

Barbados National Registry

A national registry for CVDs: the Barbados experience

Anselm JM Hennis, MBBS, PhD, FRCP, FACP
CARMEN Biennial Meeting, Peru, October 26-
29, 2009

On behalf of the Barbados Ministry of Health

Overview

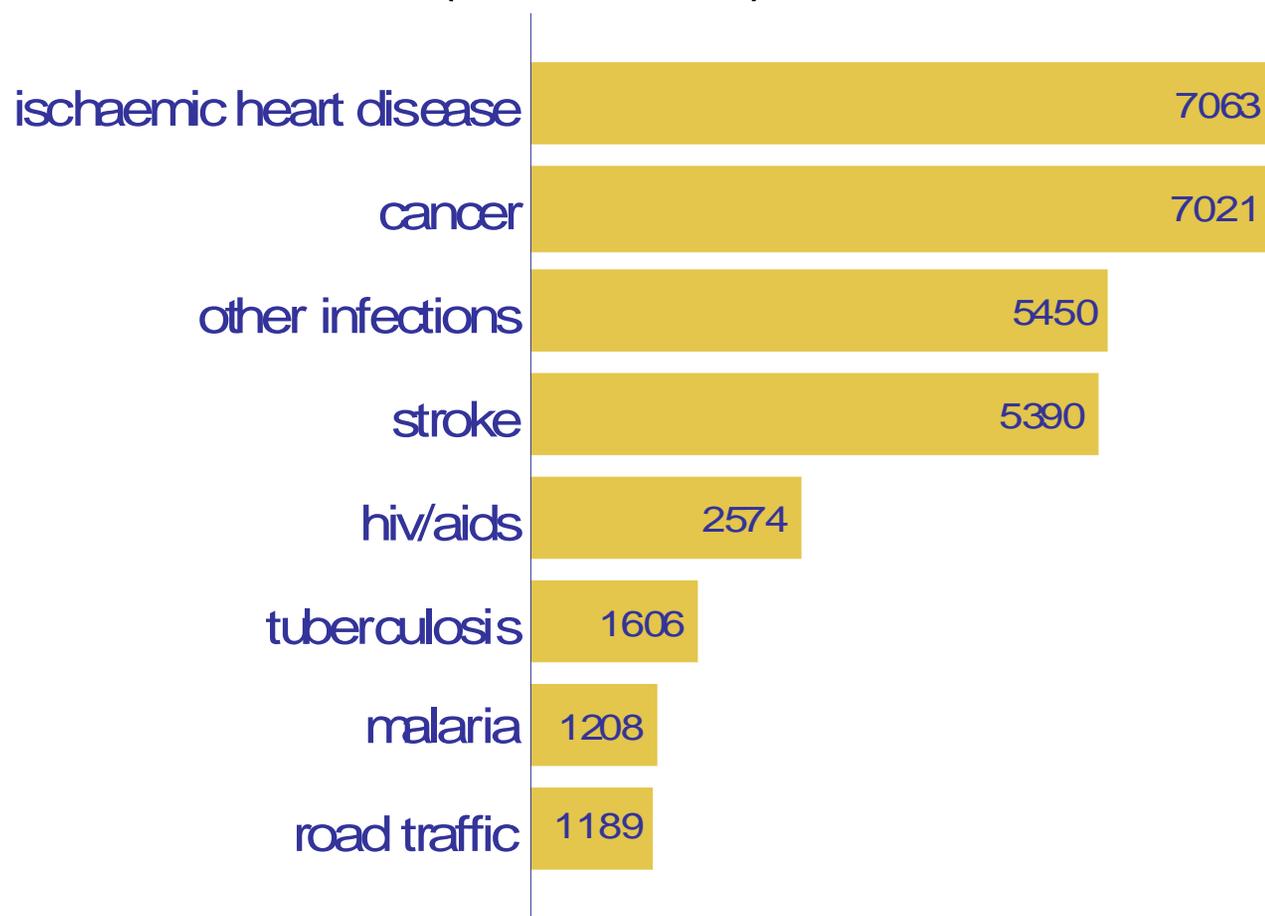


- Background
 - CNCDs worldwide and in the Caribbean
 - CNCDs in Barbados
- Barbados MoH CNCD strategy
- The Barbados National Registry for Chronic Non-communicable Disease (BNR)

