



PreSurv Suite

Birth Defects Epiinfo Database Manual

Version 3.1 – November 7, 2016

Preface

Welcome to PreSurv Suite, an open source, free, and adaptable software suite for the SURveillance and PREvention of birth defects.

Why Presurv?

Birth defects are a leading cause of mortality, morbidity, and disability among children, and increasingly among adolescents and adults. As overall infant mortality decreases, the burden of birth defects is increasing and may continue to increase in many countries, including many low and middle income countries. Surveillance of birth defects is an effective tool with several objectives, among them it facilitates measuring the impact of evidence based interventions aimed at the prevention of birth defects in the population as a whole.

Efforts of many organizations, including the World Health Organization (WHO), the Centers for Disease Control and Prevention (CDC), and the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) are currently aimed precisely at tackling this monumental challenge – improving health and survival throughout the lifespan through birth defect surveillance and prevention.

To implement a birth defect surveillance program, one needs tools that are *effective, simple, and widely available*. However, electronic tools for this activity, if available at all, are typically expensive, difficult to adapt, and often developed or focused on developed countries.

PreSurv Suite was developed as a solution to these challenges: a free, simple, but powerful suite of tools to jumpstart surveillance and reduce time for the evaluation of primary prevention. This manual

will guide you as you begin using this tool and, if necessary, adapting it to your local needs.

What is PreSurv Suite?

PreSurv Suite is built upon the powerful framework of Epi Info 7 and leverages its many strengths: ease of use, flexibility, encryption, data transmission, geocoding, and analysis. The current version reflects the considerable experience in birth defect surveillance and prevention of the development team and its collaborators and users.

PreSurv currently include four intake forms:

- (a) Data collection form on **cases** with a birth defect – the case-record form for use in epidemiologic surveillance or case-control studies
- (b) Data collection form for **controls** -- individuals without birth defects – for use in case-control studies or population surveys
- (c) Data collection form for **denominators** – all births in the underlying population under surveillance – for use in epidemiologic assessment (e.g., prevalence by time, place, person)
- (d) Data collection form on **periconception health**—PHAST (Periconception Health Assessment Screening Tool)—to survey and monitor risk factors for adverse pregnancy outcomes (including but not limited to birth defects) in the population under surveillance

This Manual provides step by step guidelines for completing the data entry forms

How is a typical form structured?

These examples are based on the case-record form. A form is organized in **pages**, each focusing on a specific set of data (e.g., birth defects, family demographics, family history, risk factors). Each piece of data is entered in a **variable** field.

Variables, in general, may be viewed as either **core** variables, **recommended** variables, or **expanded** variables. Based on user experience in many countries, **core variables** represent, in our view, the *minimum set* of information for effective surveillance and prevention activities. **Please note that the variables marked with an asterisk (*) are mandatory and cannot be skipped.**

Recommended variables enhance the information of the core set, and are typically available from simple records (e.g., medical records). Expanded variables, such as information on risk factor exposure, usually require additional data retrieval or maternal interviews.

Several forms include **built-in intelligence**, typically to check the validity of values or to complete calculated fields. Examples include a calculated variable that, based on the values entered for gestational age and weight, automatically determines whether intrauterine growth restriction is present or not; a calculated variable for survival that uses date of birth and date of death; and a calculated variable of maternal body mass index based on values of height and weight.

Can a form be modified?

Yes, forms are purposefully designed as an open system, which can and sometimes *must* be adapted to the local setting and needs. For example, we expect that several drop down menus (e.g., on parental ethnicity) or coded variables will be adapted to the local environment. Modifications can be done by the central staff of the surveillance program or by ICBD staff (we recommend the latter, to make sure that the remainder of the system remains functional)

Who developed PreSurv?

The core development team is from the International Clearinghouse for Birth Defects Surveillance and Research (www.icbdsr.org), with technical and grant support from the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC).

Core Development Team (ICBDSR): Pierpaolo Mastroiacovo, MD, Lorenzo Botto, MD, Allan Hill, BS, Antonino Bella, BS.

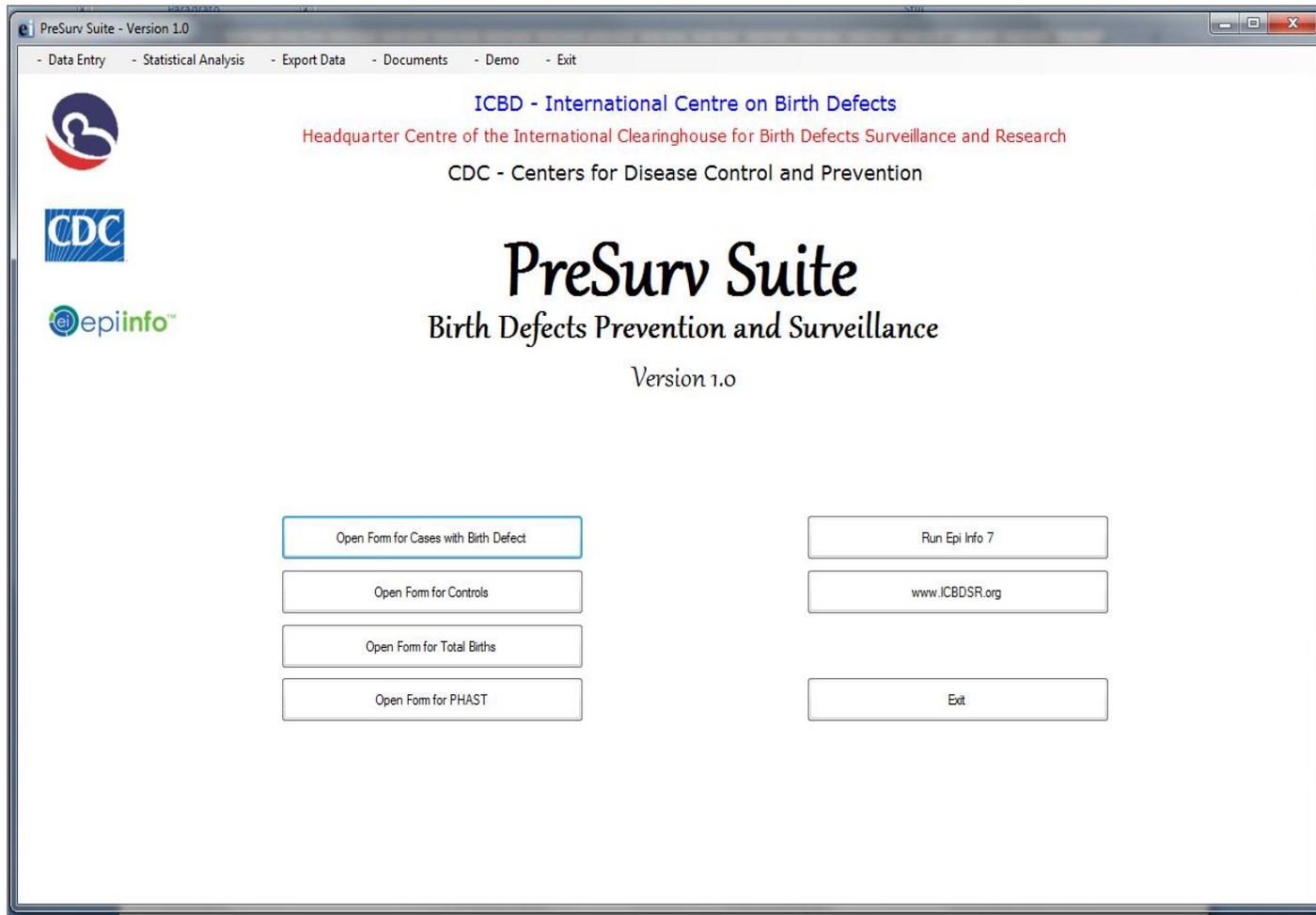
Support and Review Team (CDC): Diana Valencia, MS, RJ Berry, MD, Alina Flores, MPH, Csaba Siffel, MD PHD

How can you improve PreSurv?

Use it, and if you find problems or wish to suggest improvements, email us at centre@icbdsr.org. Even better, because the platform is open and easy to adapt (Epi Info 7), try out enhancements and let us know about your success so we can share it with other. Our hope is to have a community of developers who will continue to improve this product for the benefit of all.

The PreSurv Development Team

7 November 2016 Rome, Salt Lake City, Atlanta

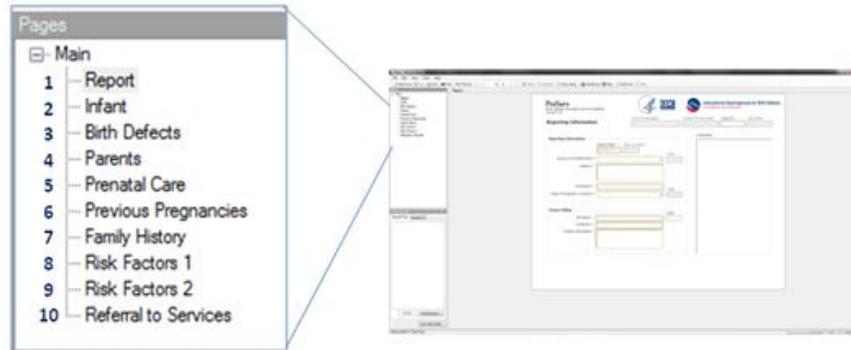


**Once the PreSurv Suite is installed on your computer, this page will appear.
Please use the installation guide for more information.**

Data Reporting Form for Cases (individuals with a birth defect) General Notes

Pages

Each section of the Database in this Manual is numbered from 1 to 10. Each page has one or more sections.



