# Powering Data Systems for Key Public Health Decisions

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# Finagle's Law of information

"The data we have…

are not the data we want."


"The data we want…

are not the data we need."


"The data we need ….

are not available."

# National data …… or modeled estimates ?

**Monitoring country progress and achievements by making global predictions: is the tail wagging the dog?**

*Ties Boerma, Cesar Victora, Carla Abouzahr*

Lancet April 13, 2018

- Increased reliance on modeled estimates was driven by desire to fill data gaps for the MDGs;
- Enormous investments in advanced Bayesian methods, geospatial modeling, & compelling visualizations;
- Global health initiatives, experts and academics often oblivious to the limitations of models;
- Gross over-interpretation of the "numbers", especially for under-five and maternal mortality;
- Even more so for cause specific mortality and trends;
- Comparatively little investment in country led, real-time data production for HIS;
- This cannot continue as we move into the SDG 2030 agenda.

"Prediction is very difficult, especially about the future" Niels Bohr

# A quick illustration of the risk of global predictions

## DHS point data 1992, 1996, 1999, 2004, 2010 as source of predictive models



Model predicted MDG4 could not be achieved before 2035
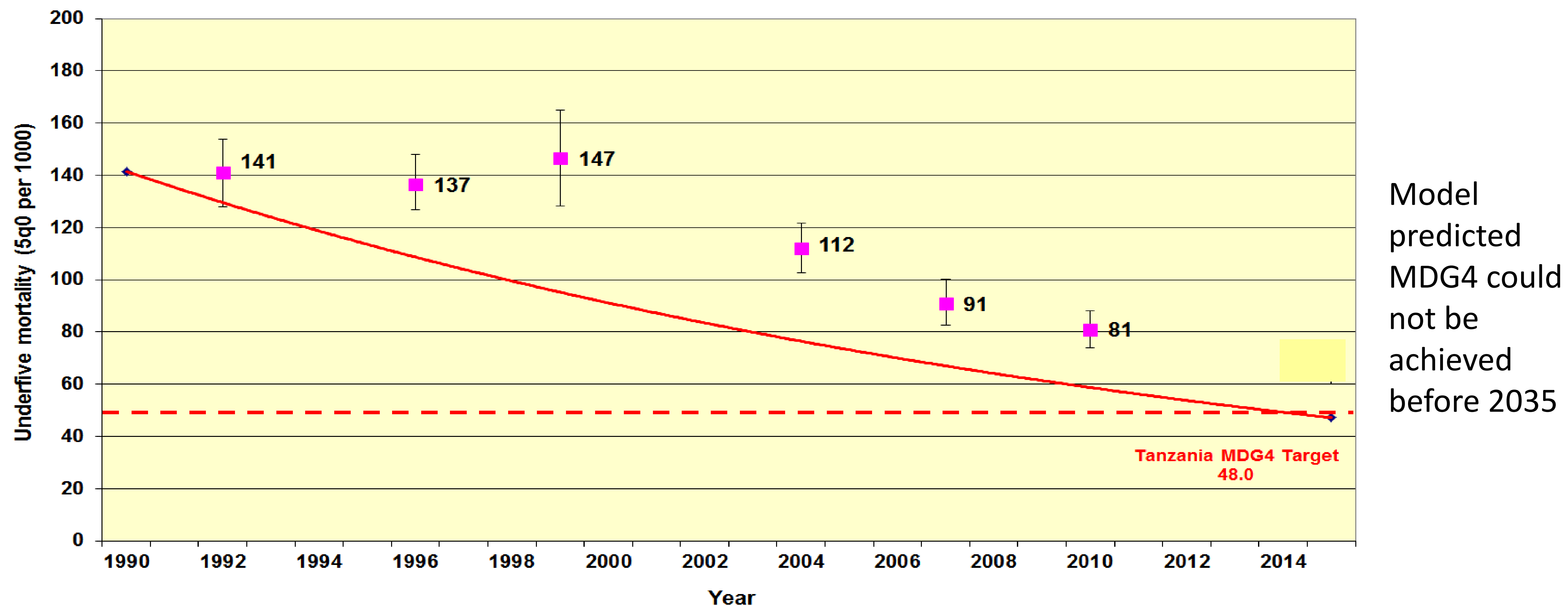
Source data: Tanzania DHS All Surveys, Tanzania National Bureau of Statistics & Macro International.

