

Congenital Anomalies Surveillance Yukon

CASY

Procedures manual

2013

Adapted in part from the Congenital Anomalies Surveillance – Saskatchewan and Alberta Congenital Anomalies Surveillance System's Procedures Manuals

Table of contents

History	3
Objectives	3
System	3
CASY data collection flow chart	4
Referring to CASY	5
Who to refer?.....	5
How to refer?	5
Who should refer?	5
Why the referral?.....	6
Referable congenital anomalies.....	6
Non-referable congenital anomalies	7
Legislative framework	7
Consent	8
Communications	9
Communication to public.....	9
Communication to health care providers	9
Evaluation	9
Reporting	9
Confidentiality	9
Contact information	10

Congenital Anomalies Surveillance Yukon

History

Congenital anomalies surveillance Yukon or CASY was established through funding from the Public Health Agency of Canada (PHAC) in 2013 after the need for better surveillance data for congenital anomalies across jurisdictions in Canada was identified. CASY is a stand-alone database that collects pertinent information on congenital anomalies on all Yukon births whether they occur at Whitehorse General Hospital, under the care of a local midwife or in another jurisdiction.

Objectives

Major congenital anomalies are a leading cause of morbidity and mortality in infants in Canada. They create a considerable emotional and economic burden on families and society. Rates of infant mortality are higher in the north. We are only beginning to tease out the reasons why our rates are different from the south. CASY will be a great help with this work.

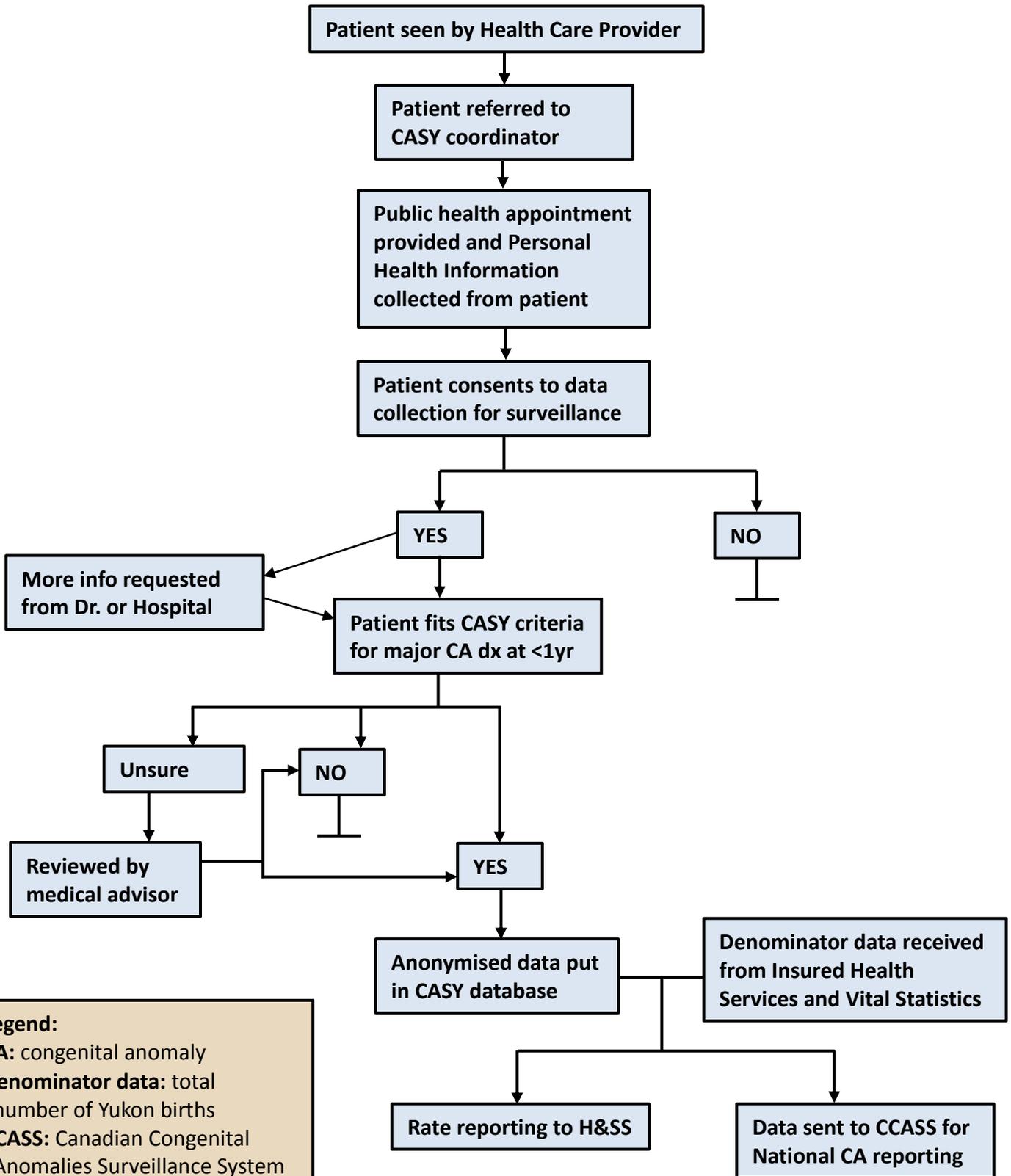
One of the objectives of CASY is to provide support to those individuals who are born with a birth defect and their families in terms of raising a child with a birth defect and accessing services available to those individuals in need. CASY is also in a position to provide advice to future parents on what they can do to minimise their risk of having a child with a birth defect.