Classification of variables.

- Colors in the manual indicate different things: please take note of the different colors, and become familiar with the manual.

1. **Red bold underlined letters and asterisk***: mandatory variables, must be entered. If not entered, a warning will appear when trying to save the form.
2. **Text color blue bold and underlined**: core set of variables.
3. Text color blue underlined: recommended set of variables.
4. *Text color blue italics*: expanded set of variables.
5. **Black bold with grey background**: codes given by the system. Data should not be entered, the system will generate it automatically.

Green italics: drop downs that will likely need to be customized by the program and defined systematically by the program's Central Staff.

Local Notes

Local Notes is the free space left in the Manual for comments/local standards or guidelines developed by each program.

Page 1: Reporting Information

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1

   **International Clearinghouse for Birth Defects**
Surveillance and Research

Case ID calculated: Further Review Notes: Case ID*: Last Name:

Reporting Information

Reporting Information

Report Date * Days to Report

Source of Ascertainment * Code

Address *

City/Region * Code

Place of Pregnancy Outcome * Code

Form Completed by

Full Name * Code

Profession *

Contact Information *

Comments

This is how the Reporting Information page looks like.
The next pages provide guidelines for each section of the page.

Page 1 – Section 1

				International Clearinghouse for Birth Defects Surveillance and Research
Case ID calculated	Further Review Notes	Case ID*	Last Name	
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	
Reporting Information				

TOP section

1. **Case ID calculated:** the system will give a case ID based on date of birth, sex, and birth weight. This is an additional ID, for double checking. You should also use a specific local ID for each case.
2. **Further Review Notes:** this box is displayed as a reminder on every page. It is completed by the user (typically the central reviewer) in the Birth Defects page (Page 4), and should contain synthesized notes on the case records.
3. **Case ID*:** completed locally as the first essential piece of information in the Reporting Information page. Decide on a system to be used consistently for generating ID codes. The field accepts numbers and letters in any combination. Case ID can be used for several purposes: to retrieve a form or to check for duplicate entries. Having two or more forms with the same ID should trigger a case review to resolve the issue.
4. **Last Name:** after the last name is first entered on Page 2, it is displayed on each page.

Notes Case: Fetus, stillbirth, or neonate (live born), infant, child with a birth defect. Fetus here refers to a pregnancy termination due to fetal anomalies. Do not include spontaneous abortions with a birth defect (or if you include them, exclude them from epidemiologic analyses). To minimize unwanted variability in the system, define stillbirth, live birth and length of follow up of live births. Infant (0-1 year) and child (≥ 1 year) are reported in some programs. See “Definitions” in Appendix 1.

Local notes

Page 1 – Section 2

Reporting Information		Comments
Report Date *	Days to Report	
<input type="text" value="DD/MM/YYYY"/>	<input type="text"/>	
Source of Ascertainment *	<input type="text"/>	Code <input type="text"/>
Address *	<input type="text"/>	
City/Region *	<input type="text"/>	Code <input type="text"/>
Place of Pregnancy Outcome *	<input type="text"/>	

Reporting Information

1. **Report Date ***: indicate date when the local surveillance staff completed the form and sent it to the central staff.
2. **Days to Report**: the system will compute the time (in days) between the day of the outcome (ETOPFA* or birth) and the day when the report was sent to the central staff. This information will be used to evaluate the timeliness of reporting.
3. **Source of Ascertainment ***: indicate name of the health facility, e.g.: hospital / department, where the fetus/neonate/infant/child with a birth defect was identified as a case and the form completed.
The drop down should be customized by the Program's Central Staff
4. **Code**: the system will give the code of source of ascertainment.
5. **Address ***: indicate the full name and full address of the health facility where the case was ascertained. Please give also the e-mail address and telephone number(s).

6. **City/Region***:give the name of the city and the region where source of ascertainment is located.
7. **Place of Pregnancy Outcome ***:indicate the name of the place of pregnancy outcome (ETOPFA or birth). Repeat it if the place of pregnancy outcome and the source of ascertainment of the case are the same.
The drop down should be customized by the Program Central Staff and should include "home delivery" as an option if the program is population based.
8. **Code**: the system will give the code of place of Pregnancy Outcome.
9. **Comments**: provide any comments related to the reporting information you want to communicate to the Central Staff. For example, explain why the report was delayed or explain if this is a new record of the same subject.

**ETOPFA means Elective Termination of Pregnancy for Fetal Anomaly.*

Local notes

Page 1 – Section 3

Form Completed by	
Full Name *	<input type="text"/>
Profession *	<input type="text"/>
Contact Information *	<input type="text"/>
	Code <input type="text"/>

Form Completed by:

Full Name *: indicate the full name of the person that completed the form.

Code *: enter your code assigned by the Central Staff.

Profession *: indicate the profession of the person filling out the form (e.g., nurse, midwife, neonatologist, obstetrician, pediatrician, orthopedic, cardiologist).

Contact Information *: indicate how the person that completed the form may be contacted for further details. Include working health facility, address, e-mail address, and telephone number(s).

Local notes

Page 2 – Section 1

The screenshot shows the PreSurv form interface. At the top left is the PreSurv logo with the text "Birth Defects Prevention and Surveillance Version 3.1". To the right are logos for the Department of Health and Human Services, CDC, and the International Clearinghouse for Birth Defects Surveillance and Research. Below these logos are five input fields: "Case ID calculated", "Further Review Notes", "Case ID", and "Last Name". The "Infant Information" section contains five fields: "Given Name *", "Surname *", "Sex *" (a dropdown menu), "Medical Record Number", and "Vital Record Number".

Infant Information

1. **Given Name and Surname ***: indicate name and surname of the case. Usually the name is given only to live births; however always complete the surname even if the case is an ETOPFA or stillbirth. If the father is unknown the infant will usually have the mother's surname. The surname is one of the three key elements that appear on the top of each page (Last Name).
2. **Sex ***: refers to the external visible sex of the infant / fetus. Use the drop down menu. In case of ambiguous genitalia indicate ambiguous and describe in the birth

defects section along with autopsy (if done) or chromosomal analysis. Do not change the sex "ambiguous", even if a gonadal or chromosomal sex is established subsequently, for example after surgery, autopsy, or karyotype.

3. **Medical Record Number**: useful if available to track down additional medical information on the infant or of her/his mother, if needed. If not available use 99999 code.
4. **Vital Record Number**: indicate the vital record number if available (birth certificate number, fetal death number, etc.), otherwise use 99999 code. The Vital Record Number may be useful for linkage studies.

Local notes

Page 2 – Section 2

Pregnancy Outcome		Outcome Date *	Year
Pregnancy Outcome *	<input type="text"/>	<input type="text" value="DD/MM/YYYY"/>	<input type="text"/>
Delivery Type	<input type="text"/>	Plurality	<input type="text"/>
Birth Weight *	<input type="text"/>	Units	<input type="text" value="gm"/>
Birth Length	<input type="text"/>		<input type="text" value="cm"/>
Head Circ.	<input type="text"/>		<input type="text" value="cm"/>

Pregnancy Outcome:

1. **Pregnancy Outcome ***: select the appropriate option in the drop down menu. See definitions on appendix 1.
2. **Outcome Date ***: give date of the outcome. This is important information since it will be used to compute the time between pregnancy outcome and the report day and also to compute the Gestational age.
3. **Year**: The system will code only the year and will automatically get it from the previous mandatory variable. It makes easier to aggregate data by year of outcome in the analysis.
4. **Delivery Type**: select the appropriate option in the drop down menu.
5. **Plurality**: select the appropriate option in the drop down menu. If a twin, this selection will allow entries in the sections on co-twins.
6. **Birth weight ***: enter weight in grams (gm) of stillbirth and live birth cases. If available, it may be useful to also enter the weight for ETOPFAs. See definition in Appendix 1.
7. **Birth Length**: enter length in centimeters (cm) of stillbirth and live birth cases.
8. **Head Circumference**: enter the head circumference in centimeters (cm). The head circumference (HC) measures the circumference of the child's head at its largest area (above the eyebrows and ears and around the back of the head). It is also called occipito-frontal circumference (OFC).

Local notes

Page 2 – Section 3

Gestational Age

	Weeks	LMP Date
by LMP	<input type="text"/>	<input type="text" value="DD/MM/YYYY"/>
by Ultrasound	<input type="text"/>	
Computed	<input type="text"/>	
	Small for Gestational Age	
	<input type="text"/>	<input type="button" value="Calculate"/>

Gestational Age:

Typically one is faced with one of three situations:

1. Gestational age (see definition in Appendix 1) has been evaluated based on the last menstrual period that is not well reported or recalled by mother: use the **“by LMP - Weeks”** box and give the number of weeks.
2. Gestational age has been evaluated on the basis of the first day of the last menstrual period reported in the maternal medical record or remembered with precision by the mother: use the **“LMP Date”** box (Last Menstrual Period Date box) and give the date. The system will compute the gestational age in weeks in the box “Computed”
3. Gestational age has been evaluated with precision by and expert during pregnancy by ultrasound: use the **“by Ultrasound”** box and give the result.