# Tanzania MDG4 under five mortality recalculated

## MDG4 Achieved ahead of schedule
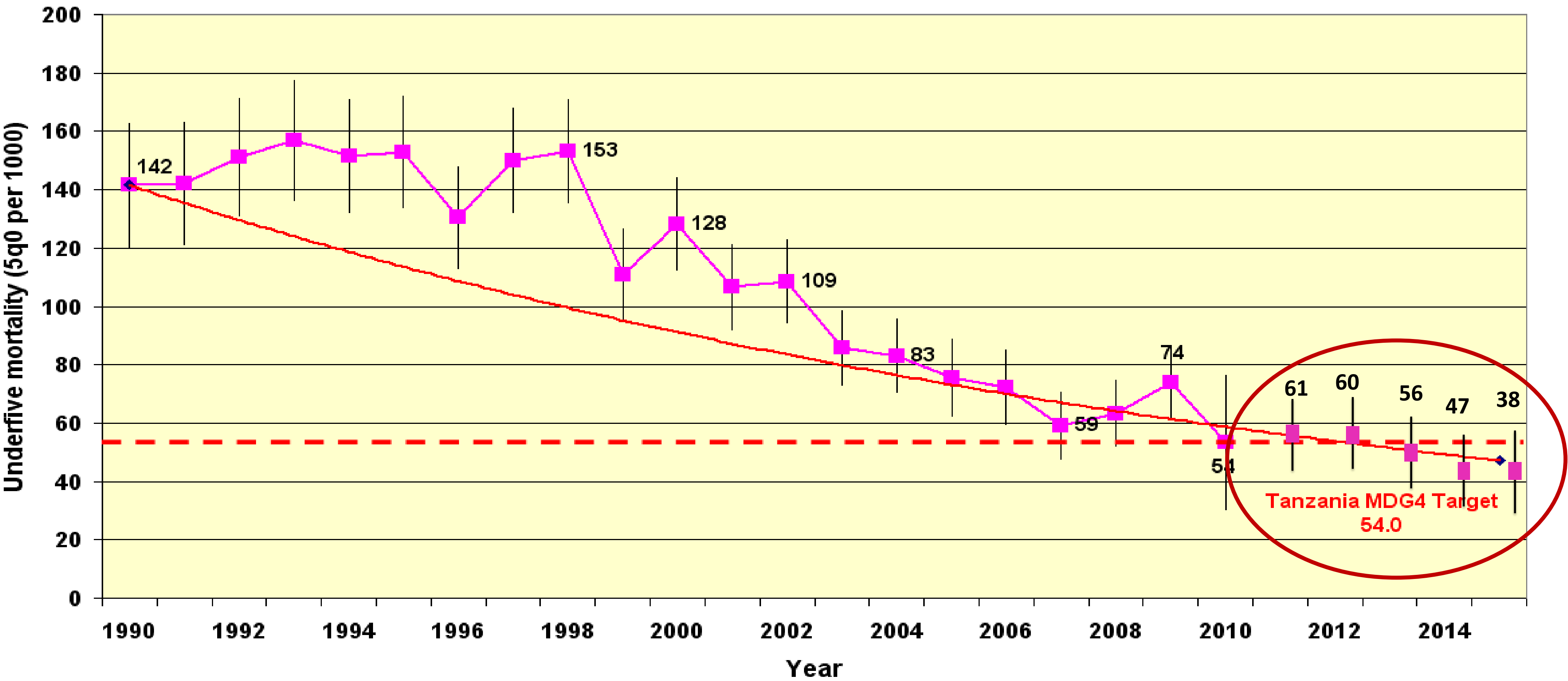


Source data: Tanzania MIS 2008 and DHS 2016, Tanzania National Bureau of Statistics & Macro International.

# From the WHO Health Metrics Network

## Sources of mortality data
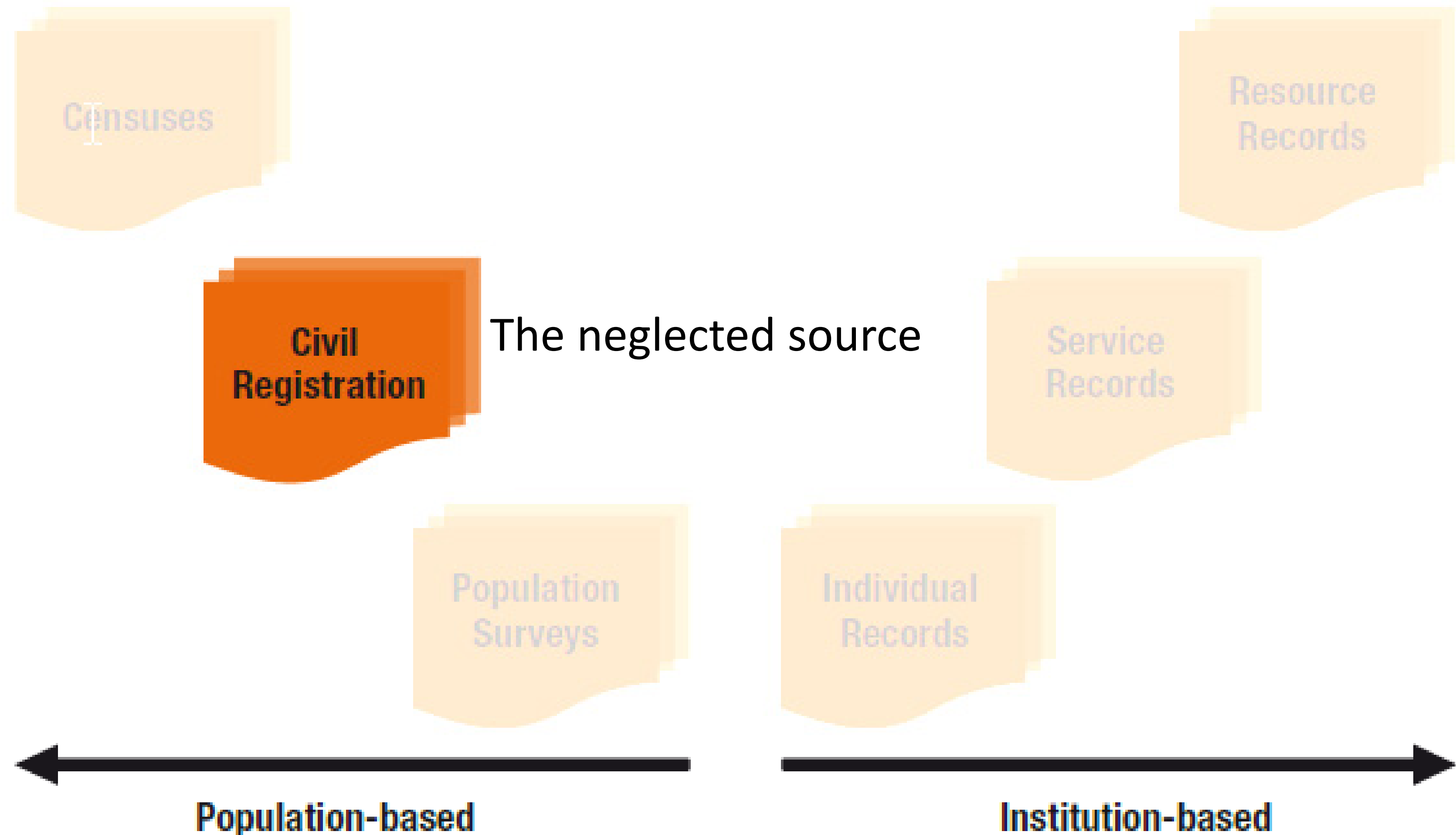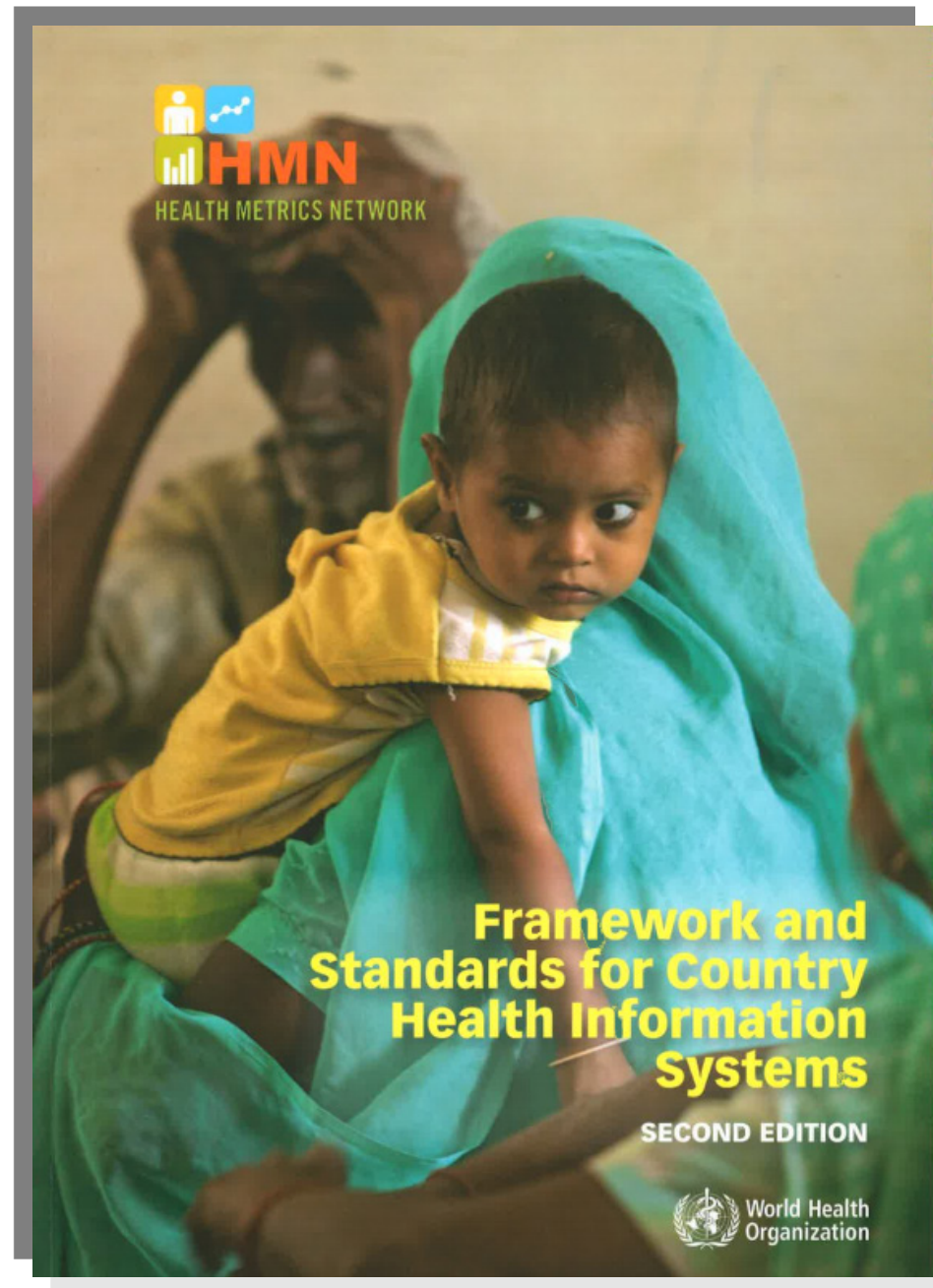
# The scandal of administrative and statistical invisibility