Worldwide, CNCDs increasing in incidence and mortality



Global deaths, 2001 (thousands)



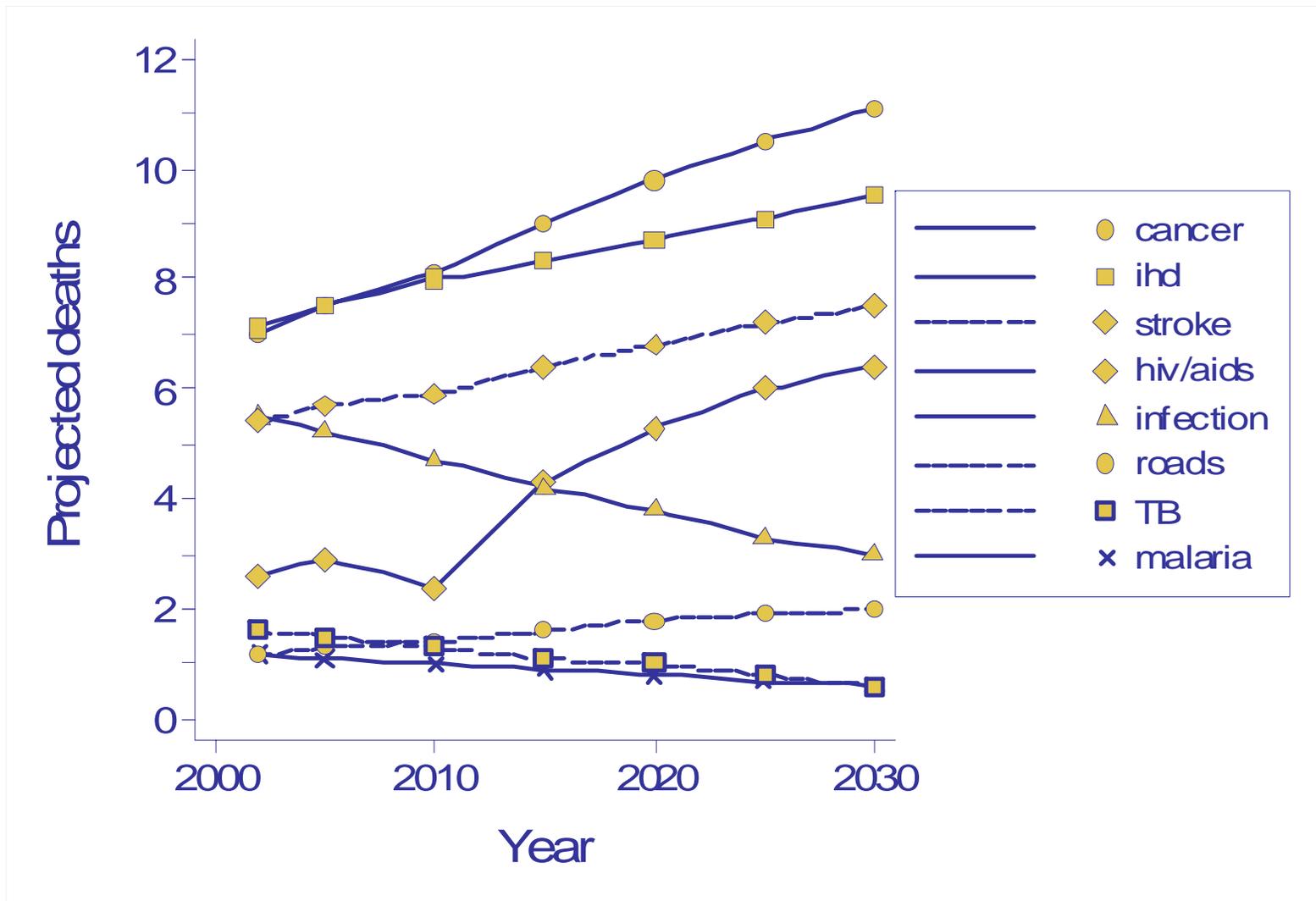


Barbados National Registry

Global Perspectives on Stroke (WHO, 2005)