You must choose the single best option to calculate gestational age. Use option “by Ultrasound” only if the ultrasound was evaluated in the first weeks of gestation by an expert operator, otherwise use option “2” or “1”.

4. **Computed:** this box contain the best estimated gestational age. If you put two sets of information, e.g., LMP Date and gestational age by ultrasound, the “Computed” box will select the “by Ultrasound” as the most valid.
5. **Small for gestational age Calculate:** **CLICK** here, the system will compute if the case (stillbirth or live birth) is a small for gestational age or not (will appear YES or NO, respectively).

Memo: the **Calculate** button must be clicked only after having filled the sex and the birth weight of the infant otherwise *ERROR* will appear. See Appendix 2 for details on small for gestational age.

Local notes

Page 2 – Section 4

Survival	Newborn Hospitalization
Follow-up <input type="text"/> Date of Death <input type="text" value="DD/MM/YYYY"/>	Result <input type="text"/> Reason for Hospitalization <input type="text"/>
Survival to Time X <input type="text"/> <input type="text"/> Child age at last contact	ICD Codes <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
Survival <input type="text"/> Weeks	Surgery in first week of life <input type="text"/>

Substitute “Child’s age at last contact” for “Child age...”

Survival

The boxes in this section will open only if pregnancy outcome is “Live Birth”.

1. **Follow-up:** Choose the option “alive” or “dead” from the drop down menu.
 - a. Alive means that the child is living at the age of the last contact with a health facility. Enter this information in the box “Survival to Time X”.
 - b. Dead means that you know the precise or approximate date of death.
 - c. If you do not know if a live birth infant is alive or dead choose alive and give 1 day in the “Survival to Time X”.
2. **Date of Death:** give the date of death. If you do not know the exact day live blank.
3. **Survival to Time X:** enter in the first box the child’s age (specify in the second box days, weeks, months or years as chosen from the drop down options) at the last contact you had (e.g., visit, telephone call to the parents). If you know that the child is alive at last contact with him or his/her parent it’s not necessary to know exactly the age, you can use the best approximation.
4. **Survival:** the system will compute the survival time in weeks.

Newborn Hospitalization

The information requested here is limited to hospital stay soon after birth. It does not apply to hospital admission after the first week of life.

5. **Result:** choose one of the two options given in the drop down: discharged to home < 5 days or still in hospital.
6. **Reason for Hospitalization:** leave blank if discharged to home before 5 days. If the admission in hospital is (or was) longer than 4 days, give the reason.
7. **ICD Codes:** you can use up to five codes for coding the condition(s) linked to the longer period of hospital stay. Use the ICD-10 code(s) corresponding to the reason why the neonate is still in the hospital.
8. **Surgery in the first week of life:** this information is limited to surgical treatment performed or not performed, or planned during the first week of life. Choose one of the five options given in the drop down: done, planned, not necessary, not done, unknown. For any given option, except for the “not necessary” (which is self- explained by the type of birth defect) please specify the details of the surgical treatment performed or planned in the comments section at the end of the page.

Local notes

Page 2 – Section 5

Plurality

Sex of the twin set

Birth defects in the co-twin

Comments

Case ID	Birth Defect	Sex

Plurality

The boxes in this section will open only if plurality is > 1.

1. **Sex of the twin set:** choose one of the three options given in the drop down. Sex concordant includes twin sets who are all of the same sex (MM or MMM or MMMM or FF or FFF or FFFF and so on). Sex discordant include twin sets where at least one has a different sex (MF, MMF, MFF, MMFF and so on).
2. **Birth defects in the co-twin:** choose one of the six options given in the drop down. None affected means that the co-twin or the co-twins do not present a birth defect. The presence of similar or dissimilar defects is usually easy but it should be validated centrally. For this reason it is important: (a) to describe the defect in the "Birth Defect" box(es) and (b) to complete a full form for the co-twin giving the ID number in the appropriate box.
3. **Case ID:** give the ID number of the co-twin(s) case(s) used in the form completed for the co-twin(s) affected by a birth defect.
4. **Birth Defect:** indicate the birth defect diagnosed in the co-twin. If there is more than one co-twin, a second line set of boxes will appear (this is why the Case ID may be colored in blue. Do not worry about it).
5. **Sex:** choose the option from the drop down of the case.
6. **Comments:** use this box for any comments related to the infant information, particularly for hospitalization and surgery.

Local notes

Page 3: Birth Defects

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1



Case ID calculated

Further Review Notes

Case ID

Last Name

Given Name *

Surname *

Sex *

Medical Record Number

Vital Record Number

Pregnancy Outcome

Pregnancy Outcome * Outcome Date * Year

Delivery Type Plurality

Birth Weight * Units

Birth Length

Head Circ.

Gestational Age

by LMP Weeks LMP Date

by Ultrasound

Computed

Small for Gestational Age

Survival

Follow-up Date of Death

Survival to Time X Child age at last contact

Survival Weeks

Newborn Hospitalization

Result Reason for Hospitalization

ICD Codes

Surgery in first week of life

Plurality

Sex of the twin set

Birth defects in the co-twin

Case ID	Birth Defect	Sex

Comments

**This is how the Birth Defects page looks like.
In the next pages you will find the instructions for each section of the page.**

Page 3 – Section 1

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

International Clearinghouse for Birth Defects Surveillance and Research

Case ID calculated:

Further Review Notes:

Case ID:

Last Name:

Birth Defects

Clinical Diagnosis:

Major #: Minor #:

Syndrome Name:

Reviewer Comments:

Resources (www.icbdsr.org)

Birth Defects

1. **Further Review Notes:** *This box is left to the central staff.*
2. **Clinical Diagnosis:** choose one of the options given in the drop down.
 - Isolated major: anomaly that requires medical or surgical treatment. The treatment may be required soon after birth or after some weeks / months / year after birth. If the case has also one or more minor anomalies and NOT a syndrome, disregard them.
 - Sequence: a pattern of anomalies that results from a primary anomaly. See Appendix 3 for a list of selected sequences.
 - Chromosomal: any anomaly of chromosomes discovered prenatally or postnatally in a case with or without a diagnosed structural birth defect.
 - Other Genetic: any anomaly of a major gene (SNPs excluded) discovered prenatally or postnatally. Teratogenic syndrome: a recognizable pattern of anomalies that can be (or is clearly due from the prenatal history) to a teratogen. See Appendix 4 for a list of syndromes due to teratogen. Do not

use the diagnosis of “teratogenic syndrome” if there is no “recognizable pattern of anomalies”.

- Multiple congenital anomalies (MCA): 2 or more major anomalies without any recognizable pattern. It includes some known associations as VACTERL or MURCS, whose definition is not definitely established. The recognition of these patterns will be done in the analysis.
 - Unknown: include syndromes with unknown etiology
3. **Major #:** this box will open when the clinical diagnosis is selected by the dropdown. Give the number of major malformations diagnosed: 1 in isolated anomaly, 2 or more in sequences, MCA, syndromes.
 4. **Minor #:** this box will open when the clinical diagnosis is selected by the . Give the number of minor anomalies observed, coded or not. You may have one or more minor anomalies in cases with isolated major.
 5. **Syndrome Name:** give the full name of the recognized syndrome.
 6. **Resources (www.icbdsr.org):** *CLICK this button you will go to the website of ICBDSR where you will find a page of “Tools for Birth Defects Surveillance”*

The above assumes that the individuals who saw the case infant or those entering the data will be able to classify the type/nature of the patterns, and this is not always the case.

Local notes

Page 3 – Section 2

Birth Defects								
Description *	Diagnosis	Confir- med	Type of BD	ICD 10 RCPCH Name	Code	Prenat Diagn	Date of Diagnosis	Days to Discovery
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	
							DD/MM/YYYY	

Birth Defects

- Description:** give the full and detailed description of the birth defect. Be precise, you can use all the words you need.
- Diagnosis:** give your diagnosis of each birth defect.
- Confirmed:** select yes or no from the drop down menu for each birth defect. Use yes when the defect is obvious and external. Use no when: (a) you are uncertain on the diagnosis although external and well described / documented by a photograph; (b) the defect is an internal defect and you need imaging or other diagnostic examinations.
- Type of BD:** select Minor, Major or Major Related for each birth defect from the drop down menu. See Appendix 5 for a selected list of minor anomalies. Major related is an anomaly which is of the same type of an anomaly classified as major. The related anomaly concept is part of the "sequence" concept. See appendix 3.
- ICD 10 RCPCH Name:** use the ICD-10-RCPCH code system. This coding system is available separately in the PreSurv Suite. Chose for each birth defect the appropriate diagnostic name. The code of the diagnosis you can use for the data analysis will appear in the box **Code**.
- Prenat Diagn** (= Prenatal Diagnosis): select yes or no from the drop down menu for each birth defect. If yes, do not forget to give details in the "Procedures" section.
- Date of Diagnosis:** give the date of discovery/diagnosis for each birth defect, it may be prenatal or post natal. Give the day, at least approximate if do not know exactly.
- Days to Discovery:** the system will compute the time of discovery; a minus sign will appear if the defect was discovered through a prenatal diagnosis (e.g.: prenatal ultrasound, amniocentesis).