In Africa, most people are born, live and die without leaving a trace in the official record.

## Counting births and deaths 4

### Towards universal civil registration and vital statistics systems: the time is now

Carla AbouZahr, Don de Savigny, Lene Mikkelsen, Philip W Setel, Rafael Lozano, Alan D Lopez

Lancet May 11, 2015
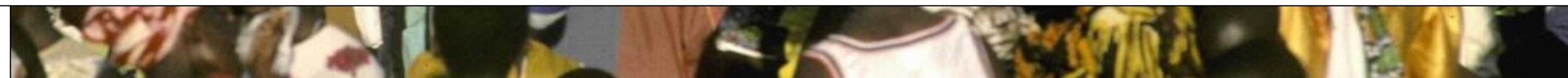
# What is CRVS?    Civil Registration & Vital Statistics

## Civil Registration

"the **continuous, permanent, compulsory and universal recording** of the occurrence and characteristics of vital events (live **births, deaths**, fetal deaths, marriages & divorces) pertaining to the population as provided through decree or regulation in accordance with the legal requirements of a country."

## Vital Statistics

"the total process of (a) **collecting information by civil registration or enumeration** on the frequency or occurrence of specified and defined vital events, as well as relevant characteristics of the events themselves and the person or persons concerned, and (b) **compiling, processing, analyzing, evaluating, presenting, and disseminating** these data in statistical form"

Source: http://unstats.un.org/unsd/demographic/sources/civilreg/default.htm

# Challenges for mortality data systems



"….. Without these fundamental health data, that is, **counting births and deaths and [reliably] recording the cause of death**, we are **working in the dark**. We may also be **shooting in the dark**. Without these data, we have no reliable way of knowing whether interventions are working."

