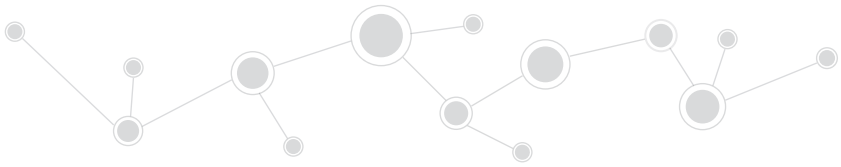
PARTICIPANT WORKBOOK



Activity 2.1

- Use the table below to complete a logic model for development of a congenital anomalies surveillance programme in your country.

Resources	Activities	Outputs	Short-term and long-term outcomes	Impact
Need the following resources in order to accomplish activities:	Need to accomplish the following activities in order to address the problem:	Once activities are accomplished expect to have the following product(s) or services:	If activities are accomplished they will lead to the following changes in 1–3 years:	If activities are accomplished, they will lead to the following changes in 4–6 years:

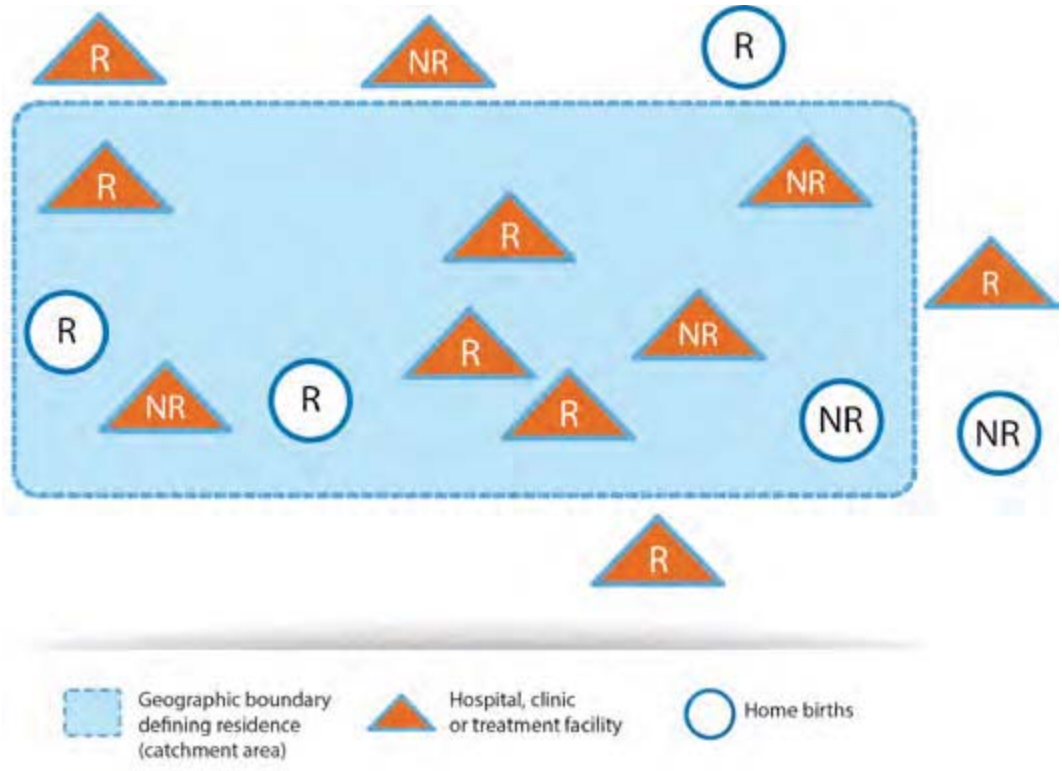
Activity 2.2

- Use the table below to complete a stakeholder's worksheet for development of a congenital anomalies surveillance programme in your country.

Likely users of outputs	Communication message	Dissemination strategy	Evaluation
Ministries of health			
Hospitals and, if relevant, hospital associations and clinics			
Champions			
Community health workers/community health volunteers			
Congenital anomalies associations, foundations and other nongovernmental organizations			
International organizations			
Medical schools/ research agencies			

Activity 3.1

- Study the figure below.