Another objective of CASY's is to identify rates and trends of birth defects in Yukon and to provide population based reporting both at a territorial level but also to contribute to data collection at a national level. Determining rates and trends of congenital anomalies is ultimately to generate knowledge to support public health programs and policies so we can endeavor to reduce the impact and effect that the morbidity and mortality of birth defects have on Yukoners.

System

The CASY database is a Microsoft ACCESS database that was provided to Yukon by EUROCAT. EUROCAT is a network of European congenital anomalies registries that has existed since 1979 and surveys over 1.7 million births a year. This same software is also being used by Nunavut and other circumpolar populations which will give us a ready platform with which to compare our data to other populations with similarities to our own here in Yukon. We are also working with the Public Health Agency of Canada and other Canadian jurisdictions to facilitate ready comparisons of our data with other jurisdictions that are using different software.

CASY data collection flowchart



Legend:
CA: congenital anomaly
Denominator data: total number of Yukon births
CCASS: Canadian Congenital Anomalies Surveillance System

Referring to CASY

Who to refer?

We are asking that all health care professionals, especially physicians, midwives and nurses refer any child less than one year of age who is diagnosed with a congenital anomaly to the CASY project coordinator for a public health consultation regarding birth defects. We also encourage the referral of any woman who has miscarried or terminated a pregnancy due to the presence of a congenital anomaly. A detailed, although not exhaustive, list of eligible congenital anomalies for referral can be found in the so named section of this procedures manual. Minor anomalies will not be included in the CASY database, a list of these can be found in the so named section of this procedures manual.

A child who is over one year of age can still be referred for the public health appointment although their data will not be included in the CASY database.

How to refer?

When a congenital anomaly is identified in a child less than one year of age or if a woman has miscarried or terminated a pregnancy due to the presence of a congenital anomaly, they can be referred using the CASY Referral form. The referral form can be found in appendix A of this procedures manual, obtained from the CASY coordinator at the coordinates below, found on the following website (www.hss.gov.yk.ca/casy.php) in interactive format or found on the PLEXIA electronic medical record platform. Confirmatory documentation such as consultation reports, radiology, ultrasound, MRI, CT scan, laboratory results and autopsy reports should be attached to the referral form. The coordinator will contact you for further information if necessary.

Referral forms and confirmatory documentation can be sent by fax or mail to the CASY coordinator at the coordinates below. Please include a cover sheet addressed to the coordinator. Please do not send by e-mail.

Contact Information

CASY coordinator

305 Jarvis Street HP-305, Whitehorse, Yukon, Y1A 2H3

Phone (867) 667-8563 / Fax (867) 667-8349

CASY@gov.yk.ca / www.hss.gov.yk.ca/casy.php

Unless documentation is apparent, do not assume the child has already been referred.

Who should refer?

- Physicians
- Midwives
- Nurses
- Other health care providers

Why the referral?

For each person referred the project coordinator will take the time to discuss in detail the diagnosis, services available to that individual, known general causes of congenital anomalies and methods to reduce the risk of congenital anomalies. She or he will also request consent to collect information for CASY.