Dr Margaret Chan
WHO Director General

*CRVS "The single most critical failure of development over the past 30 years"*
*Richard Horton, 2015*

*"You can't manage what you don't measure".*
Michael Bloomberg, 2016

# CRVS and Sustainable Development Goals



**15 SDG goals** require a functioning CRVS to measure progress

**24 SDG targets** require CRVS (14 specify cause-specific mortality)

**45 SDG indicators** will require data from CRVS systems

# CRVS: Current global situation

**230 million**

Children under 5 not registered

**2/3**

Of all deaths are not registered globally

**<10%**

Of deaths have a cause of death in some countries

# CRVS: Country situation for cause of death data



above 90% complete
less than 90% complete
data not available

70 With COD

50 Some COD

75 No COD
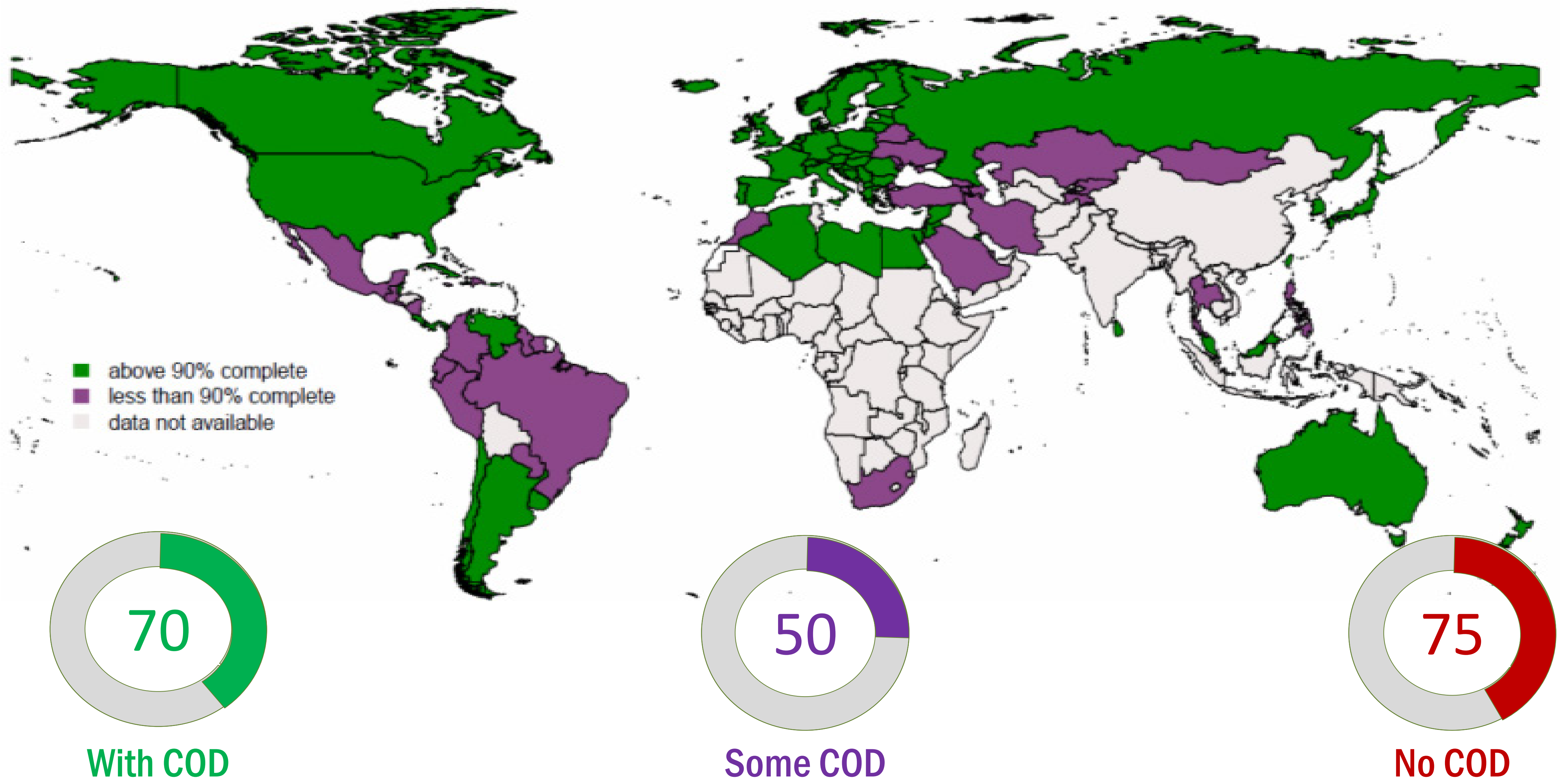
# Mortality data in a typical African Country in 2018

| | |
|---|---|
| Average national **Population** in 2018: | 25 million |
| How many **deaths** expected in a year? | 200,000 (at a CDR of 8/1,000) |
| How many deaths will occur in **health facilities?** | 30% (60,000) |
| How many deaths will be *registered for* the **fact of death?** | 13% (26,600) |
| How many deaths will be medically certified with a **cause of death?** | 8% (16,000) |
| How many of those deaths will have a cause of suitable quality for use in **vital statistics?** | **6% (12,000)** |