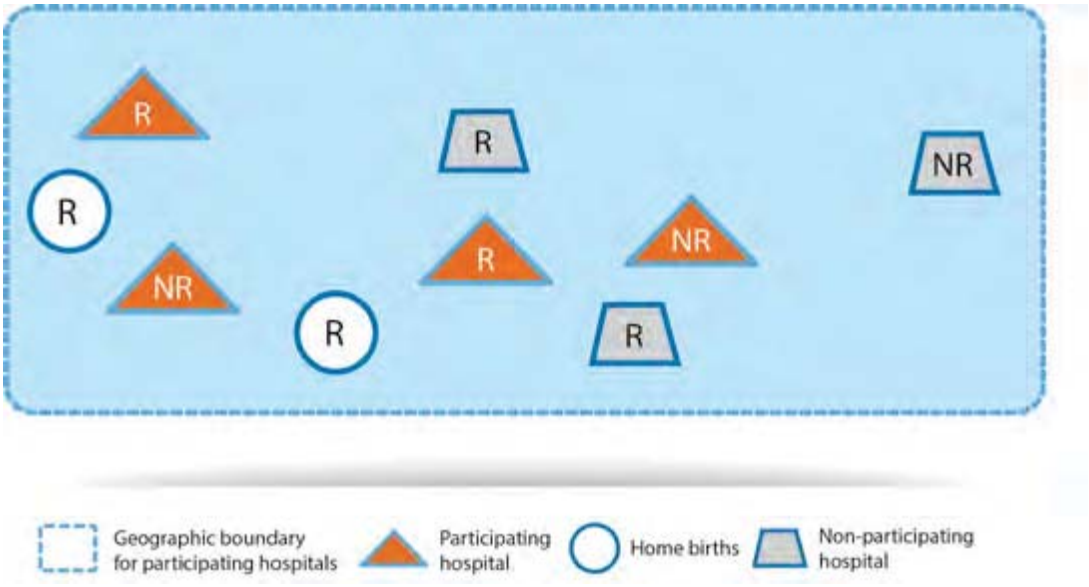
R = fetus or neonate with congenital anomaly whose mother is a *resident*.

NR = fetus or neonate with congenital anomaly whose mother is a *non-resident*.

- Questions
  - Does the figure represent a population-based or hospital-based surveillance programme?
  - What is the numerator (cases that should be registered) in this surveillance programme?
  - Is maternal residence important for this type of surveillance?
  - Are home births with congenital anomalies counted in this type of surveillance?

Activity 3.1 continued

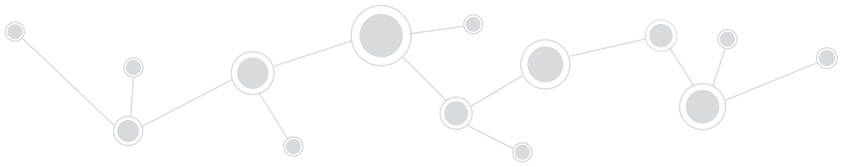
- Study the figure below.



R = fetus/neonate with a birth defect whose mother is a *resident* .

NR = fetus/neonate with a birth defect whose mother is a *non-resident.*

- Questions
  - Does the figure represent a population-based or hospital-based surveillance programme?
  - What is the numerator (cases that should be registered) in this surveillance programme?
  - Is maternal residence important for this type of surveillance?
  - Are home births with congenital anomalies counted in this type of surveillance?



Activity 3.2

- Create inclusion and exclusion criteria for population-based or hospital-based surveillance programmes. Keep in mind capacity and available data sources. Remember that inclusion and exclusion criteria will be different, depending on whether the programme is hospital based or population based.

Activity 3.3

- Review the table below and consider the suggested core ascertainment variables.
- Complete the blank column in the table with the reason each variable should be presented.

Category	Variable name	Why this variable should be collected
Report	Case record identification	
	City, province, state, or territory	
Father	Name(s)	
Mother	Name(s)	
	Mother's date of birth, or age if date of birth is not available	
	Total number of pregnancies	
Infant	Date of birth	
	Sex	
	Outcome at birth	

Activity 3.4

- Review the form below, and consider which variables you would add or delete, and why.

