https://commerce.health.state.ny.us/hcs/help/help.html

Settings for Optimal Use

Internet Explorer
1. Open Internet Explorer
2. Press Alt T and select "Internet Options".
3. Select the "Advanced" tab.
4. Scroll down to the "Security" section.
5. Locate and check "Use TLS 1.0, TLS 1.1 and TLS 1.2".
6. Deselect Use SSL 2.0, SSL 3.0 if checked.
7. Then, press the "OK" button.

Google Chrome:
1. Open Google Chrome
2. Press Alt F and select "Settings".
3. Scroll down and select "Show advanced settings…"
4. Scroll down to the Network section and click on "Change proxy settings…"
5. Select the "Advanced" tab.
6. Scroll down to the "Security" section.
7. Locate and check "Use TLS 1.0, TLS 1.1 and TLS 1.2".
8. Deselect Use SSL 2.0, SSL 3.0 if checked.
9. Then, press the "OK" button.

Safari:
1. If you are using Safari version 7 or greater, TLS 1.0, TLS 1.1 & 1.2 are automatically enabled. There are no options for enabling TLS under iOS.

Mozilla Firefox:
1. By default, they have TLS settings properly assigned.
Using the CMR Application on Health Commerce

HCS Login Screen

After an individual has applied for and obtained a Health Commerce System (HCS) account, he/she will be able to log onto the HCS. Passwords are changed every 90 days and the user must log on at least once every 24 months in order to maintain the account. An account that has not been used for more than 24 months will need to be reactivated by calling 1-866-529-1890.

Locating the CMR Application

On the left-hand side of the screen, under “My Applications” click on “Congenital Malformations.” If you data enter electronic birth certificates, or are the tumor registrar for your facility, you may have a number of applications listed under this heading.

If “Congenital Malformations” is not listed under “My Applications”, add it by clicking “All Applications” under “My Content” at the top, clicking “C”, then scrolling down and clicking on “Congenital Malformations.” You can also click on the info button to the right of “Congenital Malformations” to request access.
Scroll down:

Click on the green + button to add “Congenital Malformations Registry” to your “My Applications” list.

**Main Menu on the Congenital Malformations Registry Home Page**
Once you click on “Congenital Malformations Registry”, if you have access, you will see the following main menu:

- The icon in the top left can widen the screen when clicked. Re-click to see the sidebar again.

**Notifications**
This section on your home page lets you know if you have any outstanding queries or other important requests. Respond to queries in a timely manner!
**Reporting to the CMR**
There are two secure ways to send reports to the CMR: The Data Entry method and the File Upload method.

- If your facility uses the Data Entry method, click on “Enter Confidential Case Reports."
- If your facility uses the File Upload method, then click on “Upload Case Reports Data.”

**Data Entry Method of Reporting**

**Enter Confidential Case Reports**

- Routine Current Reports
- Stillbirth Reports
- SPARCS Audit Reports
- Hospital Site Visit Reports
- Hospital Discharge Index
- ECLRS Audit Reports

After clicking on “Enter Confidential Case Reports”, you must click on the type of report you are sending:

**ROUTINE CURRENT REPORT** - Almost all of your case reports will be this type. You will choose this link if you are sending in the everyday, current reports that your facility generates.

**STILLBIRTH REPORT** - Choose this link if you are submitting a report on a stillborn infant. See the *Frequently Asked Questions* section for more information.

**SPARCS AUDIT REPORT** - These are the cases that we have asked you to report because a SPARCS Comparison Audit is being conducted by the CMR. You may see links to the reports on the CMR home page indicating that these cases need to be reported.

**Generate SPARCS Audit Report for 2012**

- Inpatient (71)
- Outpatient (3)

**HOSPITAL SITE VISIT REPORT** - Following a review of medical records during an *in-person* site visit, unreported or partially reported cases should be entered under this link.

**HOSPITAL DISCHARGE INDEX** - Following a Discharge Summary Audit, a list of unreported cases will be sent back to you and should be reported under this link.

**ECLRS AUDIT CASE REPORT** - Choose this link if you are submitting a case following an inquiry from the CMR about a positive laboratory report.
Data Entry Screen for CMR Confidential Case Reports

By clicking “Routine Current Reports”, the Routine Current Case Report screen will open. Please fill in as many fields as possible. Note that all fields with a red star * must be completed. Many fields have drop-down boxes to aid in Data Entry. “Help Entering Data” in the top left-hand corner provides assistance in determining what information is needed in each field.