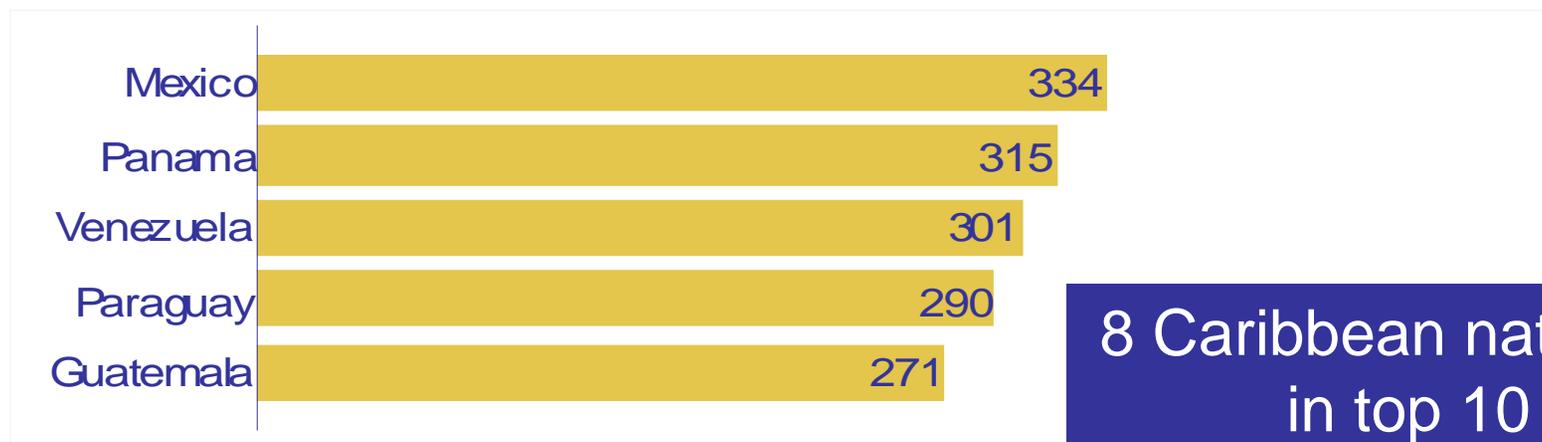
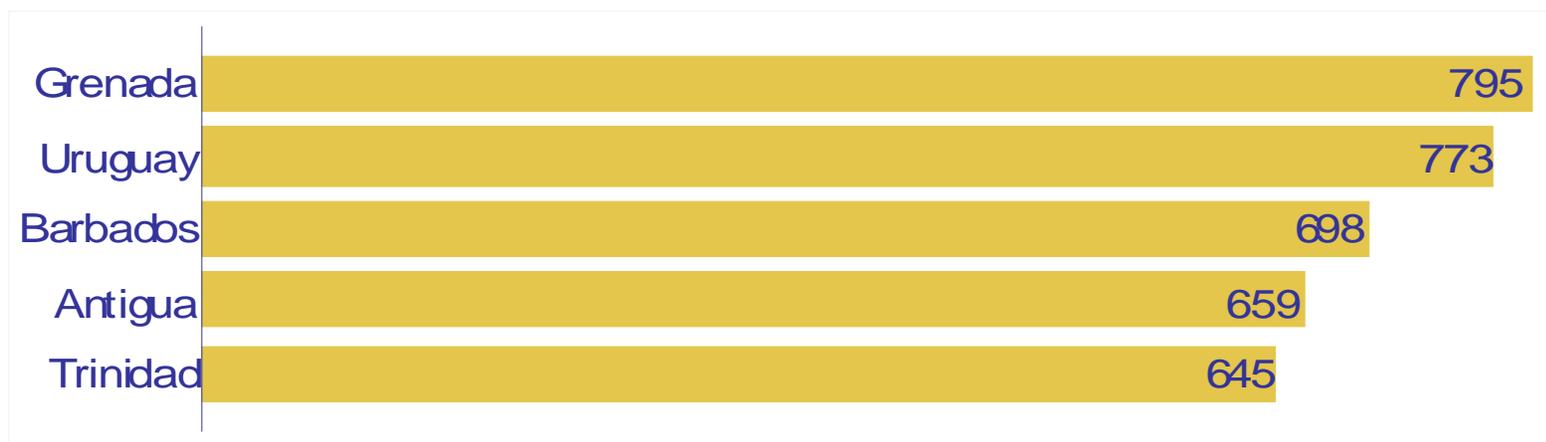
- Worldwide cerebrovascular disease (stroke) is the second leading cause of vascular-related death
- Occurs predominantly in middle aged and older adults
~30% in persons aged <70 years
- Accounts for 9.9% of all deaths globally
- Over 85% of strokes occur in low and middle income countries