Birth Defects Surveillance Programme

Case record ID:
Date of report: (dd/mm/yyyy)

Name of health facility:
City:
Province/State/Territory:

FETUS / NEONATE

Name, if available:
Date of birth: (dd/mm/yyyy) Date of diagnosis of congenital anomaly: (dd/mm/yyyy)
Sex:
○ male ○ female ○ ambiguous ○ missing/unknown
Outcome at birth:
○ live birth ○ stillbirth
○ elective termination of pregnancy with fetal anomaly
Gestational age: (completed weeks)
Best estimation: ultrasound: LMP: other:
Weight: (grams) Length: (cm)
Head circumference: (cm)
Multiple birth: ○ Yes ○ No If yes, specify:
Photographs taken: ○ Yes ○ No
Did neonate die? ○ Yes ○ No
If yes, specify date of death: (dd/mm/yyyy)
Cause of death:
Autopsy: ○ Yes ○ No If yes, specify details on back of this sheet.

PARENTS

Father's given name(s):
Father's family name(s):
Father's date of birth: (dd/mm/yyyy) Father's age: (completed years)
Race/ethnicity:

Mother's given name(s):
Mother's family name(s) (including maiden name):
Mother's date of birth: (dd/mm/yyyy) Mother's age: (completed years)
Race/ethnicity:
Primary address during 1st trimester of pregnancy:
Town/city: Province:
Current address (if different from above):
Town/city: Province:
Telephone number:
Total number of previous: live births: stillbirths:
spontaneous abortions: terminations of pregnancy:

Are parents of fetus/neonate related? ○ Yes ○ No
If yes, specify: ○ first cousins ○ second cousins ○ aunt – nephew ○ uncle – niece ○ other (specify):

Congenital anomaly present	Full description of congenital anomaly (use back of form if needed)	ICD-10 code	C or P*
1.			○ C ○ P
2.			○ C ○ P
3.			○ C ○ P
4.			○ C ○ P
5.			○ C ○ P
6.			○ C ○ P
7.			○ C ○ P
8.			○ C ○ P
9.			○ C ○ P
10.			○ C ○ P

Diagnostic tests performed, pending results, notes and comments:

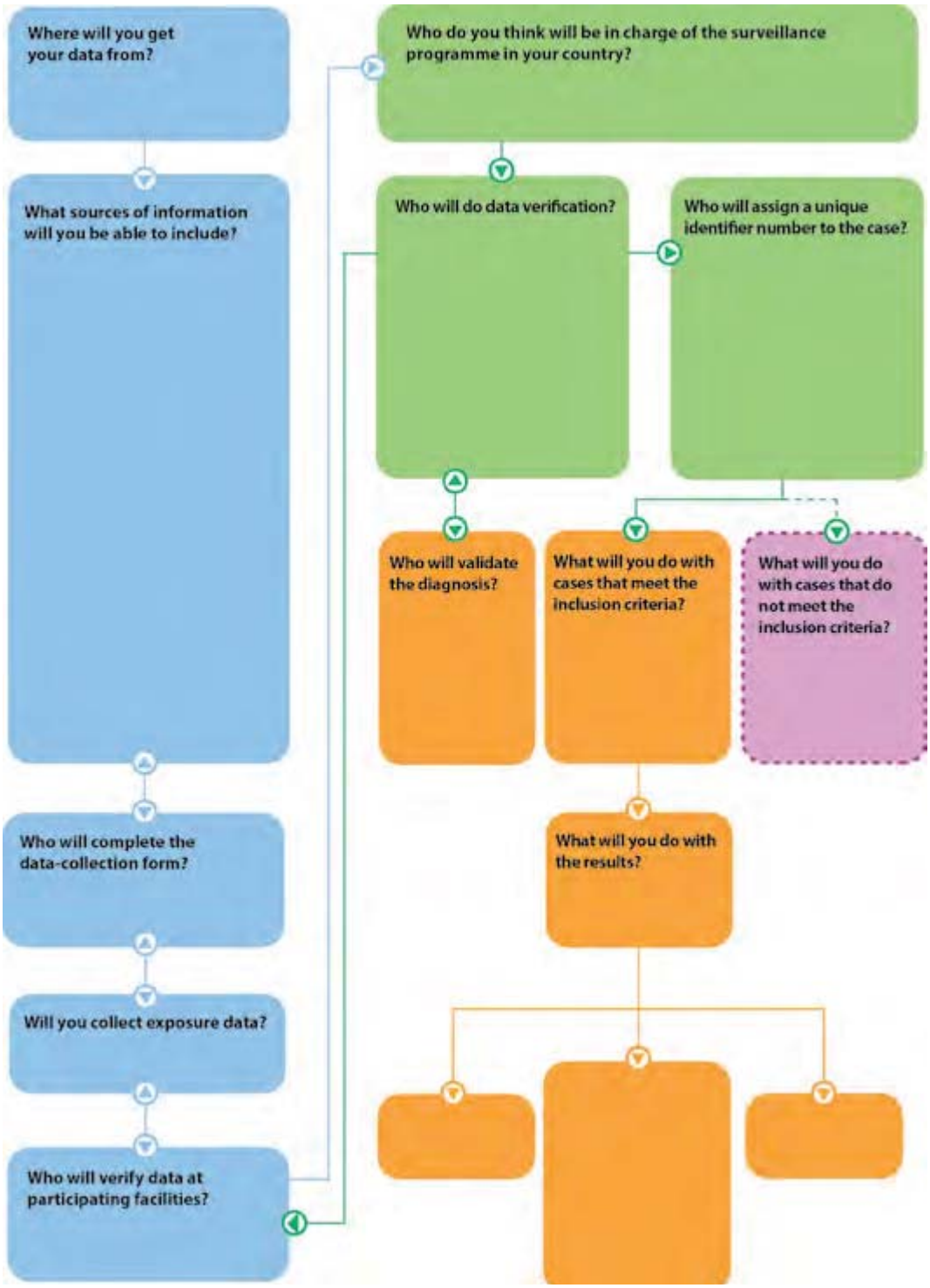
* C = Confirmed diagnosis
P = Possible diagnosis