<table>
<thead>
<tr>
<th>Child’s Information</th>
<th>Diagnostic Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>PFI Number: 0001</td>
<td>ICD 0</td>
</tr>
<tr>
<td>Child’s Last Name:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Middle Name:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Street Address:</td>
<td>[Field]</td>
</tr>
<tr>
<td>City:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Date of Birth:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Birth Weight (grams):</td>
<td>[Field]</td>
</tr>
<tr>
<td>Race:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Plurality:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Born at this facility:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Date of Discharge:</td>
<td>[Field]</td>
</tr>
<tr>
<td>Foster/Adopted:</td>
<td>[Field]</td>
</tr>
</tbody>
</table>

Note: Many fields have drop-down boxes to aid in Data Entry. “Help Entering Data” in the top left-hand corner provides assistance in determining what information is needed in each field.
Important: All narratives must be specific.
Any diagnoses that begin with "Anomaly of..." or are listed as NEC or NOS need to be more specific (e.g., “anomaly of heart”, “specified anomaly of kidney”, etc.). If the narrative fails to reveal exactly what is wrong with the child, then the narrative is not specific enough for our purposes. You will need to review the medical record and tell us what the specific anomaly is. Karyotype or chromosome study results are needed for children diagnosed with chromosomal abnormalities (e.g., Down syndrome, trisomy 21, Edwards syndrome, etc.) that are born in your facility. If the genetic testing was NOT done through your facility and results are not available, please put a note in the narrative field that says "genetic testing not done through this facility" so that your facility is not queried for this information.

Data entry screen, continued:

A list of reportable codes is available to aid in data entry.
Remember to click on “Send to CMR” after completing data entry for each record!

A screen similar to the following will appear when a case report has been sent successfully to the CMR.

When you view this information, if there are any errors, you can return to the prior screen and make corrections by clicking “Make Changes to this Report” found at the bottom right. Be sure to hit “Send to CMR” after making changes. To enter another case, click “Enter Another Routine Current Case Report”.
File Upload Method of Reporting

For File Upload Method: An ASCII (text) file that contains the required information and has a specific record layout must be created. This is often done by the Information Technology (IT) department. Once this has been accomplished, anyone with HCS and CMR access may upload a file. Simply, click on “Upload Case Reports Data” from the left-hand column. You will still need to indicate what type of report you are sending as is done for routine reporting.

Congenital Malformations Registry Routine Current Data Upload

You must first choose whether the reports to be sent are complete or incomplete.

1. **Incomplete Reports:** If your file contains missing data or insufficient narratives that have been retrieved directly from the medical record face sheet or attestation and therefore, are not specific enough for the CMR, then select the incomplete reports button. After the file has been uploaded to the CMR, someone from your hospital staff must open the unprocessed file and add the specific narratives and any other missing information.

2. **Complete Reports:** If your data system allows you to report all necessary data including a specific narrative, then click the complete reports button. If you click this, you should not need to reopen the unprocessed files to add narratives.

3. Next, you must click on the “Browse” button to retrieve the file that will be uploaded to the CMR. Once the file name is in the Browse window, then click on “Upload Data to CMR.” You will receive an acknowledgement when a file is uploaded successfully, as shown below.
You will receive an error message if a file has not been uploaded successfully. If this happens, try to submit the file once more. If you continue to have problems, contact the CMR at cmr@health.ny.gov.

**Using the Secure File Transfer 2.0 Utility on the Health Commerce System**

Facilities can use the Secure File Transfer 2.0 (SFT 2.0) Utility to send files or messages that contain confidential information, such as medical records. In general, the CMR reporting application is mostly used to submit Routine Reports and SPARCS Comparison Audit reports. For complete instructions on using SFT 2.0, please click here (insert link to instructions).
**Edit/View Unprocessed Case Reports**

An “unprocessed” case report is a record that your facility has sent to the CMR that has not been processed and added to the CMR database. You may view or edit any case report that you have recently sent to the CMR by clicking on “View/Edit Unprocessed Case Reports.” If you have uploaded files to the CMR, then this is the button you click to add the correct, specific narratives to each case report (as described below).

**Adding Narratives or Other Information to Case Reports**

If narratives or other information need to be added to reports, click on “Edit/View Unprocessed Case Reports.” All cases that have a “no” in the “completed” column need to be addressed.

