

# Birth Defects Surveillance: The way forward

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# A look at the past



1. Overview of current (old) system
  - Standardised birth defects notification tool
  - 52 districts
  - Data for 2006-2017 - +/- 20,000 notifications
2. Challenges of current system
  - Underreporting (+/- 2%)
  - Inconsistent reporting
  - Incomplete
  - Unknowns
  - Data flow
  - Not ICD 10 compliant – not comparable to other surveillance systems

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## South African congenital disorders data, 2006 - 2014

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**Background.** The National Department of Health in South Africa (SA) routinely collects congenital disorder (CD) data for its national CD surveillance system. The current system has been implemented since 2006, but no reports on the data collected, methodology, achievements or challenges have been published to date.

**Objectives.** To ascertain the effectiveness of the current national CD surveillance system and its implementation.

**Method.** A descriptive, retrospective study using an audit of the current database was undertaken to evaluate the number of notifications received, types of CDs reported and the quality of reporting across SA for data received from 2006 to 2014.

**Results.** A total of 14 571 notifications were received, including 13 252 CDs and 1 319 zero notifications, across all nine provinces. Commonly reported CDs included Down syndrome, cleft lip and palate, talipes equinovarus, neural tube defects and albinism.

**Conclusions.** The major challenges identified included erratic compliance by health facilities and a lack of healthcare providers trained in human genetics related to CDs. This has led to misdiagnosed and undiagnosed CDs, collectively resulting in under-reporting of cases by >98% during the review period. Owing to limited human and financial resources, it is recommended that the surveillance system be modified into an electronic format. This should be piloted alongside relevant training in specific sentinel sites, to improve data coverage and quality for further evaluation.

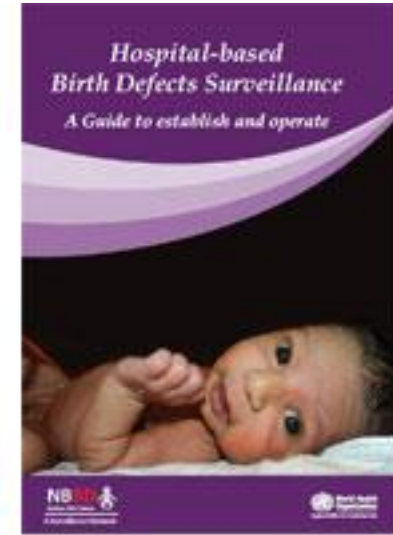
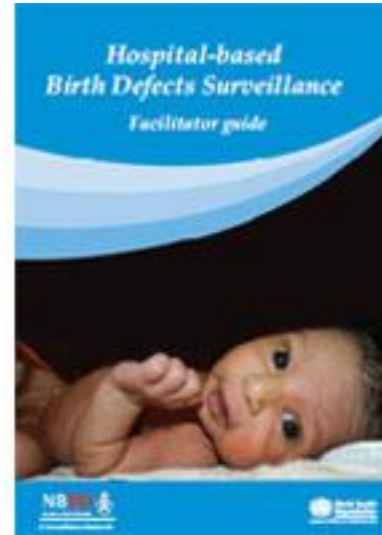
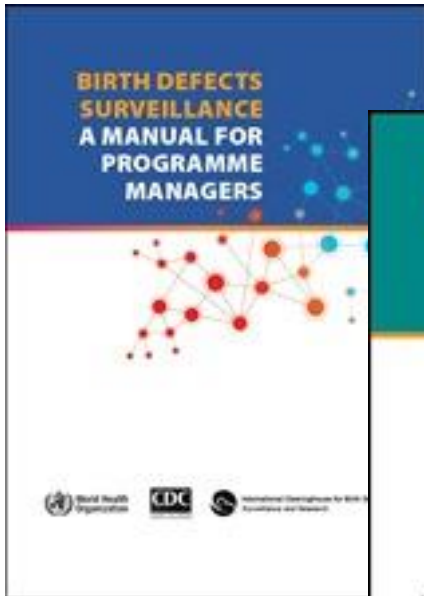
*S Afr Med J* 2016;106(10):992-995. DOI:10.7196/SAMJ.2016.v106i10.11314



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# RESOURCES



Best practices from other countries



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# Paving the way forward



## Pillars of birth defects surveillance

- Objectives of birth defects surveillance:
- Define the magnitude and distribution of birth defects by time, person and place To identify high-risk populations or identify clusters (aggregation of cases) To refer affected infants to appropriate services in a timely manner To monitor trends in the prevalence of different types of birth defects in a defined population.
- Hospital-based or population based: It is proposed to begin with hospital-based surveillance, initially starting in selected hospitals with a high load of childbirths. Bias will be reduced with time and expansion. What level hospital to aim at. Champion driven.