Name of professional completing the form:
○ physician ○ nurse ○ other (specify):
Contact information:

Version: January 2014

Activity 3.5

- Complete the flow chart below.



Activity 3.6

- Read the case-study below.

Case-study: Cases of neural tube defects by type of ascertainment, United States of America (USA), 2004–2006

The United States National Birth Defects Prevention Network collects state-specific congenital anomalies surveillance data for annual publication of prevalence estimates and collaborative research projects. In 2010, data for 21 congenital anomalies from 2004–2006 were presented as national congenital anomalies prevalence estimates. The data presented in the table below are from population-based programmes that have different types of case ascertainment: active, hybrid and passive. Active ascertainment occurs when there is active review of multiple data sources to identify cases. Active ascertainment usually requires that the programme hires trained personnel to conduct abstraction from data sources. Passive ascertainment occurs when hospital staff report cases directly to the programme without verification of cases by the programme staff. An example of hybrid ascertainment is when hospital staff report cases and programme staff verify them.

Cases of neural tube defects by type of ascertainment, USA, 2004–2006

	Number of cases			
Neural tube defects	**Active ascertainment (11 programmes)[a]**	**Hybrid ascertainment (6 programmes)[b]**	**Passive ascertainment (7 programmes)[c]**	**National**
Anencephaly	697	211	192	1100
Spina bifida	1162	561	820	2543
Encephalocele	261	125	184	570
Total neural tube defects	2120	897	1196	4213

Source: Parker SE, Mai CT, Canfield MA, Rickard R, Wang Y, Meyer RE et al. Updated national birth prevalence estimates for selected congenital anomalies in the United States 2004–2006. Birth Defects Res A Clin Mol Teratol. 2010; 88:1008–16.

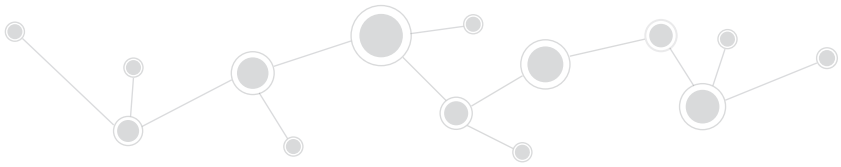
Data from programmes with active, hybrid or passive ascertainment.
[a] Number of live births in the active ascertainment programmes: 3 120 605.
[b] Number of live births in the hybrid ascertainment programmes: 2 075 973.
[c] Number of live births in the passive ascertainment programmes: 2 145 287.