For each case:

1) Click on the child’s name to open the case report.

2) Review the report, including the codes and narratives:

   All narratives that are not specific (Anomaly of..., NOS, NEC, unspecified anomaly of..., etc.) need to be corrected. Make sure it is clear exactly what the child has by reading the narrative (i.e. “anomaly of heart”), otherwise it is not specific enough for our purposes.

   Any code for a chromosome-related anomaly needs to have the chromosome karyotype listed. These include ICD-9 codes for 752.7 and all of the 758’s or ICD-10 codes Q56.4, Q90-Q99. If the child was not born at your facility and you therefore do not have the chromosome (chrom) results, write a note in the narrative column stating something to the effect of “child not born here, no chromosomes in chart.”

3) After you have reviewed the case, make sure you click “send changes to the CMR,” even if you have not made any changes. This will send the corrected/finalized report to us as well as change the “no” in the “completed” field to a “yes.”

If you discover that a case is not reportable to the CMR (for example: 1) a skin anomaly that is only a minor; or 2) no longer a reportable condition, like maternal cocaine use), you can delete the case by clicking the “delete report” button. This is permanent, and you cannot retrieve the case once it has been deleted.

The “reset values” button at the bottom of the screen will delete everything you have added to the record since the last time it was changed. If you are making changes, and made a mistake, you can click the “reset values” button and it will return the original information.
**View/Search All Case Reports**

A reporting facility is able to view all the cases they have ever submitted since the CMR initiated HCS reporting. Click on “View all case reports” and the following screen will open (data on the form has been purposely covered). You may sort the data by clicking on any of the column headings. For example, if you want to see the earliest cases that you submitted to the CMR, click on either “Date of Birth” or “Date of Discharge.”

Click on “Search all case reports” and the following screen will open. You can look for a particular case. You do not have to fill in all the fields; you can search for any case using only one field if you want (such as last name or medical record number).

**View the Transaction Log**

The transaction log shows who from your facility reported cases and when. Under Type of Transaction, you can see if cases were 1) added; 2) updated; 3) deleted because the defect was not reportable for the given birthweight- or sex-; 4) deleted because they were a minor malformation without a major malformation; 5) deleted because they were a duplicate report; or 6) deleted for other reasons. This will allow you to keep track of any case even if it is not listed in the unprocessed or all case reports files.
**Check Outstanding Queries**

A query is a **request for additional information** on a report that does not have enough detail for CMR staff to fully process the report. Someone from your hospital or healthcare facility must sign into the CMR application on the Health Commerce System to securely respond to queries. Responding to queries in a timely manner is extremely important for completing reports and allowing them to be fully processed within the Registry.

On the left-hand menu of the CMR application, you will find the link to ‘Check outstanding queries.’ The number that appears in parentheses is the number of outstanding queries sent to your facility. **Your facility will not be credited with having sent the original report until the query is satisfactorily answered. Queries must be answered within 10 days of when they are sent to your facility.**

Click on **Check outstanding queries** and a list of cases will come up.

**Click on each child’s name to see the query.**

**Additional Information Requests**

![Image: CMR Information Request]

Click the child’s name to view the report.

**Please review the medical record** and answer the query in the ‘Response’ box, then click on the ‘Send Response’ button. Please also provide any additional information found in the chart but missing in the CMR report. CMR staff will correct or add this additional information to the report in question.

Click here when done!
**View/Edit CMR Hospital Contact Information**

We ask that you review the entries under “Hospital Contact Information” regularly (at least twice a year and every time you lose/gain staff) and update the information as needed. This information includes the name and address of your facility and the names and contact information for the following staff: Director of Health Information Management, CMR Registrar, Outpatient Medical Record Contact, CMR Contact Person, and the Release of Information Officer. You must click “Send Changes to CMR” at the bottom of the screen to save any updates.

**Contact the CMR**

This page contains the CMR’s address, phone/fax numbers and email. If you wish to send a comment, concern, or question, please click on the e-mail address.

When you click on the email address shown in the figure above, the screen on the next page will open. This screen allows you to send questions, comments or suggestions directly to the Congenital Malformations Registry. Type your question in the box and you will receive a response as soon as possible.