## Ghana Crude Death Rate (1950 - 2100)



8.075 for 2017
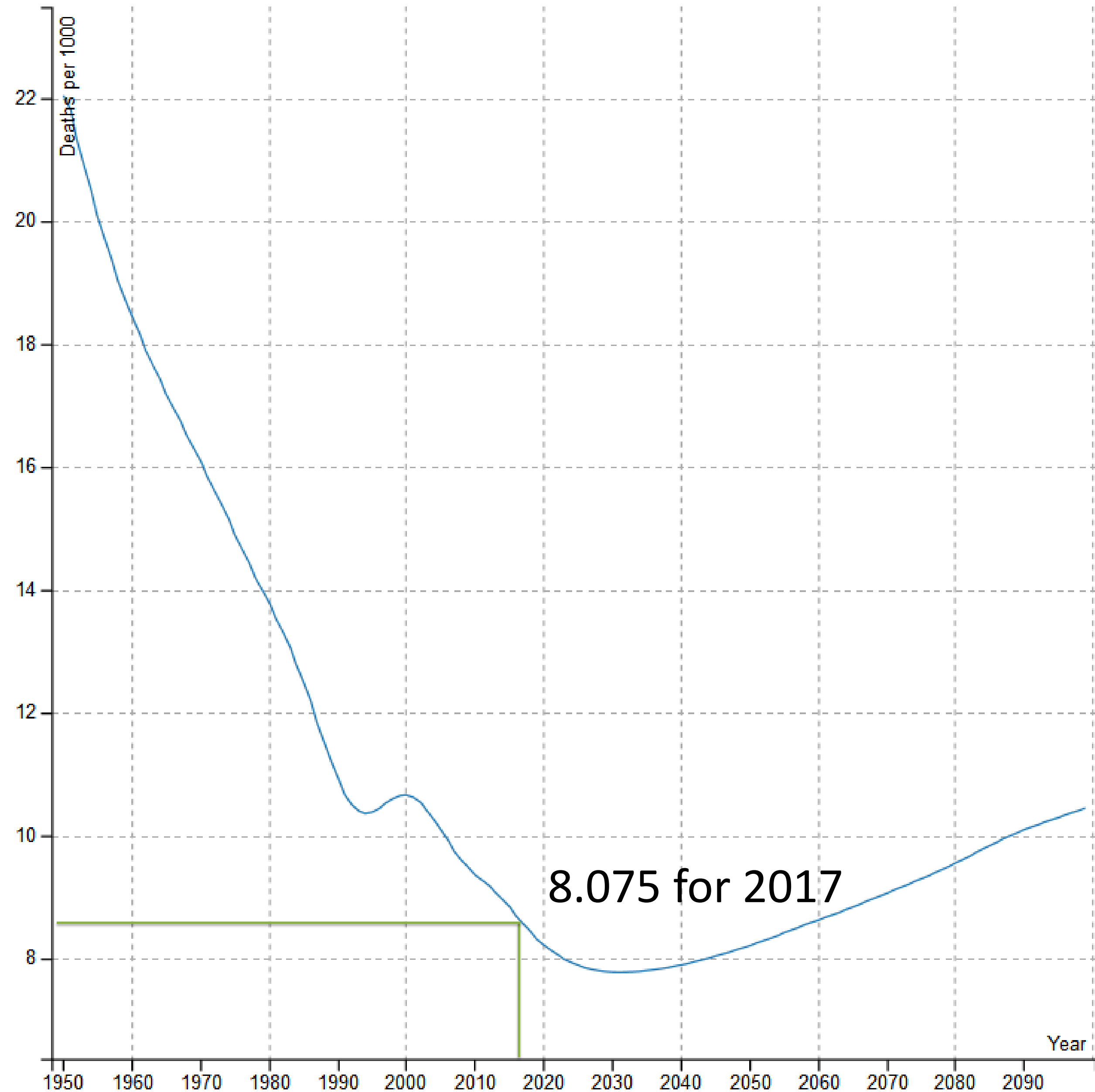
**Example from Ghana for how Crude Death Rates and Estimates are trending**

http://worldpopulationreview.com/countries/ghana-population/crude-death-rate/

# The future is not what it used to be

Never in human history have the rates of mortality and the causes of that mortality changed as fast as they are changing today in Africa.

We can no longer rely solely on models and assumptions to follow these phenomena.

But basing decisions and policies on data from only 6% of the population is like driving in the dark without headlights.

# What can we do to strengthen CRVS as a data source?

**CRVS systems are complex adaptive systems**

**Technical solutions in isolation will not take us far**

Let's look at two of several innovations underway:



- CRVS verbal autopsy for deaths in the community
- CRVS systems analysis for re-engineering processes

# Automated Verbal Autopsy
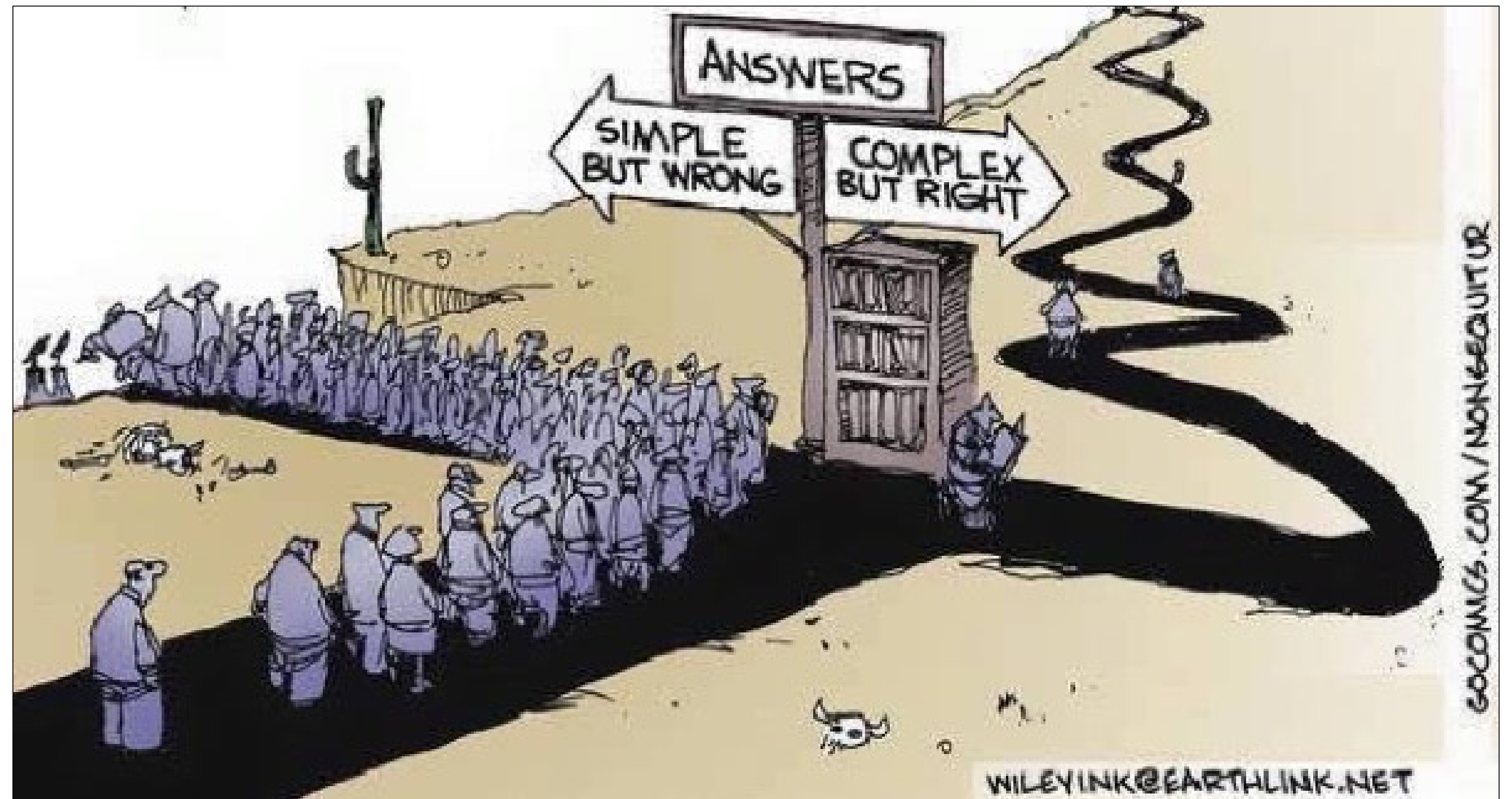
## Integrating community-based verbal autopsy into civil registration and vital statistics (CRVS): system-level considerations