- Questions
  - Estimate the national prevalence for each neural tube defect and for the total neural tube defects per 10 000 live births.
  - Estimate the birth prevalence for each neural tube defect per 10 000 live births by type of ascertainment.
  - Estimate the birth prevalence for total neural tube defects per 10 000 live births by ascertainment.
  - Enter your prevalence estimates in the table below

Cases of neural tube defects by type of ascertainment, USA, 2004–2006

	Active ascertainment (11 programmes)		Hybrid ascertainment (6 programmes)		Passive ascertainment (7 programmes)		National	
Neural tube defects	**Cases**	**Prevalence**	**Cases**	**Prevalence**	**Cases**	**Prevalence**	**Cases**	**Prevalence**
Anencephaly	697		211		192		1100	
Spina bifida	1162		561		820		2543	
Encephalocele	261		125		184		570	
Total neural tube defects	2120		897		1196		4213	

- Questions
  - Describe the differences in prevalence by ascertainment method, and provide some reasons for why differences might exist.
  - What are some possible reasons why the three ascertainment methods have different prevalence estimates for spina bifida?



Activity 3.7

- Read the case-study below.

Case-study: Pre- and post-fortification birth prevalence of neural tube defects in the USA, 1999–2007

In 1996, folic acid fortification of cereal grain products labelled as enriched became voluntary in the USA. In 1998, a mandate was passed requiring that these products be fortified with folic acid, to ensure an adequate supply of folate for women of childbearing age.

The United States National Birth Defects Prevention Network collects information on neural tube defects by three major race/ethnic groups, and has data from the time period prior to mandatory folic acid fortification (1995–1997) and following the folic acid fortification mandate (1998–2010). The estimated annual prevalence of neural tube defects for nine hospitals in the USA during these time periods is presented in the table below.

Prevalence of neural tube defects in the USA per 10 000 live births by race/ethnicity (1995–2007)

Race/ethnicity	Year												
	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007
Hispanic	9.20	10.84	9.69	7.37	7.83	6.45	6.63	6.98	6.95	6.63	6.27	5.69	6.04
Black	4.89	5.75	3.59	4.78	4.80	4.49	4.81	5.16	4.17	3.68	3.89	3.37	3.74
Caucasian	7.1	7.8	6.7	5.5	5.5	5.3	5.1	4.6	4.6	5.2	4.6	4.9	5.3

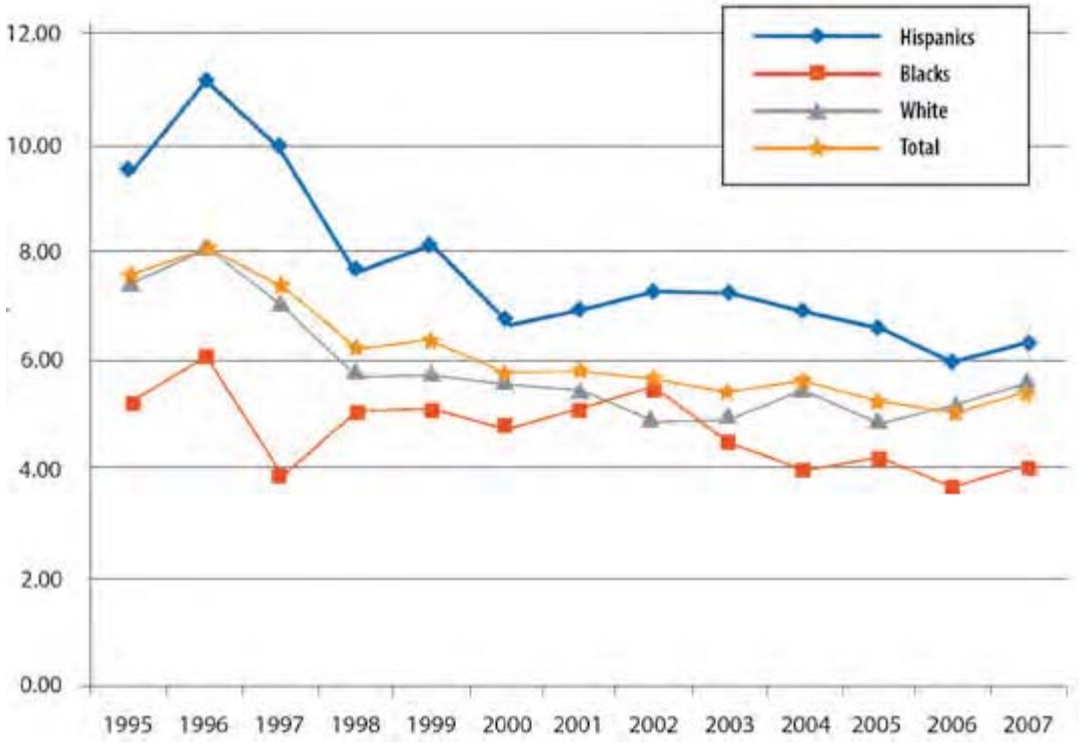
Source: CDC Grand Rounds: additional opportunities to prevent neural tube defects with folic acid fortification. MMWR Morb Mortal Wkly Rep. 2010;59(31):980–4.