WHO projected global deaths to 2030 (millions)



CNCD deaths in LAC

CNCD deaths per 100,000



8 Caribbean nations
in top 10

CNCDs in Barbados I



- CMO's Annual Report 2002-2003
 - CVDs and malignant neoplasms are the leading causes of morbidity and mortality among adults in Barbados

On behalf of the Barbados Ministry of Health



Barbados National Registry

What is stroke or 'brain attack'?

.....an acute event caused by rupture or blockage of a blood vessel within or around the brain resulting in sudden loss of brain function or a severe headache

Stroke in Barbados: BROS



- The BROS study (2001-2004)
- Population-based stroke registry
 - first-ever strokes
- Research study – funded by the Wellcome Trust , UK
- Collaboration with SLSR

On behalf of the Barbados Ministry of Health

Stroke in Barbados: BROS II



- Methods:
 - population based stroke register
 - recorded all cases of ‘first ever’ stroke using multiple notification sources – hospitals, clinics, GPs, radiology depts., death cert. etc.
 - Imaging by CT scan (MRI)
 - Questionnaire ~ risk factors, med. hx.,
 - Exam ~ stroke subtype, disability
 - Follow up ~ disability, mortality

Stroke in Barbados: III

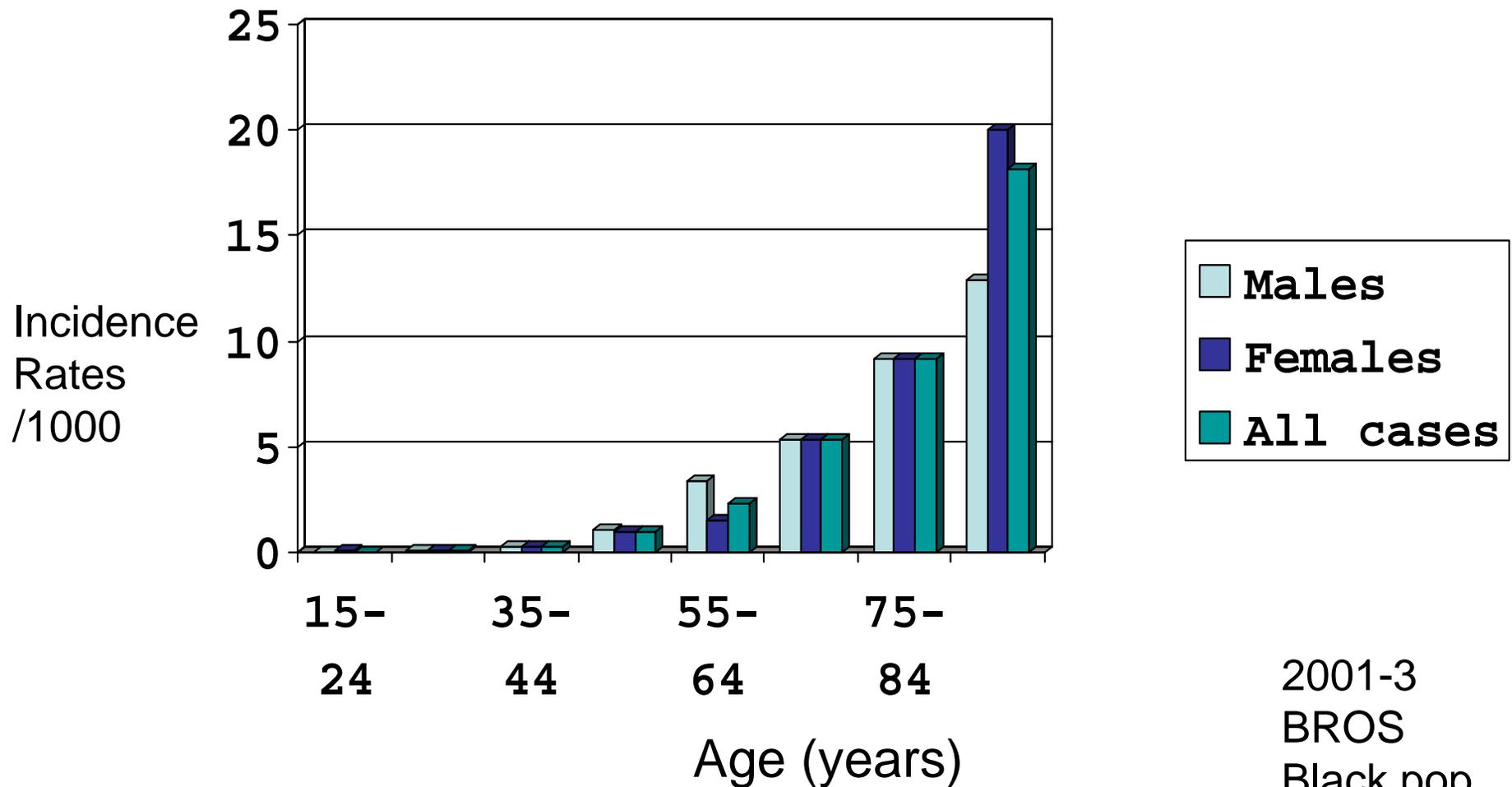


BROS results: Incident first ever stroke

- 58% female
- Average age 71.5 years (SD 14.9)
- Incidence/1000 population (world adjusted) = 0.85
(95% CI: 0.78-0.92)

On behalf of the Barbados Ministry of Health

Stroke incidence rates /1000 by age group and gender



On behalf of the Barbados Ministry of Health

2001-3
BROS
Black pop

Mortality from stroke in Barbados

- Case fatality rate at 7 days 12%
- After first ever stroke, only 50% are alive after 1 year
- Persons with large volumes of damaged brain do worse
- Persons with ischaemic tend to do better than those with haemorrhagic strokes