**Questions/Comments/Suggestions**
Record Layout & Description of Variables for File Uploads

**CSV format** (introduced Spring 2017)

Enclose text strings in double quotes. Numbers do not need quotes. Separate all values by commas. The full header line is required. Do not use spaces to represent missing values; instead, omit the values entirely. Save the file as CSV (comma delimited), not as CSV UTF-8 (comma delimited).

<table>
<thead>
<tr>
<th>Name in header line</th>
<th>Order</th>
<th>Maximum characters allowed</th>
<th>description</th>
</tr>
</thead>
<tbody>
<tr>
<td>pfi</td>
<td>1</td>
<td>6</td>
<td>Required. The permanent facility identifier (PFI) number of your hospital. Up to 6 digits.</td>
</tr>
<tr>
<td>MRN</td>
<td>2</td>
<td>17</td>
<td>Required. Medical Record Number</td>
</tr>
<tr>
<td>cLast</td>
<td>3</td>
<td>40</td>
<td>Required. Child's Last Name</td>
</tr>
<tr>
<td>cSuffix</td>
<td>4</td>
<td>6</td>
<td>Suffix of Child's last name</td>
</tr>
<tr>
<td>cFirst</td>
<td>5</td>
<td>30</td>
<td>Child's First name</td>
</tr>
<tr>
<td>cMiddle</td>
<td>6</td>
<td>30</td>
<td>Child's Middle Name</td>
</tr>
<tr>
<td>cAKA</td>
<td>7</td>
<td>20</td>
<td>Child's also known as name</td>
</tr>
<tr>
<td>cAddress1</td>
<td>8</td>
<td>36</td>
<td>Required. Child's address line 1. Should follow US Post Office/Canada Post specifications. If homeless, use 'Homeless' for this field.</td>
</tr>
<tr>
<td>cAddress2</td>
<td>9</td>
<td>36</td>
<td>Child's address line 2. Should follow US Post Office/Canada Post specifications.</td>
</tr>
</tbody>
</table>
| cState              | 11    | 4                         | Required. Child's state. Should follow US Post Office/Canada Post specifications. If homeless, use ‘NY’ for this field. If not in the US or Canada, use ‘XX’.
<p>| cZIP                | 12    | 9                         | Required. Child's ZIP. Should follow US Post Office/Canada Post specifications. No hyphens. US ZIP codes should be 5 or 9 digits. If homeless, use ‘999999’ for this field. |
| cDOB                | 13    | 8                         | Required. Child's date of birth. Use format yyyy-mm-dd. |
| BirthStatus         | 14    | 1                         | Live birth or stillbirth code. 0=missing, 1=live birth, 2=stillbirth. |
| gestweek            | 15    | 2                         | Weeks of gestation |
| Birthweight         | 16    | 4                         | Child's birth weight (grams) |
| cSex                | 17    | 1                         | Required. Child's sex. 1=Male, 2=Female, 3=Undesignated |
| cRace               | 18    | 2                         | Child's race. 01=white, 02=African American, 03=Native American, 41=Asian Indian, 42=Chinese, 43=Filipino, 44=Japanese, 45=Korean, 46=Vietnamese, 49=Other Asian, 5X=Pacific Islander, 88=Other Race, MR=Multi-Racial, 00=unknown |
| hispanic            | 19    | 1                         | Hispanic. 0=Mising, 1=Yes, 2=No, 9= Unknown |
| Plurality           | 20    | 1                         | Multiple birth: 0=unknown, 1=single birth, 2=twin, 3=triplet, 4=quadruple, 5=quintuplet, 6=sextuple, 7=septuplet, 8=octuplet. |
| birthorder          | 21    | 1                         | Birth order. 0=unknown, 1=1st, 2=2nd, 3=3rd, etc. |
| bornhere            | 22    | 1                         | Born at this facility code. 0=unknown, 1=Yes, 2=No. |</p>
<table>
<thead>
<tr>
<th>Name in header line</th>
<th>Order</th>
<th>Maximum characters allowed</th>
<th>description</th>
</tr>
</thead>
<tbody>
<tr>
<td>birthplacePFI</td>
<td>23</td>
<td>6</td>
<td>6-digit PFI of birth hospital. 000000=missing, 009990=unknown NYS hospital, 009991=hospital outside NY state, 009992=not born in a hospital</td>
</tr>
<tr>
<td>Discharge_date</td>
<td>24</td>
<td>8</td>
<td>Required. Discharge date. Use format yyyymmdd.</td>
</tr>
<tr>
<td>DeadYN</td>
<td>25</td>
<td>1</td>
<td>Deceased indicator. Blank=unknown, Y=Yes, N=No.</td>
</tr>
<tr>
<td>Death_date</td>
<td>26</td>
<td>8</td>
<td>Date of death. Use format yyyymmdd.</td>
</tr>
<tr>
<td>Fost_Adopt</td>
<td>27</td>
<td>1</td>
<td>Fostered or Adopted code. 0=missing, 1=foster, 2=adopted, 3=No.</td>
</tr>
<tr>
<td>icd10_1</td>
<td>28</td>
<td>7</td>
<td>1st ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