- Questions
  - Has folic acid fortification of staple foods impacted the prevalence of neural tube defects?
  - If so, how has it impacted the prevalence of neural tube defects?
  - If you have a computer and access to Excel, make a graph with the data provided.

Public health agencies have a long tradition of monitoring trends in rates of disease and death, and in medical, social and behavioural risk factors that may contribute to these adverse events. Trends in observed rates provide information for needs assessment, programme planning, programme evaluation, and policy development activities. Examining data over time also allows predictions to be made about future frequencies and rates of occurrence.

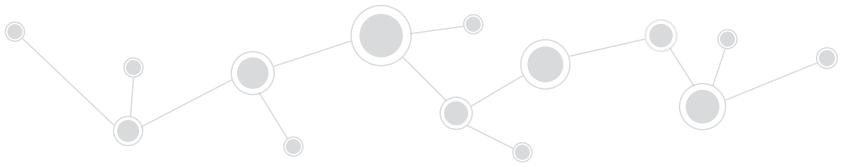
Typically in public health, trend data are presented as population-based rates. These data are accessed from large database systems such as national vital records, and show how rates change over relatively long periods of time, e.g. 10 years or more. Trend data can be visually presented through tables and graphs. The figure below shows secular trend data for the prevalence of neural tube defects in the USA by race/ethnicity.

Prevalence of neural tube defects (per 10 000 births) by race/ethnicity, United States, 1995–2010



Source: National Birth Defects Prevention Network. Neural Tube Defect Ascertainment Project 2010 (http://www.nbdpn.org/current/2010pdf/NTD%20fact%20sheet%2001-10%20for%20website.pdf).

- Questions
  - Describe the prevalence of neural tube defects and the secular (long-term) trend. Is there a change in the prevalence of neural tube defects? What is the direction of the change?
  - When was this change first evident?
  - What are some possible reasons for some of the changes observed in the prevalence of neural tube defects?
  - What are some factors that could impact the prevalence of a health condition?



Activity 3.8

- Using the sample surveillance data provided for Activity 3.9, discuss how you would communicate and disseminate the surveillance data information to your assigned group. The groups are given below.
- **Target audience**
  - Group 1: Nongovernmental organization
  - Group 2: Clinic/public health practitioners
  - Group 3: General public
  - Group 4: Policy-makers

Activity 3.9

- You are a group of paediatricians working in a large maternity facility in your country. You are seeing many babies (see table) with congenital anomalies being born in the facility and the group thinks it would be good to provide information to your target audience (assigned), to interest them in supporting a surveillance programme.
  - In the letter, you should include a description of how the data will be organized, what data will be collected and how they will be presented to make the case to your target audience.
  - Using the sample surveillance data in the table below, draft an advocacy letter requesting support for a local congenital anomalies surveillance programme to your assigned target audience.

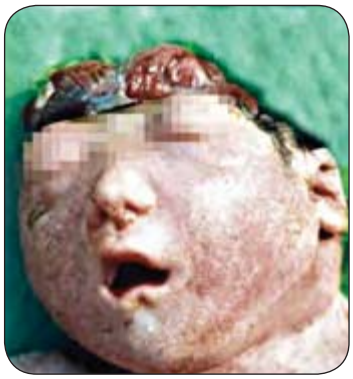
- **Target audience**
  - Groups 1 and 2: Ministry of health (government agency)
  - Groups 3 and 4: Clinic/public health practitioners (from other maternity facilities within the country)

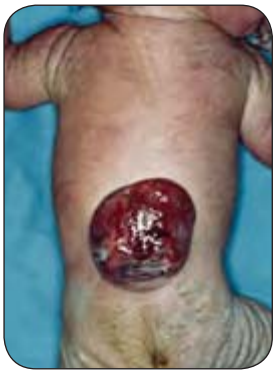
Birth prevalence of congenital anomalies by race/ethnicity