Barbados National Registry

Mortality from stroke in LAC

City, County	<u>Cerebral Infarction</u> %	ICH* %	SAH† %	Indeter. %	Total %
Joinville, Brazil	22.5 53/235	35.6 22/61	41.6 10/24	-	26.2 84/320
Martinique, French West Indies.	15.8 (73/463)	37.3 (31/83)	25 (5/20)	21.4 (3/14)	19.3 (112/580)
Barbados, West Indies.	23.2 64/276	61 25/41	85.7 5/6	58.3 7/12	29.9 101/335
Iquique, Chile.	17.8 (33/85)	28.9 (20/69)	40.0 (6/15)	39.1 (9/23)	23.3 (68/292)

Rationale for a CNCD registry



World Health Organisation:

- Assessing CNCD burden
- Monitoring trends
- Planning, implementing, evaluating programmes and services
- Supporting policy development

Potential use of registry data



Clinical outcome, care/treatment

- Baseline data for assessment of future trend
 - use of diagnostic tools, survival, disability
- Evaluation of interventions
 - new/complex therapies, prevention
- Access to/utilisation of health services
 - private vs public, rehabilitation services

Potential use of registry data (cont'd)



Clinical practice

- Indicate where treatment/facilities most need improvement
- Identify specialist training needs

Provide information to MoH for optimal utilisation of scarce resources

The MoH CNCD strategy



- National Task Force on CNCDs (2004)
 - mechanism for CNCD prevention/control
- National CNCD Commission
 - key strategy: national CNCD registries
 - outcome of BNCS, BROS: population-based registries
 - CDRC invited to develop and operate the BNR
 - essential tools to advise on CNCD policy and legislation

On behalf of the Barbados Ministry of Health

The BNR: overall objective

To collect timely and accurate national data on the occurrence of **cancer**, **stroke** and **acute myocardial infarction (AMI)**, in order to contribute to the prevention, control and treatment of these diseases in Barbados