<td>icd10_2</td>
<td>29</td>
<td>7</td>
<td>2nd ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
<td>icd10_3</td>
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<td>3rd ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
<td>icd10_4</td>
<td>31</td>
<td>7</td>
<td>4th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
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<td>32</td>
<td>7</td>
<td>5th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
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<td>7</td>
<td>6th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
<td>icd10_7</td>
<td>34</td>
<td>7</td>
<td>7th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
<td>icd10_8</td>
<td>35</td>
<td>7</td>
<td>8th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
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<td>9th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
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<td>10th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
<td>icd10_11</td>
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<td>7</td>
<td>11th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
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<td>39</td>
<td>7</td>
<td>12th ICD-10 diagnosis code. It should start with a letter. Do not include decimal point.</td>
</tr>
<tr>
<td>narra1</td>
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<td>165</td>
<td>Required. 1st specific description of the birth defect.</td>
</tr>
<tr>
<td>narra2</td>
<td>41</td>
<td>165</td>
<td>Conditionally required*. 2nd specific description of the birth defect.</td>
</tr>
<tr>
<td>narra3</td>
<td>42</td>
<td>165</td>
<td>Conditionally required*. 3rd specific description of the birth defect.</td>
</tr>
<tr>
<td>narra4</td>
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<td>165</td>
<td>Conditionally required*. 4th specific description of the birth defect.</td>
</tr>
<tr>
<td>narra5</td>
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<td>165</td>
<td>Conditionally required*. 5th specific description of the birth defect.</td>
</tr>
<tr>
<td>narra6</td>
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<td>165</td>
<td>Conditionally required*. 6th specific description of the birth defect.</td>
</tr>
<tr>
<td>narra7</td>
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<td>165</td>
<td>Conditionally required*. 7th specific description of the birth defect.</td>
</tr>
<tr>
<td>narra8</td>
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<td>165</td>
<td>Conditionally required*. 8th specific description of the birth defect.</td>
</tr>
<tr>
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<td>165</td>
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<td>165</td>
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<td>165</td>
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</tr>
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<td>Name in header line</td>
<td>Order</td>
<td>Maximum characters allowed</td>
<td>description</td>
</tr>
<tr>
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<td>-------</td>
<td>---------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>karyotype</td>
<td>52</td>
<td>55</td>
<td>Karyotype/results of chromosome studies</td>
</tr>
<tr>
<td>cytolab</td>
<td>53</td>
<td>55</td>
<td>Name of cytogenic lab</td>
</tr>
<tr>
<td>nbscreenid</td>
<td>54</td>
<td>8</td>
<td>Child's newborn screening ID number</td>
</tr>
<tr>
<td>PulseoxYN</td>
<td>55</td>
<td>1</td>
<td>Pulse oximetry screening indicator. 0=missing, 1=yes, 2=no, 3=refused, 9=undetermined.</td>
</tr>
<tr>
<td>Pulseox_date</td>
<td>56</td>
<td>8</td>
<td>Date of pulse oximetry testing. Use format yyyymmdd.</td>
</tr>
<tr>
<td>PulseoxPF</td>
<td>57</td>
<td>1</td>
<td>Pulse oximetry screening result. 1=pass, 0=fail</td>
</tr>
<tr>
<td>Pulseoxh1</td>
<td>58</td>
<td>4</td>
<td>% saturation, 1st pulse-ox screening of hand</td>
</tr>
<tr>
<td>Pulseoxf1</td>
<td>59</td>
<td>4</td>
<td>% saturation, 1st pulse-ox screening of foot</td>
</tr>
<tr>
<td>Pulseoxh2</td>
<td>60</td>
<td>4</td>
<td>% saturation, 2nd pulse-ox screening of hand</td>
</tr>
<tr>
<td>Pulseoxf2</td>
<td>61</td>
<td>4</td>
<td>% saturation, 2nd pulse-ox screening of foot</td>
</tr>
<tr>