Local notes

Page 3 – Section 3

Procedures				
			Pictures Taken <input type="text"/>	<input type="button" value="Attach Images and Documents"/>
Date	Type	Specify Other	Normal/Abnormal	Comments
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Procedures

1. **Pictures Taken:** select from the drop down: yes or no. You are encouraged to take photographs. See Appendix 6 for Suggestions for taking photographs. Photographs or images include photographs of the child, photographs of X-Ray, photographs of post-mortem examination (complete or single organ), and photographs of a drawing.
2. **Attached Images and Documents:** Click here and select the image or document, e.g., autopsy report, karyotype report, you want to send to the central staff to document the birth defect(s).
3. **Date:** Indicate date of procedure., click twice to obtain the calendar
4. **Type:** select the procedure you have used to obtain a precise diagnosis of the defect(s) from the drop down menu. In "Specify Other" add procedures not listed

in the drop down menu. A "procedure" includes: (a) procedures that excluded a diagnosis, e.g., a normal result, and (b) consultation with an expert, e.g., you may need an expert opinion for a precise diagnosis of a rare or complex limb deficiency, or a clinical geneticist to diagnose or exclude a syndrome. You may include more than one procedure.

5. **Normal/Abnormal:** select the result for each procedure from the drop down menu. If abnormal use the comments box.
6. **Comments:** give the result(s) of abnormal procedures or any other comment for each procedure you feel may be useful to the central staff . Note that this box has a limited space.

Local notes

Page 4: Parent Information

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1

   **International Clearinghouse for Birth Defects**
Surveillance and Research

Case ID calculated: Further Review Notes: Case ID: Last Name:

Parent Information

Father's Information

Given Name: Surname:

Date of Birth: Reported: Calculated:
Age:

Education (years):

Working Activity: Code:

Race/Ethnicity 1:

Race/Ethnicity 2:

Mother's Information

Given Name: Surname: Maiden Name:

Date of Birth: Reported: Calculated: ID #:
Age:

Education (years): Civil/Marital Status:

Working Activity at LMP: Code:

Race/Ethnicity 1: Foreign Born:

Race/Ethnicity 2: Birth Country:

Mother's Primary Residence

Street:

City:

State/Province:

Postal Code: Code:

Country:

Phone: Main Alternate

email Address:

Longitude:

Latitude:

Mother's Residence at LMP

Code:

Mother's Residence at Pregnancy Outcome

Code:

Comments

This is how the Parent Information page looks like.
In the next pages you will find the instructions for each section of the page.

Page 4 – Section 1

Father's Information			
Given Name	Surname		
<input type="text"/>	<input type="text"/>		
Date of Birth	Reported	Calculated	
<input type="text" value="DD/MM/YYYY"/>	Age <input type="text"/>	<input type="text"/>	
Education (years)	<input type="text"/>		
Working Activity	<input type="text"/>		Code <input type="text"/>
Race/Ethnicity 1	<input type="text"/>		
Race/Ethnicity 2	<input type="text"/>		

Father's Information

1. **Given Name and Surname:** give name and surname of the father. If the father is unknown fill the boxes with "Unknown".
2. **Date of Birth:** indicate the father's date of birth. The software will compute the number of completed years in the "Calculated" box.
3. **Age:** if you do not know the date of birth, leave the date of birth box blank and complete the box "age" with the age of the father.
4. **Education:** indicate the total years of education attained, including years when studying part time.
5. **Working activity:** select from the drop down menu the father's working activity. The system will give you the code in the **code** box, useful for analysis. The list use the terms of the International Standard Classification of Occupation - ISCO-08. Be familiar with this classification and with the definitions of each occupation. Available separately in the PreSurv Suite.
6. **Code:** the system will assign the code ISCO-08 for working activity.
7. **Race/Ethnicity 1:** *The drop down should be customized by the Program Central Staff.*
8. **Race/Ethnicity 2:** *The drop down should be customized by the Program Central Staff, if needed here can be added the tribe.*

Local notes

Page 4 – Section 2

Mother's Information			
Given Name	Surname	Maiden Name	
<input type="text"/>	<input type="text"/>	<input type="text"/>	
Date of Birth	Age	Reported	Calculated
<input type="text" value="DD/MM/YYYY"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Education (years)	Civil/Marital Status		
<input type="text"/>	<input type="text"/>		
Working Activity at LMP	Code		
<input type="text"/>	<input type="text"/>		
Race/Ethnicity 1	Foreign Born		
<input type="text"/>	<input type="text"/>		
Race/Ethnicity 2	Birth Country		
<input type="text"/>	<input type="text"/>		

Mother's Information

1. **Given Name, Surname and Maiden Name:** give name and surname of the mother. If maiden name is unknown fill the box with "Unknown"
2. **Date of Birth:** indicate the mother's date of birth. The software will compute the number of completed years in the "Calculated" box. If unknown or no number available use the "99999" code
3. **Age:** if you do not know the date of birth, leave the date of birth box blank and complete the box "age" with the age of the mother.
4. **ID#:** to be selected by program according to local usage (e.g., social security number) give the number of mother's country identification number if available, or any other identification code. Useful for linkage and to avoid duplication. If unknown or no number available use the "99999" code.
5. **Education (years):** indicate the total years of education attained, including years when studying part time.
6. **Civil/Marital Status:** select one of the options given in the drop down.
7. **Working Activity at LMP:** select from the drop down menu the mother's working activity at last menstrual period (LMP). The system will give you the code in the **code** box, useful for analysis. The list use the terms of the International Standard Classification of Occupation - ISCO-08. Be familiar with this classification and with the definitions of each occupation. Available separately in the PreSurv Suite.
8. **Code:** the system will assign the ISCO-08 code for working activity
9. **Race/Ethnicity 1:** *The drop down should be customized by the Program Central Staff.*
10. **Race/Ethnicity 2:** *The drop down should be customized by the Program Central Staff.*
11. **Foreign Born:** select by drop down: yes for women born outside the country, not outside the region/state/province of a country.
12. **Birth Country:** the field will be open only if you choose yes from the dropdown of foreign born, select the country where the mother was born from the drop down.

Local notes

Page 5: Prenatal Care

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1






International Clearinghouse for Birth Defects
Surveillance and Research

Case ID calculated

Further Review Notes

Case ID

Last Name

Prenatal Care

Pregnancy Planning

Health Counseling Before Pregnancy

Pregnancy Intention Planning

Time to Pregnancy (months)

Assisted Reproduction

BMI

Mother's Height	Mother's Weight	Timing	BMI	BMI Class	Comments
<input type="text"/> cm	<input type="text"/> kg	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Prenatal Care

Nutrition Specify Other

Prenatal Diagnosis

Procedure	Normal / Abnormal	Week	Comments
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Folic Acid Supplementation

Timing

Type

Dose (mg/pill) Frequency Per Week

Comments

**This is how the Prenatal Care page looks like.
In the next pages you will find the instructions for each section of the page.**

Page 5 – Section 1

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1

Case ID calculated: Further Review Notes: Case ID: Last Name:

Prenatal Care

Pregnancy Planning

Health Counseling Before Pregnancy: Time to Pregnancy (months):
Pregnancy Intention Planning: Assisted Reproduction:

BMI

Mother's Height	Mother's Weight	Timing	BMI	BMI Class	Comments
<input type="text"/> cm	<input type="text"/> kg	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Pregnancy Planning

1. *Health Counseling Before Pregnancy*: select yes, no, or unknown from the drop down menu. **A working definition of Health Counseling Before Pregnancy should be developed by each program.**
2. *Pregnancy Intention Planning*: select one of the four options from the drop down menu. Planned pregnancy **definition should be developed by each program and be culturally appropriate.** One definition can be: (a) the couple did not use any contraception method; (b) the couple desired a child as soon as possible in the following months; (c) the couple tried to have unprotected intercours during the woman's fertile period.
3. *Time to Pregnancy*: this box opens only if you select planned pregnancy. Give in month the time passed between the strong desire to have a child and the date of the last menstrual period of the present pregnancy.

4. *Assisted Reproduction*: select one of the five options. Specify in comments at the end of the page if there were other assisted reproduction techniques. Do not include the use of ovulation inductors. Use of ovulation inductors should be recorded on the "Medication" section, Page 9.

BMI = Body Mass Index

5. *Mother's Height and Mother's Weight*: give height (in meters) and weight (in kilograms) of the mother. The system will compute the **BMI** and the **BMI Class**. See appendix 7.
6. *Timing*: select one of the six options from the drop down menu to specify when height and weight was recorded.
7. *Comments*: specify here if the height and weight have been provided by the mother, if a clinical record is available, or if you have evaluated height and weight.