On behalf of the Barbados Ministry of Health

The BNR: specific objectives



- Create and maintain high quality databases
- Regular reporting (incidence and mortality)
 - establish baseline levels (estimate current burden)
 - monitor trends
- Use data effectively for epidemiological and clinical research
 - estimate future disease impact
 - investigate interventions and/or preventative measures

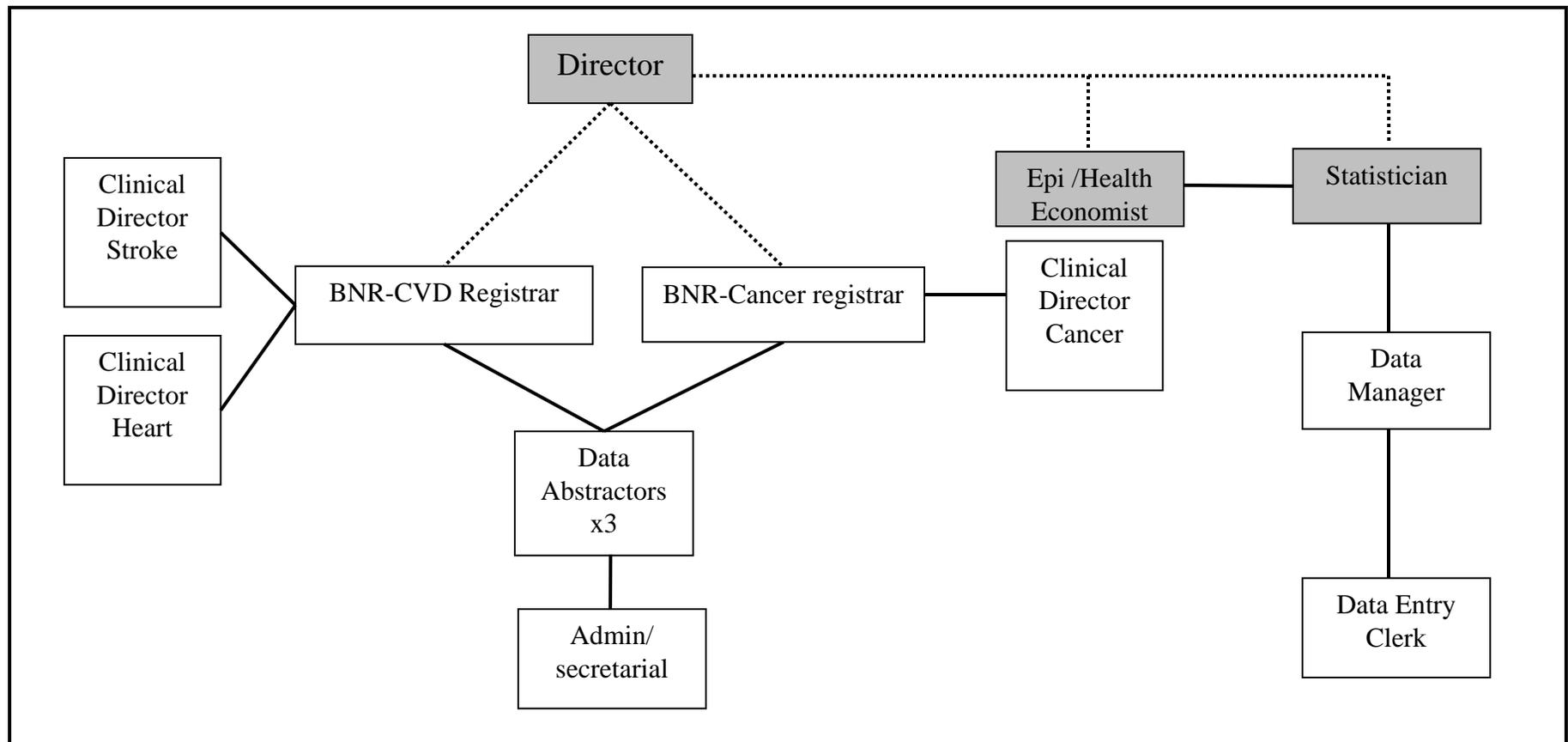
On behalf of the Barbados Ministry of Health