<td>Pulseoxh3</td>
<td>62</td>
<td>4</td>
<td>% saturation, 3rd pulse-ox screening of hand</td>
</tr>
<tr>
<td>Pulseoxf3</td>
<td>63</td>
<td>4</td>
<td>% saturation, 3rd pulse-ox screening of foot</td>
</tr>
<tr>
<td>mLast</td>
<td>64</td>
<td>40</td>
<td>Mother’s last name</td>
</tr>
<tr>
<td>mFirst</td>
<td>65</td>
<td>30</td>
<td>Mother’s first name</td>
</tr>
<tr>
<td>mMiddle</td>
<td>66</td>
<td>30</td>
<td>Mother’s middle name</td>
</tr>
<tr>
<td>mMaiden</td>
<td>67</td>
<td>35</td>
<td>Mother’s maiden name</td>
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<tr>
<td>mPhone</td>
<td>68</td>
<td>20</td>
<td>Mother’s phone number</td>
</tr>
<tr>
<td>mDOB</td>
<td>69</td>
<td>8</td>
<td>Mother’s date of birth. Use format yyyymmdd.</td>
</tr>
<tr>
<td>mssn</td>
<td>70</td>
<td>9</td>
<td>Mother’s SSN. Do not include hyphens.</td>
</tr>
<tr>
<td>flast</td>
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<td>40</td>
<td>Father’s last name.</td>
</tr>
<tr>
<td>fFirst</td>
<td>72</td>
<td>30</td>
<td>Father’s first name.</td>
</tr>
<tr>
<td>fMiddle</td>
<td>73</td>
<td>30</td>
<td>Father’s middle name.</td>
</tr>
<tr>
<td>fDOB</td>
<td>74</td>
<td>8</td>
<td>Father’s date of birth. Use format yyyymmdd.</td>
</tr>
<tr>
<td>fssn</td>
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<td>9</td>
<td>Father’s social security number. Do not include hyphens.</td>
</tr>
<tr>
<td>pLast</td>
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<td>40</td>
<td>Child’s primary care provider’s last name</td>
</tr>
<tr>
<td>pFirst</td>
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<td>30</td>
<td>Child’s primary care provider’s first name</td>
</tr>
<tr>
<td>plicense_type</td>
<td>78</td>
<td>2</td>
<td>Child’s primary care provider’s license type</td>
</tr>
<tr>
<td>plicense</td>
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<tr>
<td>pAddress2</td>
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<td>78</td>
<td>Child’s primary care provider’s address line 2</td>
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<td>40</td>
<td>Child’s primary care provider’s city</td>
</tr>
<tr>
<td>pState</td>
<td>83</td>
<td>4</td>
<td>Child’s primary care provider’s state</td>
</tr>
<tr>
<td>pZIP</td>
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<td>9</td>
<td>Child’s primary care provider’s ZIP code</td>
</tr>
<tr>
<td>pPhone</td>
<td>85</td>
<td>20</td>
<td>Child’s primary care provider’s phone number</td>
</tr>
<tr>
<td>ICD9_1</td>
<td>86</td>
<td>6</td>
<td>1st ICD-9 diagnosis code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>Name in header line</td>
<td>Order</td>
<td>Maximum characters allowed</td>
<td>description</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------</td>
<td>-----------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>ICD9_2</td>
<td>87</td>
<td>6</td>
<td>2nd ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_3</td>
<td>88</td>
<td>6</td>
<td>3rd ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_4</td>
<td>89</td>
<td>6</td>
<td>4th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_5</td>
<td>90</td>
<td>6</td>
<td>5th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_6</td>
<td>91</td>
<td>6</td>
<td>6th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_7</td>
<td>92</td>
<td>6</td>
<td>7th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_8</td>
<td>93</td>
<td>6</td>
<td>8th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_9</td>
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<td>6</td>
<td>9th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
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<td>ICD9_10</td>
<td>95</td>
<td>6</td>
<td>10th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_11</td>
<td>96</td>
<td>6</td>
<td>11th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>ICD9_12</td>
<td>97</td>
<td>6</td>
<td>12th ICD-9 code. Do not include decimal point (e.g., 758.0 as 7580). Include leading zeros where appropriate (e.g., 90.0 as 0900).</td>
</tr>
<tr>
<td>narrative</td>
<td>98</td>
<td>No limit</td>
<td>Any additional information you want to tell us. Use for description of the defect only if the description will not fit into the narr1-narr12 fields due to size limitations.</td>
</tr>
</tbody>
</table>