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# Pillars of birth defects surveillance



**Inclusion criteria** – live births and stillborns (weight and gestational).

Argentine experience – notify until discharge. Easily identifiable and diagnosable conditions. *Start small but think BIG.*

## **Electronic surveillance system**

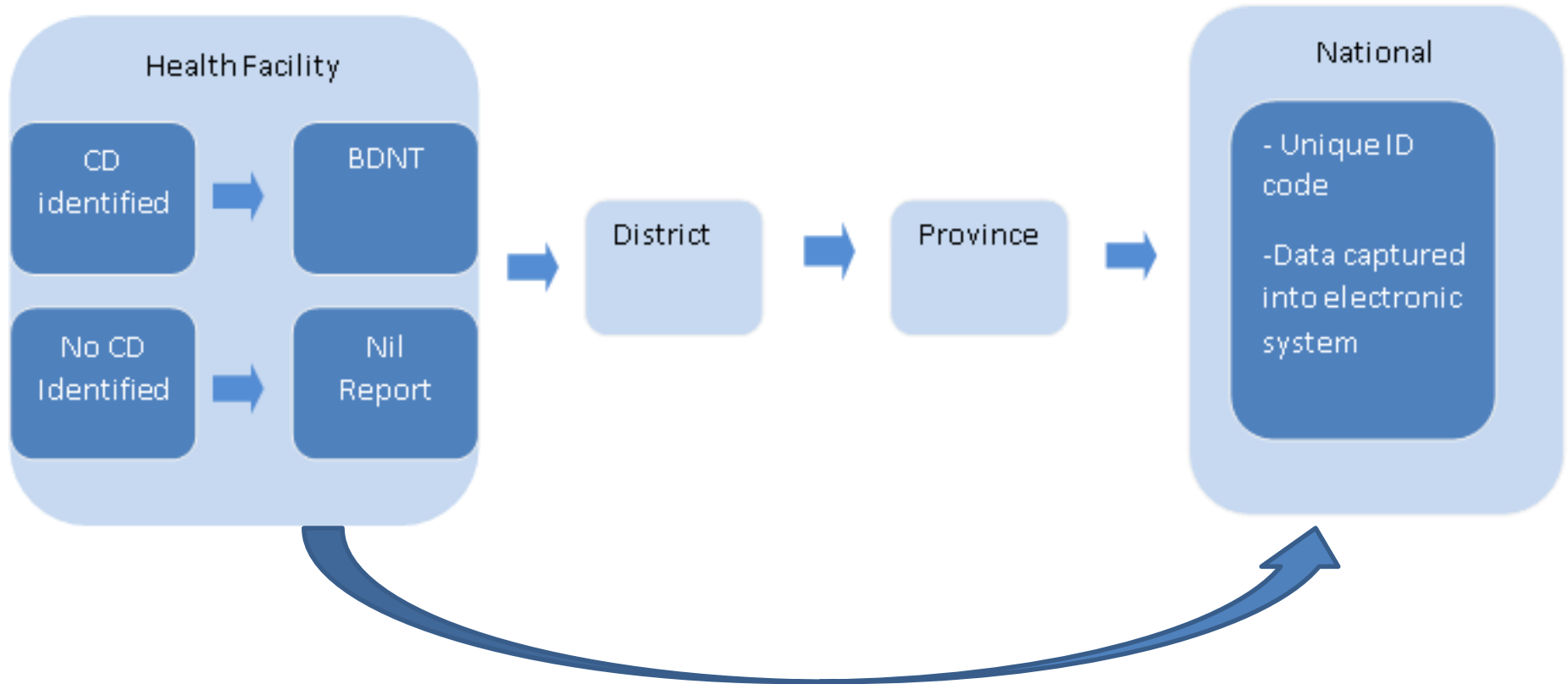
Data flow – from participating facilities directly to National?



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# Data flow



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# Technical Working Group



- Entry point through the TWG
- Chairperson Prof Raj Ramesar
- Development of Guidelines



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