Confidentiality



- Ethical approval obtained
- All BNR staff sign confidentiality agreements
- Highest international standards of data encryption and storage for full confidentiality
- Secure database
- Informed patient/relative consent for interviews

BNR team structure



 = Core CDRC staff

On behalf of the Ministry of Health

The BNR – CVD



- Population-based CVD registries
- Collecting information on all events nationwide
- BNR – Stroke began in July 2008
- BNR – Acute myocardial infarction pilot from May 2009

On behalf of the Barbados Ministry of Health

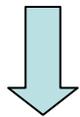
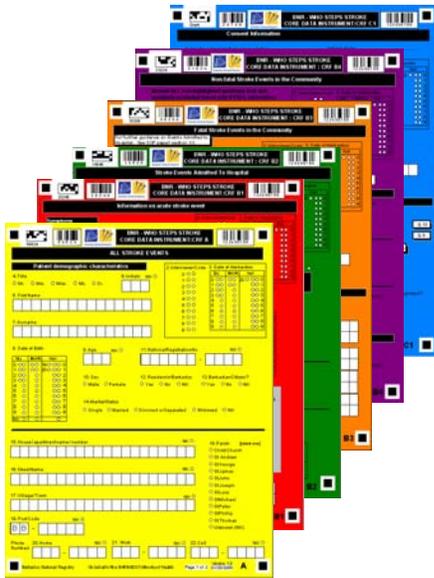
BNR – CVD methods



- Data collection follows WHO's STEPS Stroke Surveillance model
 - in hospital; fatal in community; non-fatal in community
- Abstraction triggered by notification
 - follow-up at 28 days and 1 yr post event
- Pre-printed CRFs scanned in after abstraction
 - bespoke databases for processing and analysis
- Medical staff assist with case definition

On behalf of the Barbados Ministry of Health

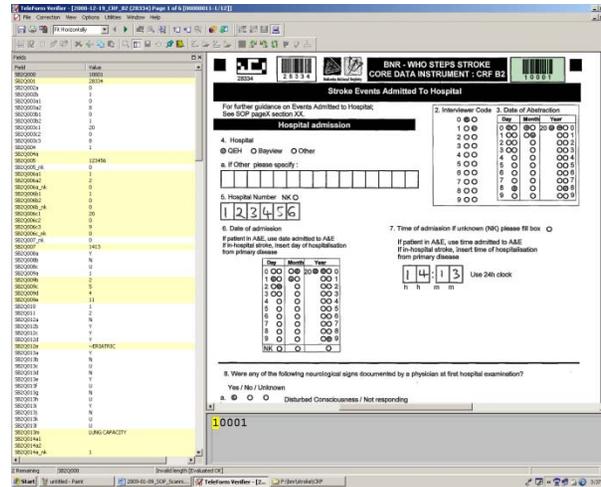
Once the form has been designed, printed



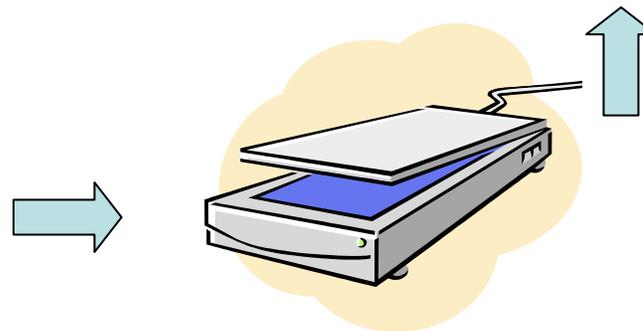
and filled in, by Data Abstractors



VERIFY



Invalid or unrecognisable data are highlighted during verification



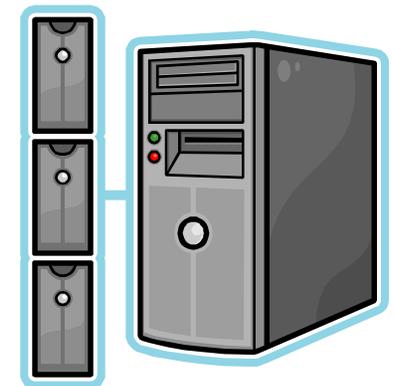
Data are converted from paper to an electronic image