Local notes

Page 5 – Section 2

Prenatal Care	<input type="text"/>		
Nutrition	<input type="text"/>	Specify Other	<input type="text"/>
Prenatal Diagnosis			
Procedure	Normal / Abnormal	Week	Comments
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Prenatal Care

1. *Prenatal care*: select one of the six options from the drop down menu. The needed info is the first prenatal visit (after conception and before delivery) performed by a health care provider expert in pregnancy evaluation.
2. *Nutrition*: select one of the five options from the drop down menu. If you select "others," please specify in the next box. Specify in "Comments," at the end of the page, if the woman ate enough food fortified with folic acid. This is important information even in countries where fortification with folic acid is mandatory. **The definition of nutritional patterns should be decided by each program.**

Prenatal Diagnosis

3. *Procedure*: select one of the eleven options from the drop down menu. You have four rows to specify the procedures.
4. *Normal / Abnormal*: select the option from the drop down for each performed procedure
5. *Week*: give the gestational age when the diagnosis was performed. Be precise
6. *Comments*: give any useful comment for each procedure to understand if a birth defect, and which one, was detected.

Local notes

Page 5 – Section 3

Folic Acid Supplementation	Comments
Timing <input type="text"/>	<input type="text"/>
Type <input type="text"/>	
Dose (mg/pill) <input type="text"/> Frequency Per Week <input type="text"/>	

Folic Acid Supplementation

1. **Timing:** select one of the seven options from the drop down menu. Correct use is defined: 0.4 mg at least 6 days per week in average, at least three months before conception, (2 and one half months before LMP). **Other definition of correct use can be decided by each program.**
2. **Type:** select one of the two options from the drop down menu. Alone means folic acid only; with other vitamins means strictly with other vitamins, exclude association, for example, with iron, omega-3, and inositol. If so specify in "Comments".
3. **Dose (mg/pill):** give the daily dose in mg per pill taken in the specified period of time.
4. **Frequency per Week:** give the frequency per week of the pills used.
5. **Comments:** any comments given to the central staff should be as precise as possible to classify the correct use of folic acid supplementation. Use this box for any other comments related to Preconception or prenatal care.

Local notes

Page 6: Previous Pregnancies

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1






International Clearinghouse for Birth Defects
Surveillance and Research

Case ID calculated

Further Review Notes

Case ID

Last Name

Previous Pregnancies

Previous Pregnancies (excluding case)

Date of Outcome	Birth Outcome	Comments (specify if they had any birth defects)
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>
<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>	<input style="width: 100%; height: 20px;" type="text"/>

Number of previous pregnancies: birth(s)

 (birth = stillbirth / fetal death or live birth, singleton or twin)

Previous Parity

Total number of births

 (includes twins)

Number of previous pregnancies: abortion(s)

 (abortion = miscarriage/abortion/ early fetal death, spontaneous or induced, singleton or twin)

Previous Gravidity

Comments

**This is how the Previous Pregnancies page looks like.
In the next pages you will find the instructions for each section of the page.**

Page 6 – Section 1

Previous Pregnancies (excluding case)		
Date of Outcome	Birth Outcome	Comments (specify if they had any birth defects)
DD/MM/YYYY		

Previous Pregnancies

1. *Date of Outcome*: list all the previous pregnancy of the mother of this infant. Disregard half sibs of the same father with a different woman. If you do know exactly the date of outcome, but you know the month give "15" for the day, the month and the year; if you do not know the day and the month, and you know only the year give "15 June" and the year
2. *Birth Outcome*: specify the type of outcome selecting form the drop down menu: Live births, Stillbirths, Spontaneous Abortions, Induced Abortions or Elective Termination Of

Pregnancy for Fetal Anomaly (ETOPFA). See Appendix 1 for definitions. You may list any number of previous outcomes. If the woman had a previous pregnancy with twins list each twin in separate row. In other words a pregnancy outcome of three twins 1 stillbirth and 2 live births will have three rows.

3. *Comments*: give all relevant comments for each outcome you feel useful for the central staff. Include information on health status of the living children, including detected birth defects

Local notes

Page 6 – Section 2

Number of previous pregnancies: birth(s) <input type="text"/> (birth = stillbirth / fetal death or live birth, singleton or twin)	Previous Parity <input type="text"/>	Total number of births <input type="text"/> (includes twins)
Number of previous pregnancies: abortion(s) <input type="text"/> (abortion = miscarriage/abortion/ early fetal death, spontaneous or induced, singleton or twin)		
Total number of previous pregnancies <input type="text"/>	Previous Gravidity <input type="text"/>	
Comments <input type="text"/>		

Previous Pregnancies

1. *Number of previous pregnancies: birth(s)*: after having filled the above fields the system will compute the number of previous pregnancy ended in a "birth" (single or multiple) = parity
2. *Number of previous pregnancies: abortion(s)*: after having filled the above fields the system will compute the number of previous abortions (spontaneous or induced)
3. Total number of previous pregnancies: the system will calculate the Total number of previous pregnancies = Previous Gravidity
Remember that the gravidity and parity is a mother attribute and the unit of count is the number of pregnancies not the **number of fetuses/infants**.
4. *Total number of births*: for the sake of completeness give here the total number of live birth and stillbirths including the twins.
5. *Comments*: give the specification or comments if needed.

Local notes

Page 7: Family History

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1

   **International Clearinghouse for Birth Defects**
Surveillance and Research

Family History

Case ID calculated Further Review Notes Case ID Last Name

Birth Defects in the Family

Name	Relationship	Diagnosis	Major/Minor	ICD 10 RCPCH Code	Comment

Previous Affected Sibling(s)

Sibs with Identical or Similar Defect

Parental Consanguinity

Comments

Scanned Image of Family Tree

**This is how the Parent Information page looks like.
In the next pages you will find the instructions for each section of the page.**

Page 7 – Section 1

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1






International Clearinghouse for Birth Defects
Surveillance and Research

Family History

Case ID calculated

Further Review Notes

Case ID

Last Name

Birth Defects in the Family

Name	Relationship	Diagnosis	Major/Minor	ICD 10 RCPCH Code	Comment
			▼	▼	

Family History

Family Definition: in this section family includes mother, father, the four grandparents, the maternal and paternal uncle(s) and aunt(s). Exclude siblings, they have their own section below.

Birth Defects in the Family

1. Name: use only the given name, not the surname. May be useful for reviewing.
2. Relationship: give the relationship with the case.

3. Diagnosis: give the diagnosis of the birth defect. Include only major structural birth defects. Exclude any other disease, e.g., cancer, cardiovascular diseases, diabetes.
4. Major/minor: specify if the anomaly is major or minor.
5. ICD 10 RCPCH Code: select from the drop down the ICD-10-RCPCH code..
6. Comment: give any comment useful for the central staff. The most important info to give in comment section is the quality of information, e.g., if the family member or her/his clinical record was examined by the filing person (or her/his colleague).

Local notes

Page 7 – Section 2

<p>Previous Affected Sibling(s) <input type="text"/></p> <p>Sibs with Identical or Similar Defect <input type="text"/></p> <p>Parental Consanguinity <input type="text"/></p> <p>Comments <input type="text"/></p>	<p>Scanned Image of Family Tree <input type="text"/></p>
--	--

1. Previous Affected Sibling(s): give the number of previous sibling(s) affected by a birth defect. Include ETOPFA.
2. Sibs with Identical or Similar Defects: give the number of affected sibling(s) including ETOPFA with an identical or similar defect. Do not forget to give the diagnosis of birth defects in sibling(s) and all the useful info in the comments section.
3. Parental Consanguinity: select one of the seven options from the drop down menu.

4. Comments: give info on anomalies in previous siblings in detail.
5. Scanned Image of Family Tree: click here and select the image of family tree you have done, may be scanned or photographed. It is useful to always include the family tree when at least one family member is affected, to have information on the total number of family members.

Local notes

Page 8: Risk Factors-1

PreSurv
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Case ID calculated



International Clearinghouse for Birth Defects
Surveillance and Research

Risk Factors

Life Style

	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
Smoking <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Smokeless Tobacco <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Alcohol <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Water <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Illicit Drugs

Name	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Chemical Exposures

Mother / Father	Name	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Chronic Conditions

Name	Code	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

**This is how the Risk Factors -1 page looks like.
In the next pages you will find the instructions for each section of the page.**

Page 8 – Section 1

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1






**International Clearinghouse for Birth Defects
Surveillance and Research**

Case ID calculated

Further Review Notes

Case ID

Last Name

Risk Factors

Life Style

	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
Smoking <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Smokeless Tobacco <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Alcohol <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Water <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Risk Factors – General Rule

Please note that for all risk factors you should specify the exposure time. **B** means: before last menstrual period (LMP). The day of beginning of LMP is the best proxy for estimate the date of conception, it is much better known by the women. **P** means post (after) the LMP. The **numbers** after B and P mean the months before or after the LMP. **2nd** and **3rd** mean second and third trimester. Thick the right box(es) when the information on the exposure time is available in the clinical record or given by the mother at interview (recommended). If uncertain or unknown leave blank. Use the **Comments** box to specify the quantity, or any other information useful to understand the type of exposure.