*required if a corresponding ICD code is present.

### Healthcare Provider’s License Type Codes
(license_type)

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Licensed Practical Nurse (LPN)</td>
</tr>
<tr>
<td>11</td>
<td>Medical Physicist, medical health</td>
</tr>
<tr>
<td>22</td>
<td>Nurse, RN</td>
</tr>
<tr>
<td>23</td>
<td>Physician Assistant</td>
</tr>
<tr>
<td>33</td>
<td>Nurse -Practitioner, Family Health</td>
</tr>
<tr>
<td>35</td>
<td>Nurse -Practitioner, Neonatology</td>
</tr>
<tr>
<td>36</td>
<td>Nurse -Practitioner, Obstetrics and Gynecology</td>
</tr>
<tr>
<td>38</td>
<td>Midwife</td>
</tr>
<tr>
<td>39</td>
<td>Nurse -Practitioner, Perinatology</td>
</tr>
<tr>
<td>43</td>
<td>Nurse -Practitioner, Acute care</td>
</tr>
<tr>
<td>60</td>
<td>Physician</td>
</tr>
<tr>
<td>61</td>
<td>Physician with 3-year limited license</td>
</tr>
</tbody>
</table>

Example Fragment of CSV file (fake data):

```
"pfi","MRN","cLast","cSuffix","cFirst","cMiddle","cAKA","cAddress1","cAddress2","cCity","cState","cZIP","cDOB","BirthStat 0001,82","Adraksin","Stepanovich","Stepan","297 NEW ARBAT AVE","South Floral Pa","NY","99999,20160926,",2,",",2016092 001,19","Akhroimova","Dmitriyeva","Maya","63 First Ave","Cortland","NY",13045,20160926,",1,",",20160928,","Q6433 001,56","Tsar","l","Alexander","n","807 Mokhovaya St","Bovina","NY",99999,20170131,",1,",",20170204,","Q361",",", 0001,45","Bagghubwud","Karla","Gustav","28791 NYS Rte 34","Pamella","NY",13637,20170223,",2,",",20170224,","Q611", 0001,41","Bazdeev","Joseph","Aleseievich","23 Bolshaya Lubyanka St","Perinton","NY",14450,20170212,",1,",",20170214,",
```