Don de Savigny [a,b,c], Ian Riley[c], Daniel Chandramohan[d], Frank Odhiambo[e], Erin Nichols[f], Sam Notzon[f], Carla AbouZahr[g], Raj Mitra[h], Daniel Cobos Muñoz[a,b], Sonja Firth[c], Nicolas Maire[a,b], Osman Sankoh[i,j], Gay Bronson[k], Philip Setel[k], Peter Byass[l,m], Robert Jakob[n], Ties Boerma[n] and Alan D. Lopez[c]

Health Sector

Weeks

Family

Burial permit

Local Government

Central Server

CRVS database

Information is stored in a central data store and used to influence public health policies and practice

Statistics or Registration Authority

Complexity: Multiple ministries / agencies

Every death must be legally registered

The cause is linked to the registered death for each individual

# How process mapping can be useful

Describes how systems operates **capturing their complexity**

Identifies all relevant stakeholders and **align their views** of how the systems operates

Illuminates **inefficiencies, duplications, information silos and bottlenecks** in the process

**Enables stakeholders to consider the end-to-end system as a whole**

Clarifies functional **relationships among actors** (where interoperability is required)



Process diagram (CRVS and NID integrated system):

**Mother**
- Mother takes the birth notification form to the civil registration office in the hospital
- The mother reads the details that will be registered and approves by signing it

**Health Facility**
- Birth in a health facility
- Midwife fills a birth notification form including basic information and the mother ID number

**Civil registration office**
- CRO staff receives the notification form and enters the information in the digital registration system
- The system validates the information entered with the NID database
- The CRO system receives the validation and prompt a window with the information that will be recorded in the birth registration book
- The information is registered and the system request the generation of a unique ID number to the NID system
- The CRO system receives the unique ID number generated and records it in the birth registration register

**National ID office**
- The NID system validates the information entered with existing records
- Is it valid? No → The process ends here
- The system confirms that the information is correct and the registration can continue
- A unique ID number is assigned to this birth event and the information is stored in the NID database

# CRVS processes

**Ten CRVS**

**Milestones**

There was no notification step for deaths in the community



**Birth or death occurred**

**Civil Registration sub-system**
Individual level information

**1. NOTIFICATION**

The capture and onward transmission of minimum essential information on the fact of birth or death by a designated agent or official of the CRVS system using a CRVS authorized notification form (paper or electronic) with that transmission of information being sufficient to support eventual registration and certification of the vital event.

**2. VALIDATION & VERIFICATION**

The act by which a relevant authority validates that all necessary documentation to proof the vital event information so that the registration process can continue

**3. REGISTRATION**

The act of formally registering a vital event at a civil registration office. At this point, details of the event are entered into the official civil register by the registrar.

**6. STORAGE & ARCHIVING**

The process whereby individual registration information is stored either digitally or in paper and incorporated into the permanent archives so that copies of certificates can be retrieved as required.

**5. SHARING OF INFORMATION**

Activities in which certain information items pertaining to the individual event is shared with other government systems (e.g. population register, electoral register, national ID).

**4. CERTIFICATION**

The issuance by the civil registrar of a legal document certifying a birth or death.

**Vital Statistics sub-system**
Aggregated information

**7. COMPILATION OF VITAL STATISTICS**

The process of aggregating and summarizing information on vital events by classifying and tabulating the data within categories or groups in order to produce vital statistics according to a predetermined tabulation program.

**8. QUALITY CONTROL OF VITAL STATISTICS**

Standardized systematic set of controls and checks to assess the quality of vital statistics.

**9. GENERATION OF VITAL STATISTICS**

Activities whereby national or regional vital statistics are produced (excluding production of reports for administrative purposes).

**10. DISSEMINATION OF VITAL STATISTICS**

Timely publication of an annual national vital statistics report on births and deaths disaggregated by age, sex and sub-national region, including numbers, completeness (coverage) rates, fertility and mortality levels and trends, and distribution of leading causes of death, in a public repository accessible to the different users.