	Prevalence of anomalies per 10 000 live births		
	Ethnic group 1	**Ethnic group 2**	**Ethnic group 3**
Cleft lip	243 (10.59)	136 (6.19)	91 (11.28)
Spina bifida	76 (3.31)	53 (2.41)	35 (4.34)
Anencephaly	40 (1.74)	30 (1.37)	21 (2.60)
Encephalocele	19 (0.83)	31 (1.41)	9 (1.12)

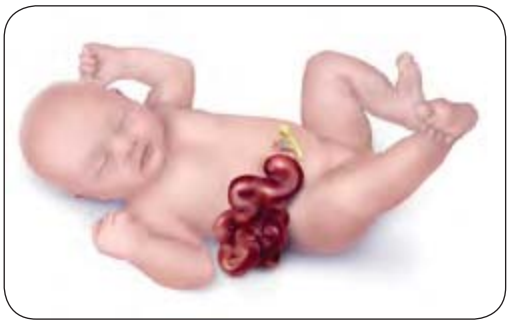
Activity 4.1

- Look at the three photos of congenital anomalies below and describe the differences.

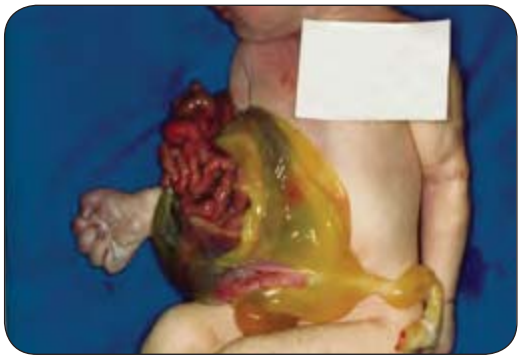




- Look at the two illustrations of congenital anomalies below and describe the differences.



- Look at the following photo. Do you think the baby has gastroschisis or omphalocele?



- Identify the diagnoses for each of the congenital anomalies below.

Photo A

Photo B

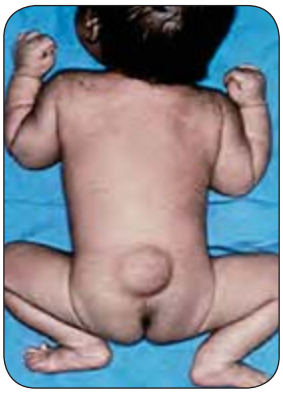


Photo C

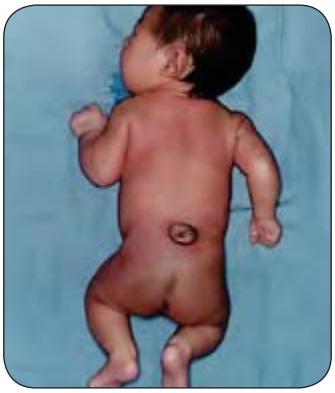


Photo D

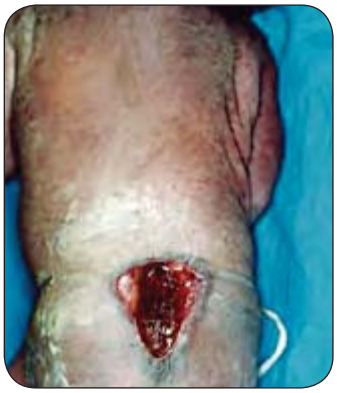
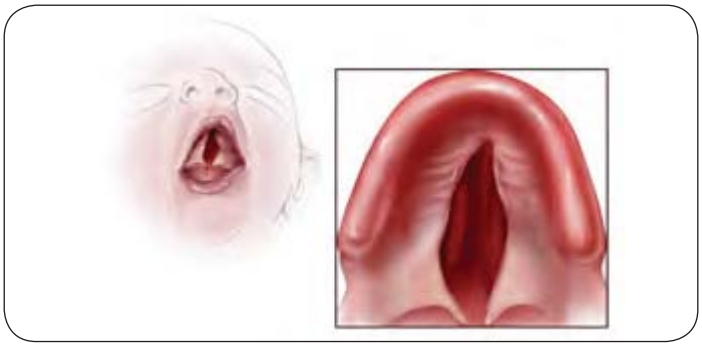