SUMMARY OF OVERALL DATA MANAGEMENT PROCESS

EXPORT



Once data have been verified there is automatic export to a secure database



SECURE DATABASE

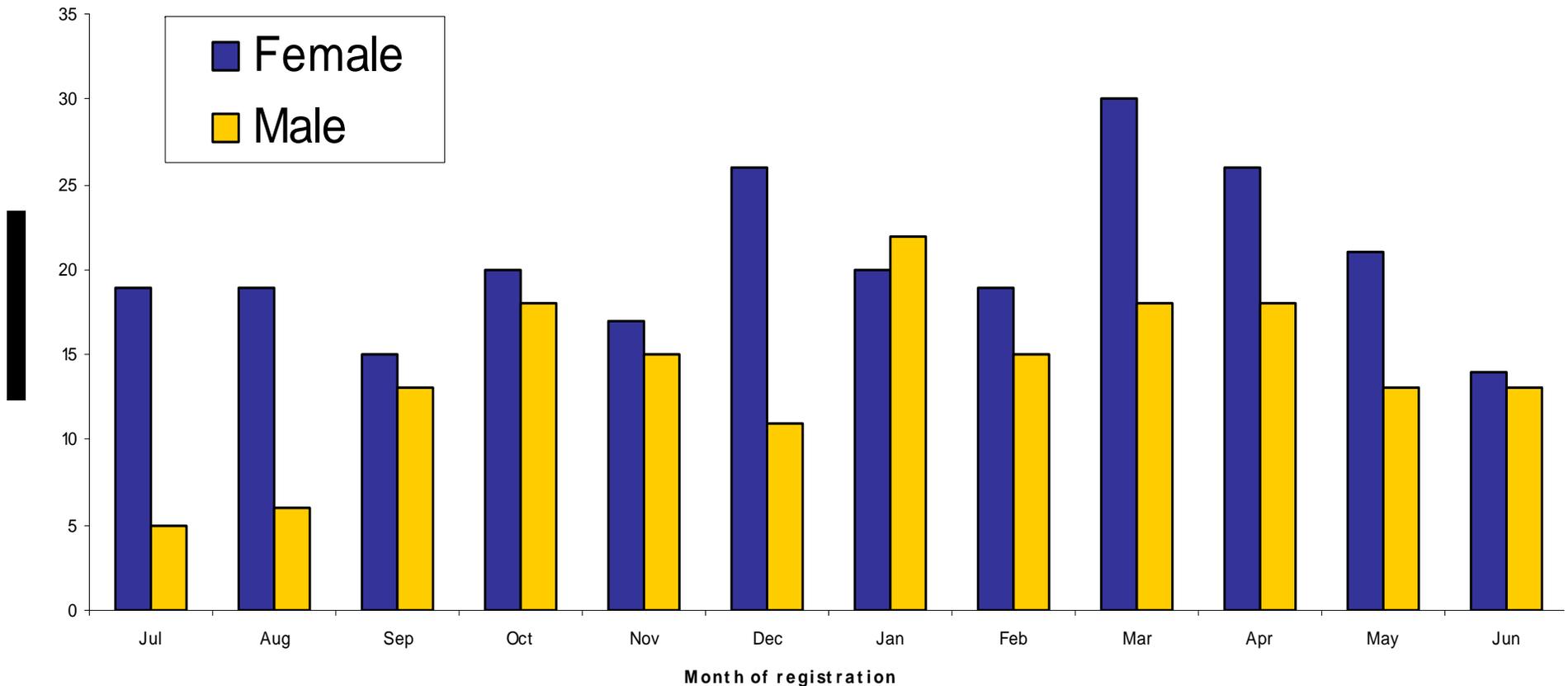
Where images of original forms are also exported

BNR – Stroke

Preliminary data (N=413)



Number of stroke events registered in Barbados, 1 Jul 2008-30 Jun 2009



Summary



- Increasing CNCDs in LAC
- Limited CNCD data in the region
- Political support in Barbados → BNR
- Political support in the region – Port of Spain Declaration
- Multi-CNCD registries: a Caribbean model?

On behalf of the Barbados Ministry of Health