Life Style

1. **Smoking**: select yes, no, unknown from the drop down. Yes means 1 or more cigarettes per day, specify the number of cigarettes smoked, in comments and the time period in the right box(es) box. **No** means never smoked or quit smoking more than 3 months before LMP. See the Risk Factors General Rules for timing of exposure.
2. **Smokeless Tobacco**: select yes, no, unknown from the drop down. Specify which type of smokeless tobacco used in comments. Follow the “smoking rules” for the meaning of yes and no. See the Risk Factors General Rules for timing of exposure.
3. **Alcohol**: select one of the nine options from the drop down. See the Risk Factors General Rules for timing of exposure.
4. **Water**: select one of the four options. Water means water used for drinking, not for cooking. See the Risk Factors General Rules for timing of exposure.

Local notes

Page 8 – Section 2

Illicit Drugs			B3	B2	B1	P1	P2	P3	2nd	3rd
Name	Comments		<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>		<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>		<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>		<input type="checkbox"/>							

Chemical Exposures			B3	B2	B1	P1	P2	P3	2nd	3rd
Mother / Father	Name	Comments	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Illicit Drugs

You have the possibility to list the exposure to three different illicit drugs.

1. *Illicit Drugs Name*: select the name of the illicit drug from options of the drop down menu, and specify other in the Comments box.
2. *Comments*: give comments for each illicit drugs if needed.
See the Risk Factors General Rules for risk factors for timing of exposure.

Chemical Exposures

You have the possibility to list the father's or mother's exposure to three different chemical products

5. *Mother / Father*: select from the drop down if the mother or the father was exposed to a chemical product. Evaluate the working and leisure activities.
6. *Name*: select one of the 3 most common chemical exposures, if others specify in Comments.
7. *Comments*: give comments for each chemical exposure
See the Risk Factors General Rules for timing of exposure

Local notes

Page 8 – Section 3

Chronic Conditions										
Name	Code	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Chronic Conditions

Chronic Conditions - Definition: any condition existing from several months before conception. It includes conditions that required treatment or not. Also includes infertility defined as failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse. As you can see you have the possibility to list four different chronic conditions of the mother.

1. **Name:** select one of the already listed conditions from the drop down menu. If the condition is not included in this list select others and specify in comments.
2. **Code:** if you have selected one of the already list conditions the system will give the ICD-10 code, useful for analysis. Other will be collectively coded with "88888".
3. **Comments:** give the needed comments, e.g.: specify other conditions, year of diagnosis, treatment used in the last year before conception.

See the Risk Factors General Rules for timing of exposure.

Local notes

Page 9: Risk Factors-2

PreSurv
Birth Defects Prevention and Surveillance
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International Clearinghouse for Birth Defects
Surveillance and Research

Risk Factors

Case ID calculated
Further Review Notes
Case ID
Last Name

Diseases During Pregnancy

Name	Code	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Fever Comments

 B3
 B2
 B1
 P1
 P2
 P3
 2nd
 3rd

Reason for Fever:

Medications

Name	ATC Code	Indication	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Contraception Comments

 B3
 B2
 B1
 P1
 P2
 P3
 2nd
 3rd

Surgeries

 B3
 B2
 B1
 P1
 P2
 P3
 2nd
 3rd

Injuries

 B3
 B2
 B1
 P1
 P2
 P3
 2nd
 3rd

This is how the Risk Factors-2 page looks like.
In the next pages you will find the instructions for each section of the page.

Page 9 – Section 1

Risk Factors

Case ID calculated Further Review Notes Case ID Last Name

Diseases During Pregnancy

Name	Code	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Fever Comments B3 B2 B1 P1 P2 P3 2nd 3rd

Reason for Fever

Diseases /Conditions/Exposures During Pregnancy – Working Definition: any condition occurred in pregnancy or in the three months before. This means that this type of condition are not chronic and not present before the three months before pregnancy. It includes conditions requiring treatment or not.

Diseases During Pregnancy

You have the possibility to list four different conditions.

1. *Name:* select one of the already listed conditions from the drop down menu. If the condition is not included in this list select others and specify in comments.
2. *Code:* if you have selected one of the already list conditions the system will give the ICD-10 code, useful for analysis. Other will be collectively coded with "88888".
3. *Comments:* give the needed comments, e.g.: specify other conditions, treatment used, any other useful specific information. See the Risk Factors General Rules for timing of exposure.
4. *Fever:* select one of the four options from the drop down menu.
5. *Comments:* give the needed comments, e.g.: treatment used, any other useful specific information.
6. See the Risk Factors General Rules for timing of exposure.
7. *Reason for Fever:* select one of the six options from the drop down menu.
8. *List in dropdowns can be adapted by the country.*

Local notes

Page 9 – Section 2

Reason for fever

Medications				B3	B2	B1	P1	P2	P3	2nd	3rd
Name	ATC Code	Indication	Comments								
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

	Comments	B3	B2	B1	P1	P2	P3	2nd	3rd
Contraception <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Surgeries <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							
Injuries <input type="text"/>	<input type="text"/>	<input type="checkbox"/>							

Medications – Include also Vaccinations

1. *Name*: select one of the twelve options from the drop down menu. Specify other in the Comments box. The drop down menu includes wide groups of medication specify the chemical denomination of the product used in the Comments box, do not use brand name.
2. *ATC Code*: use the ATC code, see details at http://www.whocc.no/atc_ddd_index/. You can **click** on the top right box to have easy access.
3. *Indication*: specify the reason why the medication has been used. Review the section of conditions before and after conception (LMP), correct if necessary. Use of medications and conditions must be consistent.
4. *Comments*: give any comments to characterize the type of medication used, e.g., dose, times per week.
5. See the Risk Factors General Rules for timing of exposure.

Others

6. *Contraception*: select one of the five options from the drop down menu. See smoking rules for timing. Timing is limited to the three month before and 2 month after LMP.
7. *Surgeries*: select yes, no, unknown from the dropdown menu. Yes means any kind of surgery performed with general anesthesia.
8. *Injuries*: select yes, no, unknown from the drop down menu. Yes means any kind of injury or accident. It includes also any injury not requesting medical attention, e.g., a fall at home, domestic violence.
9. See the Risk Factors General Rules for timing of exposure.

Local notes

Page 10: Referral to Service

PreSurv
Birth Defects Prevention and Surveillance
Version 3.1

International Clearinghouse for Birth Defects
Surveillance and Research

Referral to Service

Case ID calculated:

Further Review Notes:

Case ID:

Last Name:

Referrals

Date of Referral	Service Type	Service Name	Name of Health Care Provider	Comments

NTD Recurrence Prevention

Referred:

Date:

Comment:

Referral to Service: Since the program registers cases with a major defect, all cases observed in live births and alive the day of discharge should be referred to a service for follow-up or treatment. Complete this section in all such cases. Include all referrals for prevention of recurrence, follow-up, diagnostic evaluation, and treatment. A specific section for NTD Recurrence Prevention is provided.

1. *Date of Referral:* give date of referral to service.
2. *Service Type:* give the type of referral, e.g., geneticist, pediatrician, genetic counselor
3. *Service Name:* give the name of service where the case was referred.
4. *Name of HCP:* give the name of the health care provider (HCP) to whom the case was referred.
5. *Comments:* give any comments to characterize the type of referral, e.g., the plan of follow-up or treatment
6. *NTD Recurrence Prevention:*
7. *Referred:* select from the drop down menu yes or no
8. *Date:* give date of referral.

Local notes

Appendices

Appendix 1. Definitions

Pregnancy outcome: the result of conception and ensuing pregnancy, including live birth, stillbirth, spontaneous abortion and induced abortion (1).

Live birth: the complete expulsion or extraction of a product of conception from its mother, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached. Each product of such a birth is considered live born (2).

Stillbirth or Late Fetal Death: a fetus that is deceased at delivery; fetal death refers to death prior to the complete expulsion or extraction of a product of conception from its mother, irrespective of the duration of pregnancy; the death is indicated by the fact that, after such separation, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles (2).

ETOPFA: Elective Termination of Pregnancies for Fetal Anomaly is a termination performed after a prenatal diagnosis of a severe birth defect. The parents as a consequence of the diagnosis opted for a termination of pregnancy. ETOPFA does not include termination of pregnancy performed for other reasons (e.g., psycho-social).

References

- (1) WHO/CDC/ICBDSR. Birth defects surveillance: a manual for programme managers. Geneva: World Health Organization; 2014.
- (2) International Statistical Classification of Diseases and Related Health Problems, 10th revision. Geneva: World Health Organization; 2010 (<http://apps.who.int/classifications/icd10/browse/2010/en>, accessed 28 October 2013).

A full glossary is available on WHO/CDC/ICBDSR. Birth defects surveillance: a manual for programme managers. Geneva: World Health Organization; 2014.

Birth weight: the first weight of the fetus or neonate obtained after birth; for live births, birth weight can be measured within the first hour of life before postnatal weight loss has occurred; actual weight is recorded to the degree of accuracy by which it is measured (2).