44
**Example Data for CSV file (fake data):**

```
"pfi","MRN","cLast","cSuffix","cFirst","cMiddle","cAKA","cAddress1","cAddress2","cCity","cState","cZIP","cDOB","BirthStatus","gestweek","Birthweight","cSex","cRace","hispanic","Plurality","birthorder","bornhere","birthplacePFI","Discharge_date","DeadYN","Death_date","Fost_Adopt","icd10_1","icd10_2","icd10_3","icd10_4","icd10_5","icd10_6","icd10_7","icd10_8","icd10_9","icd10_10","icd10_11","icd10_12","narra1","narra2","narra3","narra4","narra5","narra6","narra7","narra8","narra9","narra10","narra11","narra12","karyotype","cytolab","nbscreenid","PulseoxYN","Pulseox_date","PulseoxPF","Pulseoxh1","Pulseoxf1","Pulseox2","Pulseoxf2","Pulseoxh3","Pulseox3","mLast","mFirst","mMiddle","mMaiden","mPhone","mDOB","mssn","flast","ffirst","fMiddle","fDOB","fssn","pLast","pFirst","plicense_type","plicense","pAddress1","pAddress2","pCity","pState","pZIP","pPhone","ICD9_1","ICD9_2","ICD9_3","ICD9_4","ICD9_5","ICD9_6","ICD9_7","ICD9_8","ICD9_9","ICD9_10","ICD9_11","ICD9_12","narrative"
```

```
0001,82,"Adraksin",""Stepanovich",""Stepan",""297 NEW ARBAT AVE",""South Floral Pa",""NY","99999,20160726,,2,,,,20160727,"","Q120","","Congenital cataract","0,20160725,,,,,,,,19790202,,,,,19980623,,,,60,244,""245 EAST 124 STREET",""Manhattan",""NY","99999,,,,"","Congenital cataract"

0001,19,"Akhrosimova",""Dmitriyevna",""Maya",""63 First Ave",""Cortland",""NY","13045,20160926,,,,1,,,,20160928,,""Q6433",""Q6650",,,,,,,,,,"Congenital stricture of urinary meatus",""Congenital pes planus, unspecified foot","0,20160926,,,,,,,,19770506,,,,19790409,,60,6074,""3456 Leningradskoye Highway",""Geneseo",""NY","14454,,,,,""Congenital stricture of urinary meatus,Congenital pes planus, unspecified foot"

0001,56,"Tsar",""I",""Alexander","","807 Mokhovaya St",""Bovina",""NY","99999,20170131,,,,1,,,,20170204,,""Q361",,,,,,,,,,"Cleft lip, median","0,20170129,,,,,,,,19860430,,,,20010131,,,,60,7022,""234 Pennsylvania",""Buffalo",""NY","14201,,,,,,,,,""Cleft lip, median"

0001,45,"Baggeufwudt",""Karl",""Gustav",""28791 NYS Rte 34",""Pamelia",""NY","13637,20170223,,,,2,,,,20170224,,""Q011",,,,,,,,,,"Nasofrontal encephalocele","1,20170223,,,,,,,,19860302,,,,19961116,,60,4063,""4567 Varshavskoye Highway",""Clay",""NY","99999,,,,,,""Nasofrontal encephalocele"

0001,41,"Bazdeev",""Jeseph",""Alexeevich",""23 Bolshaya Lubyanka St",""Perinton",""NY","14450,20170212,,,,1,,,,20170214,,""Q659",""Q930",""Q011",""Q672",,,,,,,,,,"Congenital deformity of hip, unspecified",""Whole chromosome monosomy,nonmosaic (meiotic nondisjunction"",""Nasofrontal encephalocele",""Dolichocephaly","3,20170210,,,,,,19920531,,,,19730814,,60,1571,""6789 Mira Ave",""Milton",""FL","32570,,,,,,,,,""Congenital deformity of hip, unspecified,Whole chromosome monosomy,nonmosaic (meiotic nondisjunction,Nasofrontal encephalocele,Dolichocephaly"
```

**Fixed length format**

Fixed length format files (*.txt) will no longer be accepted in the future, and we encourage the use of the new comma separated value format (*.csv). If you submit data in fixed-length format files, please change to comma separate value files as soon as possible. If you need assistance or have questions, please contact us at cmr@health.ny.gov.
## CMR Handbook Changes

### Revision History

<table>
<thead>
<tr>
<th>Section</th>
<th>Date</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Record Layout &amp; Description of Variables for File Uploads</strong></td>
<td>March 2017</td>
<td>Added specifications for the *.CSV file layout</td>
</tr>
<tr>
<td>Appendix 1</td>
<td>March 2017</td>
<td>Added and removed codes</td>
</tr>
<tr>
<td><strong>CSV format</strong></td>
<td>Fall 2017</td>
<td>Added ‘maximum characters allowed’ column to CSV format instructions and fixed typos in the CSV format instructions and examples.</td>
</tr>
<tr>
<td><strong>Healthcare Provider License Type Codes</strong></td>
<td>Fall 2017</td>
<td>Added healthcare provider license type codes</td>
</tr>
<tr>
<td><strong>Secure File Transfer Instructions</strong></td>
<td>Fall 2017</td>
<td>Added instructions for using Secure File Transfer for troubleshooting assistance</td>
</tr>
<tr>
<td><strong>Staff changes</strong></td>
<td>Fall 2018</td>
<td>Deb Fox (former CMR Director) left the CMR, Michele Herdt was appointed the new CMR Director, Douglas Done and Adrian Michalski joined the CMR; Mary Anne Giaconia retired</td>
</tr>
<tr>
<td><strong>Fixed Length Format</strong></td>
<td>Fall 2018</td>
<td>Detailed instructions removed to prepare for transition to CSV format</td>
</tr>
<tr>
<td><strong>Staff changes</strong></td>
<td>Spring 2019</td>
<td>June Moore left the CMR</td>
</tr>
<tr>
<td>Appendix 1</td>
<td>Fall 2019</td>
<td>Removed- please see ICD-10 Coding Manual for reportable codes and history of changes. See <a href="#">What to Report</a> section for instructions on how to access the manual.</td>
</tr>
</tbody>
</table>