# CRVS processes

**Identify the ten CRVS milestones in the process (e.g. Notification missing)**

**Find silos, inefficiencies and bottlenecks in the system**
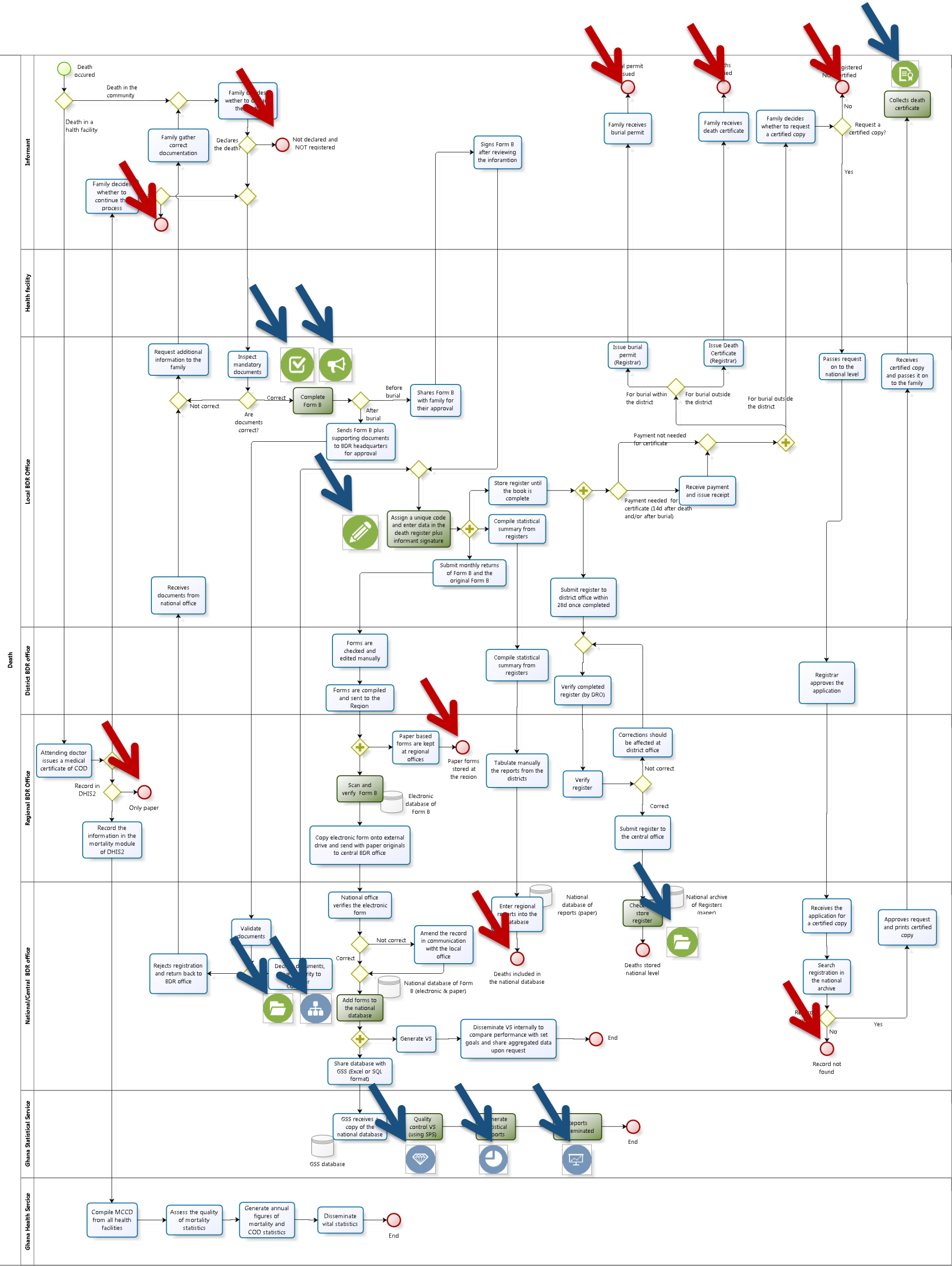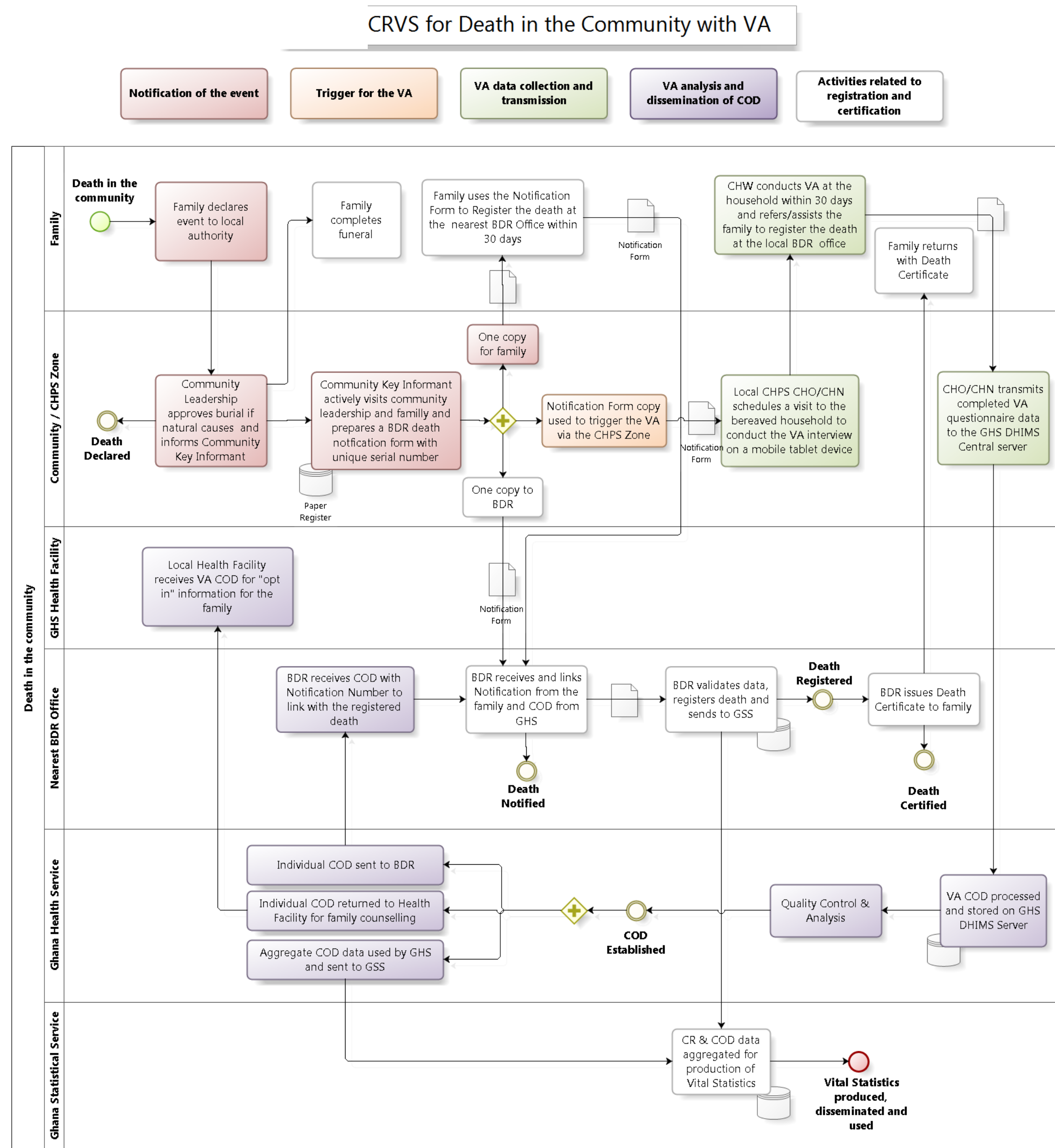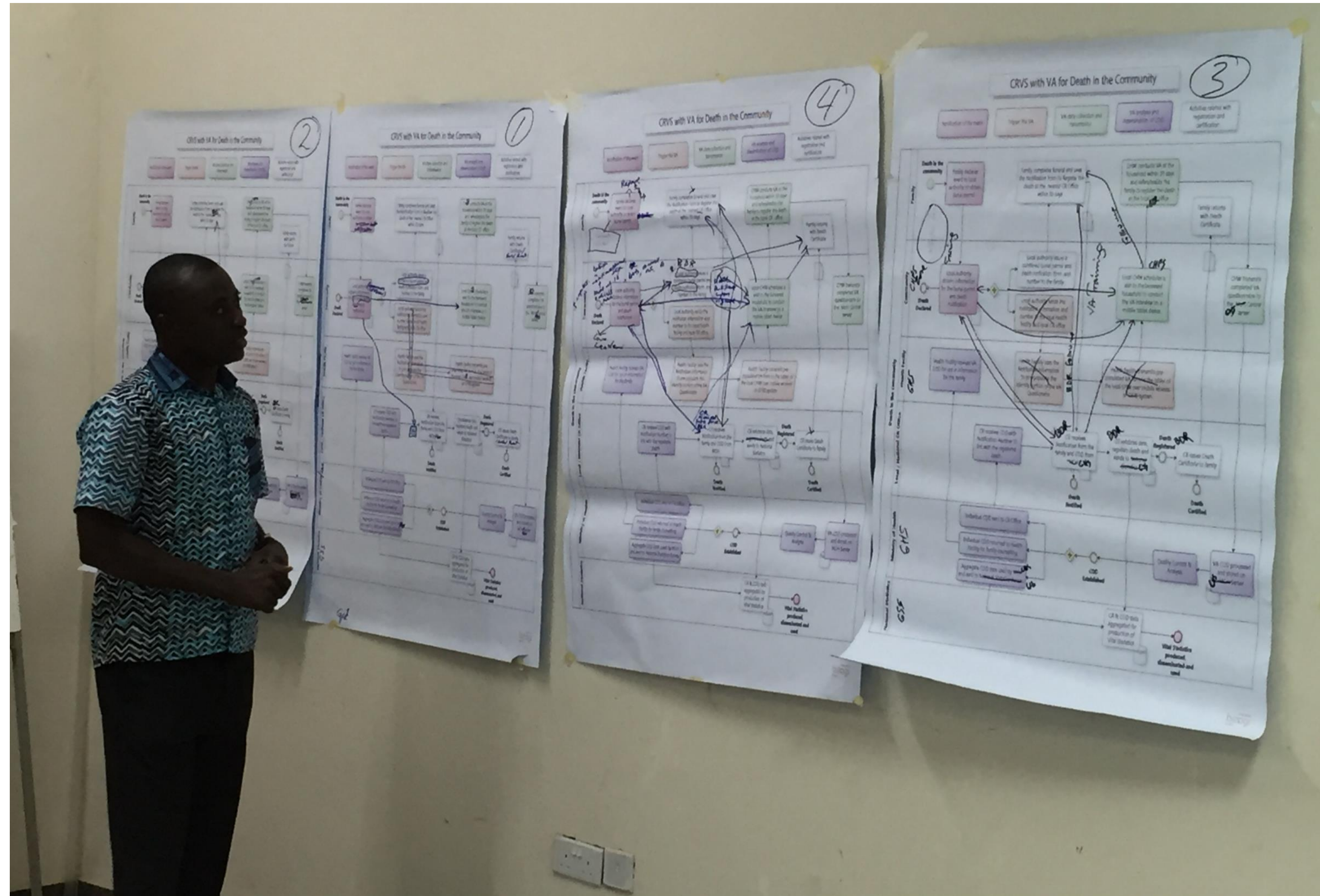
**Draft process maps for integrating Verbal Autopsy into CRVS for community deaths**