Referable congenital anomalies

A congenital anomaly is an abnormality of structure, function, or metabolism, whether genetically determined or as the result of environmental interference during gestation that is present at birth. Of note, there is still no known cause for over half of congenital anomalies. The following list of conditions outlines those for which CASY would like to see referrals for. This list is not exhaustive but should give you a good idea of what is appropriate to refer for. If you have any questions regarding a particular referral please contact the CASY coordinator at the coordinates at the end of this manual. If you are unsure of whether to refer for a particular anomaly we prefer you refer and let the CASY staff decide whether to include it in the registry.

- Cardiac & circulatory system abnormalities:
 - Bulbus cordis anomalies and anomalies of cardiac septal closure
 - Other congenital anomalies of the circulatory system
 - Other congenital anomalies of the heart
- Cerebral palsy, infantile
- Chromosomal abnormalities
- Cleft palate and cleft lip
- Digestive system congenital anomalies
- Ear, **face and neck congenital anomalies**
- Eye **congenital anomalies**
- Fetal **alcohol spectrum disorder**: Alcohol affecting fetus via placenta or breast milk
- Genital **organs congenital anomalies**
- Hearing **loss**: conductive, sensorineural and combined
- Hemolytic anemias, hereditary
- Hypothyroidism, congenital
- Immune mechanism disorders
- Integument congenital anomalies
- Maternal conditions which may be unrelated to present pregnancy affecting fetus or newborn
- Metabolic disorders:
 - Amino metabolic disorders
 - Glycogenosis and galactosemia
 - Other and unspecified disorders of metabolism
- Muscular dystrophies & other myopathies
- Musculoskeletal anomalies, congenital
- Neural tube defects:
 - Anencephalus and similar anomalies
 - Spina bifida
- Neurofibromatosis
- Neurological disorders:
 - Anterior horn cell disease
 - Other cerebral degenerations
 - Other congenital anomalies of the nervous system
 - Spinocerebellar disease
- Other and unspecified congenital anomalies
- Pigmentary retinal dystrophy
- Respiratory congenital anomalies
- Upper alimentary tract congenital anomalies
- Urinary system congenital anomalies

Non-referable congenital anomalies

Soft markers for aneuploidy: It is not necessary to refer children when a soft marker for aneuploidy is identified on ultrasound prenatally. These soft markers include: nuchal thickening, echogenic foci, echogenic bowel, choroid plexus cysts, and pyelectasis.

Anomalies found in premature infants (≤ 36 weeks gestation or < 2500 grams):

The following anomalies are not included in CASY when identified in a premature infant; however they are acceptable when identified in a term infant

- Patent foramen ovale (PFO)
- Patent ductus arteriosus (PDA)
- Undescended testes
- Nasolacrimal stenosis / blocked tear duct

Congenital anomalies that will be rejected regardless of gestational age at birth:

- Anal fissure
- Ankyloglossia
- Asymmetry of face, head, jaw
- Bifid ventricles
- Bowing of tibia or bow legs
- Bronchopulmonary dysplasia
- Deviated nasal septum
- Diabetic cardiomyopathy
- Diastasis recti
- Ears low set
- Esophageal diseases: achalasia, chhalasia
- High arched or V-shaped palate
- Heart murmurs
- Hemangioma – simple
- Hematemesis
- Hemorrhage, intracranial
- Hip clicks
- Hydrocele
- Hymen – imperforate
- Hyperbilirubinemia – transient
- Immaturity of neurological system (tremulous)
- Intrauterine growth retardation
- Isolated pulmonary hypertension
- Laryngomalacia / laryngeal stridor
- Moles, nevi, hemangioma if small isolated
- Pilonidal dimple
- Pneumothorax
- Positional deformities (deformities due to intrauterine position such as positional club foot, dislocated due to breech, etc)
- Ranula
- Rectal prolapse
- Right ventricular strain
- Septal hypertrophy
- Small anterior fontanelle
- Strabismus
- Testis – retractile
- Tongue tie – ankyloglossia
- Tracheomalacia
- Tyrosine, transient increase / elevation
- Vaginal tags

Legislative framework

The creation of CASY for congenital anomalies data collection is for surveillance purposes. Yukon's Chief Medical Officer of Health has the legal authority to collect this information under Yukon's *Public Health and Safety Act (PHSA)*. Specifically, sections 2.1(1) and 2.2(2)(d) in the *PHSA* allow the Chief Medical Officer of Health to collect personal information indirectly (without consent) for surveillance purposes.

Personal information in the custody or control of Yukon's Chief Medical Officer of Health or Department of Health and Social Services is subject to limitations upon collection, use and disclosure in accordance with the Yukon *Access to Information and Protection of Privacy Act (ATIPP)*, RSY 2002, C. 1. Specifically, Health and Social Services must protect personal information by making reasonable security arrangements against such risks as accidental loss or alteration, and unauthorised access, collection, use, disclosure or disposal.