- **Low birth weight:** less than 2500 g, up to and including 2499 g.
- **Very low birth weight:** less than 1500 g, up to and including 1499 g.
- **Extremely low birth weight:** less than 1000 g, up to and including 999g.

Gestational age: the time elapsed, measured in weeks, since conception. Because the exact date of conception is not always known, gestational age may also be defined as the time elapsed from the first day of the woman's last normal menstrual cycle. The duration of a normal pregnancy can range from 38 to 42 weeks. Gestational age is frequently a source of confusion when calculations are based on menstrual dates; for the purposes of calculation of gestational age from the date of the first day of the last normal menstrual period and the date of delivery, it is borne in mind that the first day is day zero and not day one; days 0–6 therefore correspond to "completed week zero"; days 7–13 to "completed week one"; and the 40th week of actual gestation is synonymous with "completed week 39"; where the date of the last normal menstrual period is not available, gestational age is based on the best clinical estimate; in order to avoid misunderstandings, tabulations are indicated both weeks and days (2).

- **Pre-term or premature:** less than 37 completed weeks (less than 259 days) of gestation.
- **Term:** from 37 completed weeks to less than 42 completed weeks (259 to 293 days) of gestation.
- **Post-term:** 42 completed weeks or more (294 days or more) of gestation.

Appendix 2. Weight parameters to define Small for Gestational Age, by week of gestational age and sex.

GA (weeks)	Weight (g), less than	
	Males	Females
20	270	256
21	328	310
22	388	368
23	446	426
24	504	480
25	570	535
26	644	592
27	728	662
28	828	760
29	956	889
30	1117	1047
31	1308	1234
32	1521	1447
33	1751	1675
34	1985	1901
35	2205	2109
36	2407	2300
37	2596	2484
38	2769	2657
39	2908	2796
40	2986	2872
41	3007	2891
42	2998	2884
43	2977	2868
44	2963	2853

Note: The parameters to define small for gestational age are not country specific,. The analysis of the proportion of infants small for gestational age with particular

birth defect will be performed in comparison with infants with other birth defects or (better) with infants without a birth defects using the same parameters.

Appendix 3.

Selected list of related anomalies

Primary defect	Related defect(s) - one or more of the listed anomalies
Anencephaly	Spina bifida , any defect of brain, any defect of cranial bones, any facial or ear dysmorphic feature, hypoplastic adrenal glands, hypoplastic penis.
Spina bifida	Hydrocephalus (1), vertebral and costal anomalies, clubfoot any type, hip dislocation,
Encephalocele	Defect of cranial bone, microcephaly, nose anomaly if nasofrontal type
Iniencephaly	Any defect of cervical and upper thoracic vertebra and cost, any dysmorphic feature of neck and face, anterior spina bifida, diaphragmatic defect
Hydrocephaly	Macrocephaly
Holoprosencephaly	Any brain defect, microcephaly, cyclopia, microphthalmia, iris coloboma, hypotelorism, lack of ethmoid bone, any facial and nose dysmorphic feature, cleft lip .
Anophthalmia	Microphthalmia on the other side
Anotia	Microtia on the other side
Cleft palate	Micrognathia - Pierre Robin sequence (2)
Hypospadias	Cryptorchidism
Limb deficiency	Limb deficiency on another limb
Digit deficiency	Syndactyly
Gastroschisis	Intestinal atresia, malrotation

Appendix 4. List of Recognized Syndromes Due to a Well Known Teratogen

Aminopterin / Methotrexate syndrome	Hydantoin syndrome	Thalidomide syndrome
Anticonvulsant syndrome	Methimazole syndrome	Toxoplasmosis, congenital
Cytomegalovirus syndrome	Mycophenolate mofetil syndrome	Valproic acid syndrome
Fetal alcohol spectrum disorder	Retinoid syndrome	Varicella syndrome
Fetal alcohol syndrome	Rubella syndrome	Warfarin syndrome

However, it is essential to recognize that the majority of these teratogenic exposures do not present as “syndromes.”
Jones KL. Smith’s Recognizable Patterns of Human Malformations 6th Edition 2006 Elsevier Inc.

Appendix 5. Selected List of External Minor Congenital Anomalies

Congenital Anomaly	ICD-10
EYE	
Congenital ectropion	Q10.1
Congenital entropion	Q10.2
Absence of eyelashes	Q10.3
Dystopia canthorum	Q10.3
Epicanthal folds	Q10.3
Epicanthus inversus	Q10.3
Fused eyelids	Q10.3
Long palpebral fissure(s)	Q10.3
Upward or downward slanting palpebral fissures	Q10.3
Short palpebral fissures	Q10.3
Long eyelashes	Q10.3

Weakness of eyelids	Q10.3
Stenosis or stricture of lacrimal duct	Q10.5
Iris coloboma	Q13.0
Brushfield spots	Q13.2
Iris freckles	Q13.2
Blue sclera	Q13.5
Exophthalmos	Q15.8
Strabismus	Q15.8
EAR	
Accessory tragus	Q17.0
Auricular tag or pit	Q17.0
Double ear lobule	Q17.0
Ear pit or tag	Q17.0
Preauricular appendage, tag, or lobule	Q17.0

Large ears	Q17.1
Macrotia	Q17.1
Absent tragus	Q17.3
Asymmetric sized ears	Q17.3
Crumpled ears	Q17.3
Cup ear	Q17.3
Ear lobe crease	Q17.3
Ear lobe notch	Q17.3
Lack of helical fold	Q17.3
Lop ear	Q17.3
Misshapen ears	Q17.3
Pointed ear	Q17.3
Primitive shape of ear	Q17.3
Protruding ears	Q17.3
Simple ear	Q17.3
Small ears (excludes true microtia)	Q17.3
Thickened or overfolded helix	Q17.3
Low-set ears	Q17.4
Misplaced ear	Q17.4
Posteriorly rotated ears	Q17.4
Bat ear	Q17.5
Prominent ears	Q17.5
Darwinian tubercle	Q17.8
Narrow external auditory meatus	Q17.8
FACE AND NECK	
Branchial vestige	Q18.0
Branchial tag or pit	Q18.0
Fistula of auricle, congenital and fistula cervicoaural	Q18.1
Preauricular sinus and cyst	Q18.1
Redundant neck folds	Q18.3
Webbed neck (pterygium colli)	Q18.3
Macrostomia	Q18.4
Microstomia	Q18.5
Hypertrophy of lip, congenital or Macrocheilia or large wide lips	Q18.6
Short or long columella	Q18.8
Angular lip pits	Q18.8
Small lips	Q18.8
Short neck	Q18.8 (?)
Thin vermilion border	Q18.8
Synophrys, confluent or medial flare eyebrows	Q18.80

PERIPHERAL VASCULAR SYSTEM	
Single umbilical artery	Q27.0
NOSE	
Notched or hypoplastic alae nasi	Q30.2
Anteverted nares	Q30.8
Flat or wide nasal bridge	Q30.8
Small nares	Q30.8
Smooth philtrum	Q30.8
MOUTH	
Cleft uvula	Q35.7
Tongue-tie	Q38.1
Macroglossia	Q38.2
Adhesion of tongue	Q38.3
Bifid tongue	Q38.3
Fissure of tongue	Q38.3
Hypoglossia	Q38.3
Hypoplasia of tongue	Q38.3
Microglossia (hypoplasia of tongue)	Q38.3
Ranula	Q38.4
Absent uvula	Q38.5
High arched palate	Q38.50
Aberrant frenula	Q38.6
Broad alveolar ridge	Q38.6
Cleft gum (in the absence of cleft lip)	Q38.6
Natal teeth	Q38.6
ANUS AND GENITALIA	
Anterior anus (ectopic anus)	Q43.5
Imperforate hymen	Q52.3
Embryonal cyst of vagina	Q52.4
Fusion of labia	Q52.5
Fusion of vulva	Q52.5
Prominent clitoris	Q52.6 or Q52.8
Hypoplastic labia majora	Q52.8
Hypoplastic labia minora	Q52.8
Undescended testicle, unilateral	Q53.1
Undescended testicle, bilateral	Q53.2
Undescended testicle, unspecified	Q53.9
Chordee (without hypospadias)	Q54.4
Hypoplasia of testis and scrotum	Q55.1
Shawl scrotum	Q55.2

Retractile testis	Q55.20
Bifid scrotum	Q55.21
Absent or hooded foreskin of penis	Q55.6
Curvature of penis lateral	Q55.6
Phimosis	Q55.6
Redundant foreskin	Q55.6
Small penis (unless documented as micropenis)	Q55.6
Hydrocele of testis	Q55.8
Scrotalization of phallus	Q55.9
FOOT	
Metatarsus varus or metatarsus adductus	Q66.2
Hallux varus	Q66.3
Congenital pes planus	Q66.5
Hallux valgus	Q66.6
Metatarsus valgus	Q66.6
Pes cavus	Q66.7
Hammer toe, congenital	Q66.8
Long toes	Q66.8
Prominent calcaneus	Q66.8
Prominent heel	Q66.8
Short great toe	Q66.8
Vertical talus	Q66.8
Widely spaced first and second toes	Q66.8
Recessed fourth and fifth toes	Q66.8
Short fourth metatarsus	Q66.8
Short or broad great toe	Q66.8
Rocker-bottom feet	Q66.80
Overlapping toe	Q66.89
HEAD , FACE, SPINE AND CHEST	
Facial asymmetry	Q67.0
Compression facies	Q67.1
Dolichocephaly	Q67.2
Flat occiput	Q67.3
Head asymmetry	Q67.3
Plagiocephaly	Q67.3
Squashed or bent nose, congenital	Q67.4
Deviation of nasal septum	Q67.41
Funnel chest	Q67.6
Pectus excavatum	Q67.6
Congenital pigeon chest	Q67.7
Pectus carinatum	Q67.7