Photo E

Activity 5.1

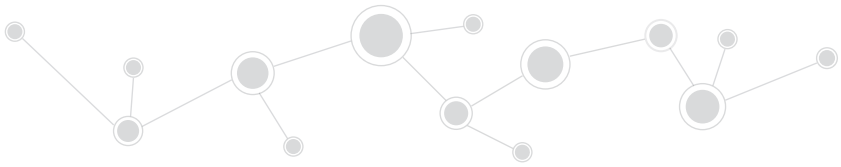
- Identify the diagnoses for each of the following congenital anomalies, and code each case.



Activity 5.2

A total of 20 cases are included in the activity.

- Break out into your small group.
- Each group will receive a set of pictures labelled with numbers.
- Write the number of the photo and describe it on the answer sheet.
  DO NOT write down the ICD-10 or ICD-10-RCPCH code.
- Exchange answer sheets (but not photos) with another group.
- Based on the description, write down the ICD-10 or ICD-10-RCPCH code.
- Provide photos and, if necessary, re-code.
- Discuss all responses in a larger group.



Activity 5.3

Assign an ICD-10-RCPCH code or codes, based on the available clinical description of the different fetuses or infants with congenital anomalies.

- **Case 1**

  Spina bifida with LS meningocele; massive hydrocephalus.
- **Case 2**

  Frontal encephalocele; clubbing of left foot
- **Case 3**

  Cleft lip and palate; omphalocele
- **Case 4**

  Facial cleft; amniotic band evidence on face
- **Case 5**

  Small encephalocele in the parietal area; cleft palate NOS; fused toes NOS

The next 25 cases can be done in your own time.

- **Case 6**

  Anencephaly; heart defect NOS; spinal anomalies NOS; lower extremity abnormal development
- **Case 7**

  Hypospadias, penoscrotal; unilateral absent middle phalanx on foot (no further description)
- **Case 8**

  Transposition of the great arteries with intact ventricular septum (D-TGA); bilateral cleft lip and palate
- **Case 9**

  Occipital encephalocele; subcoronla hypospadias; bilateral club feet
- **Case 10**

  Cleft palate; micrognathia; low set ears; posteriorly rotated ears; excess nuchal skin posteriorly; bilateral 5th finger clinodactyly; missing middle phalanx on finger; moderate to severe right hydronephrosis with thinning of the renal cortex
- **Case 11**

  Craniorachischisis
- **Case 12**

  Cleft lip NOS; spina bifida NOS; ear tags
- **Case 13**

  Anencephaly; absence of digits NOS; malformed feet NOS
- **Case 14**

  Myelomeningocele, T3–T4 open; epicanthal folds; high arch palate; hypoplastic nipples

- **Case 15**

  Hypoplastic left heart syndrome (HLHS); spina bifida occulta
- **Case 16**

  Unilateral (right side) cleft lip with cleft hard palate; bilateral talipes equinovarus
- **Case 17**

  Left radial hypoplasia; transposition of the great arteries, secundum ASD, 3–4 mm
- **Case 18**

  Gastroschisis – large and intact pink intestine outside abdominal wall; large hiatal hernia; very narrow malrotated bowel
- **Case 19**

  Urethral meatus opens in the shaft of the penis; tetralogy of Fallot with massive ASD ostium secundum type
- **Case 20**

  Holoprosencephaly; cleft lip bilateral
- **Case 21**

  Gastroschisis with most of the abdominal contents expelled through abdominal wall defect; split-hand
- **Case 22**

  Absent right foot; hypoplasia of femur and tibia right leg; 3 toes missing on left foot; club right hand
- **Case 23**

  Spina bifida, cervical without hydrocephalus
- **Case 24**

  Cleft soft palate; tetralogy of Fallot; spina bifida, sacral with hydrocephalus; oligodactyly on foot
- **Case 25**

  Tibial hypoplasia, right; ulnar hypoplasia, right
- **Case 26**

  Pierre Robin sequence
- **Case 27**

  Anencephaly infant with gross abnormalities; bilateral cleft lip; cleft palate
- **Case 28**

  Iniencephaly; complete amelia of upper limb
- **Case 29**

  Short limbs (possible achondroplasia)
- **Case 30**

  Amelia upper and lower limbs