The public health appointment is provided under similar authority under the *PHSA* section 2.2(2)(a) and (b) the purpose of which is to prevent disease and to promote health.

CASY's authority to provide information to the Canadian Congenital Anomalies Surveillance System falls under the *Health Act* section 4.1(1)(d) and 4.1(2)(3) and (4). It is for the purpose of congenital anomalies surveillance and pursuant to an agreement signed between Yukon Health and Social Services and the Public Health Agency of Canada.

Consent

Although Health and Social Services can collect the congenital anomaly and perinatal data for the purposes of surveillance, Yukon's legislation does not easily allow physicians to provide this information to Health and Social Services. Until such time as a Yukon Health Information Act is in place which should make clear who can provide such information we are requesting that the parent or guardian of a child in whom a congenital anomaly is identified provide their explicit consent for the collection of this data.

The CASY coordinator will be accepting referrals of any child in whom a congenital anomaly is identified before one year of age or any mother who has had a termination of pregnancy or a miscarriage due to a congenital anomaly. The coordinator will then discuss the congenital anomaly, causes of congenital anomalies and ways to reduce the risk of occurrence of congenital anomalies with the parents of the child or the mother referred. At this same time, the coordinator will request the written consent from the parent or guardian to allow CASY to collect the pertinent data.

Should you prefer to obtain consent yourself from your patient's parent/guardian please contact the CASY coordinator who can provide you with the appropriate consent to use for this purpose. If your patient is not interested in attending the Public Health Appointment but has consented to the collection of their information, then send the signed consent along with the referral form with a clear note on it saying that the patient is not interested in being contacted for the public health appointment.

Communications

Communication to public

At the time that CASY began to collect information on congenital anomalies, the Chief Medical Officer of Health, Dr. Brendan Hanley, spoke of this surveillance initiative on his weekly radio address. Written media was also produced in the form of a press release by Health and Social Services.

Bilingual versions of a patient pamphlet were produced and distributed to all clinics where women are provided with prenatal care, all family physicians' offices, all community nursing stations and the Whitehorse Health Center. This pamphlet was also provided to every woman who delivered at Whitehorse General Hospital. A copy of this pamphlet in each official language can be found by following this link. Should you wish to receive copies of this pamphlet please contact the CASY coordinator.

Communication to health care providers

When CASY began to collect information on congenital anomalies there were numerous information sessions conducted with local physicians, midwives and community and maternity nurses. These sessions included a brief overview of the importance of surveillance for congenital anomalies as well as a description of who to refer and how. A flyer was distributed to all health care professionals who might be in a position to refer a patient. This flyer outlines the procedure to follow to refer a patient and can be posted in offices for easy reference where referrals are likely to happen on a more frequent basis. A list of conditions appropriate for referral can be found on the reverse of the flyer for reference. A copy of this flyer can be found by following this link. Should you wish to receive copies of this flyer please contact the CASY coordinator.

Evaluation

CASY began collecting congenital anomalies data in spring of 2013. The first evaluation of the effectiveness of the referral process is scheduled to be performed in 2014 when CASY will have been collecting data for a one year period.

Reporting

CASY will be providing Yukon Health and Social Services with an annual report outlining the numbers and types of congenital anomalies identified in Yukon babies. CASY will also be reporting annually to the Canadian Congenital Anomalies Surveillance System (CCASS). Each Canadian jurisdiction has been asked to do the same.

Confidentiality

Health and Social Services must adhere to the principles detailed in the *Access to Information and Protection of Privacy Act* or *ATIPP*. Additionally, the CCASS as part of PHAC will undertake to do descriptive analysis on the data provided to them and will generate aggregate statistics for reporting purposes nationally. They will not publish rates based on numbers greater than zero (0) and less than five (5) without the approval of CASY as part of Yukon Health and Social

Services as stated in the Memorandum of Agreement between the Government of Yukon and PHAC signed in March 2012.

Contact information

If you have any questions or require any additional information please do not hesitate to contact the program coordinator at the coordinates below:

CASY coordinator

305 Jarvis Street HP-305, Whitehorse, Yukon, Y1A 2H3

Phone (867) 667-8563 / Fax (867) 667-8349

Email: CASY@gov.yk.ca / website: www.hss.gov.yk.ca/casy.php