Barrel chest	Q67.8
Deformed chest	Q67.8
Prominent sternum	Q67.8
Shield-like chest	Q67.8
OTHER MUSCULOSKELETAL (INCLUDING LIMBS)	
Congenital deformity of sternocleidomastoid muscle	Q68.0
Contracture of sternocleidomastoid (muscle)	Q68.0
Congenital torticollis	Q68.0
Camptodactyly	Q68.1
Congenital clubfinger	Q68.1
Long fingers	Q68.1
Overlapping digits, not otherwise specified	Q68.1
Short fourth metacarpal	Q68.1
Single crease fifth finger	Q68.1
Tapered fingers	Q68.1
Short fingers	Q68.1
Clinodactyly	Q68.10
Genu recurvatum	Q68.21
Cubitus valgus	Q68.8
Hyperextended joints, not otherwise specified	Q68.8
Hyperextended knee	Q68.8
Polydactyly type B of fingers. (Type B is, by definition, post axial and rudimentary (postminimi). Type A is postaxial, fully developed.)	Q69.02b
Polydactyly type B, not otherwise specified	Q69.02b
Polydactyly type B of toes	Q69.22b
Syndactyly (involving second and third toes)	Q70.3
Genu valgum	Q74.1
OTHER ANOMALIES OF SKULL,FACE AND SPINE	
Scaphocephaly	Q75.0
Trigonocephaly, other head deformations without synostosis	Q75.0
Hypertelorism	Q75.2
Macrocephaly (includes familial benign macrocephaly)	Q75.3
Hypotelorism	Q75.8
Maxillary hypoplasia or prominence	Q75.8
Micrognathia	Q75.8
Prognathia	Q75.8
Frontal bossing	Q75.8 or Q75.80
Large or small fontanels	Q75.8 or Q75.80
Metopic suture open to bregma	Q75.8 or Q75.80
Narrow bifrontal diameter	Q75.8 or Q75.80
Prominent occiput	Q75.8 or Q75.80

Prominent or hypoplastic supraorbital ridges	Q75.8 or Q75.80
Third fontanel	Q75.8 or Q75.80
Congenital lordosis, postural	Q76.43
ABDOMEN	
Diastasis recti	Q79.5
Inguinal hernia	Q79.8
Umbilical hernia	Q79.8
SKIN, BREAST AND OTHER INTEGUMENT	
Skin cyst	Q82.4 or Q84.4
Angioma	Q82.5
Benign skin neoplasm, pigmented nevus (ear and auditory canal)	Q82.5
Benign skin neoplasm, pigmented nevus (eyelid)	Q82.5
Benign skin neoplasm, pigmented nevus (face)	Q82.5
Benign skin neoplasm, pigmented nevus (lip)	Q82.5
Benign skin neoplasm, pigmented nevus (lower limb, hip)	Q82.5
Benign skin neoplasm, pigmented nevus (other specified site)	Q82.5
Benign skin neoplasm, pigmented nevus (scalp, neck)	Q82.5
Benign skin neoplasm, pigmented nevus (trunk)	Q82.5
Benign skin neoplasm, pigmented nevus (unspecified site)	Q82.5
Benign skin neoplasm, pigmented nevus (upper limb, shoulder)	Q82.5
Café-au-lait spot	Q82.5
Hemangioma (other than face and neck)	Q82.5
Lymphangioma	Q82.5
Noncavernous, single, small hemangioma (<4" diameter)	Q82.5
Pigmented naevus, congenital non-neoplastic naevus	Q82.5
Birthmark	Q82.50
Nevus flammeus	Q82.51
Port-wine stain	Q82.51
Strawberry naevus	Q82.51
Mongolian spot	Q82.52
Cutis marmorata	Q82.8 or Q84.8
Dimple, hand	Q82.8 or Q84.8
Dimple, shoulder	Q82.8 or Q84.8
Extra or absent hand or interphalangeal creases	Q82.8 or Q84.8
Pilonidal or sacral dimple	Q82.8 or Q84.8

Plantar furrow	Q82.8 or Q84.8
Rectal fissure	Q82.8 or Q84.8
Sole crease	Q82.8 or Q84.8
Vaginal or hymenal tags	Q82.8 or Q84.8
Single transverse palmar crease	Q82.80
Anal tag	Q82.81
Skin tag	Q82.81
Unusual dermatoglyphics	Q82.84
Absent nipple	Q83.2
Extra nipples (supernumerary nipples)	Q83.3
Supernumerary nipple	Q83.3
Inverted nipples	Q83.8
Small nipple (hypoplastic)	Q83.8
Widely spaced nipples	Q83.8
Monilethrix	Q84.1
Pili annulati	Q84.1
Pili torti	Q84.1
Aberrant scalp hair patterning	Q84.1 or Q84.2
Depigmentary hair changes	Q84.1 or Q84.2
Hair upsweep	Q84.1 or Q84.2
Low posterior hairline	Q84.1 or Q84.2
Persistent lanugo	Q84.2
Congenital hypertrichosis	Q84.20
Absent nails (major if third phalanx is missing)	Q84.3
Enlarged or hypertrophic nails	Q84.5
Pachyonychia	Q84.5
Congenital clubnail, koilonychia, malformation of nail, NOS	Q84.6
Duplication of thumbnail	Q84.6
Hyperconvex fingernails	Q84.6
Hyperconvex toenails	Q84.6
Hypoplastic fingernails	Q84.6
Hypoplastic toenails	Q84.6
Thickened toenails	Q84.6
Cutis aplasia (major if large)	Q84.8

WHO/CDC/ICBDSR. Birth defects surveillance: a manual for programme managers. Geneva: World Health Organization; 2014.

Appendix 6: Suggestions for Taking Photographs of a Fetus or Newborn with a Congenital Anomaly

- If parental consent is required for taking the photograph:
 - Ensure the consent form is signed before taking the photograph.
 - *Note: If parents do not consent to a photograph, the fetus or neonate still should be included in the surveillance program.
- Prior to taking the photograph:
 - Have a clean, simple, non-patterned light or dark blue background (no blankets or other things in the bassinet or on the examination table).
 - If there are objects on the examination table that should not be in the photograph, remove them before taking the photograph.
- When taking the photograph:
 - Take a view of entire fetus or neonate plus several focused views of the congenital anomaly (ies).
 - Take a separate view of the face, if possible.
 - Take a front or back view, or both, plus a side view depending on the congenital anomaly.
 - Avoid taking photographs at an angle, i.e., take all photographs holding the camera at 90° to the fetus or neonate.
 - Use no personal identification; instead use coded identification.
- Make sure, if more than one photograph is taken, that all photographs can be identified with a code for that particular fetus or neonate.
- Assign identifiers to the photograph files using a unique code and adding an extra number to indicate the number of photograph taken of the same fetus or neonate (for example: 0001_1; 0001_2, etc.).
- Place a label next to, but not touching, the fetus or neonate, if needed. Similarly, place a ruler or measuring tape next to, but not touching, the fetus or neonate to help estimate size.
- Ensure that there are adequate lighting and no shadows in the photograph. Use a flash if needed.
- Consider the cost of photograph storage.
- When a digital camera is used:
 - Use high resolution, at least 300 ppi (pixels per inch).
 - Review photographs quickly while on site.
 - Save the image in jpeg (jpg) format; make sure each photograph is transferred to a computer file or other secure storage before deleting it from the camera.

*Tablets, smart phones can also be used to take photographs

WHO/CDC/ICBDSR. Birth defects surveillance: a manual for programme managers. Geneva: World Health Organization; 2014.

Appendix 7: Categories associated with BMI ranges for adults

Body Mass Index (BMI) = Weight in kilograms (Kg) / Height in meters (m), squared
E.g., women of 85 kg and 1.65 m = $85 / 1.65^2 = 31.2 = \text{Obese}$

BMI	Category
Below 18.5	Underweight
18.5 – 24.9	Normal
25.0 – 29.9	Overweight
30.0 and above	Obese

More categories, if needed

BMI	Category
Below 15	Very severely underweight
15.0 - 16.0	Severely underweight
16.0 - 18.5	Underweight
18.5 - 24.9	Normal (healthy weight)
25.0 – 29.9	Overweight
30 – 34.9	Obese Class I (moderately obese)
35 - 39.9	Obese Class II (severely obese)
40 and above	Obese Class III (very severely obese)