CRVS for Death in the Community with VA

- Notification of the event
- Trigger for the VA
- VA data collection and transmission
- VA analysis and dissemination of COD
- Activities related to registration and certification

**Family**

Death in the community → Family declares event to local authority → Family completes funeral → Family uses the Notification Form to Register the death at the nearest BDR Office within 30 days → Notification Form

CHW conducts VA at the household within 30 days and refers/assists the family to register the death at the local BDR office → Family returns with Death Certificate

**Community / CHPS Zone**

Death Declared → Community Leadership approves burial if natural causes and informs Community Key Informant → Community Key Informant actively visits community leadership and family and prepares a BDR death notification form with unique serial number

One copy for family

Notification Form copy used to trigger the VA via the CHPS Zone → Local CHPS CHO/CHN schedules a visit to the bereaved household to conduct the VA interview on a mobile tablet device

CHO/CHN transmits completed VA questionnaire data to the GHS DHIMS Central server

Paper Register

One copy to BDR — Notification Form

**GHS Health Facility**

Local Health Facility receives VA COD for "opt in" information for the family

Notification Form

**Nearest BDR Office**

BDR receives COD with Notification Number to link with the registered death → BDR receives and links Notification from the family and COD from GHS → BDR validates data, registers death and sends to GSS → **Death Registered** → BDR issues Death Certificate to family

**Death Notified**

**Death Certified**

**Ghana Health Service**

Individual COD sent to BDR

Individual COD returned to Health Facility for family counselling

Aggregate COD data used by GHS and sent to GSS

Quality Control & Analysis ← VA COD processed and stored on GHS DHIMS Server

**COD Established**

**Ghana Statistical Service**

CR & COD data aggregated for production of Vital Statistics → **Vital Statistics produced, disseminated and used**
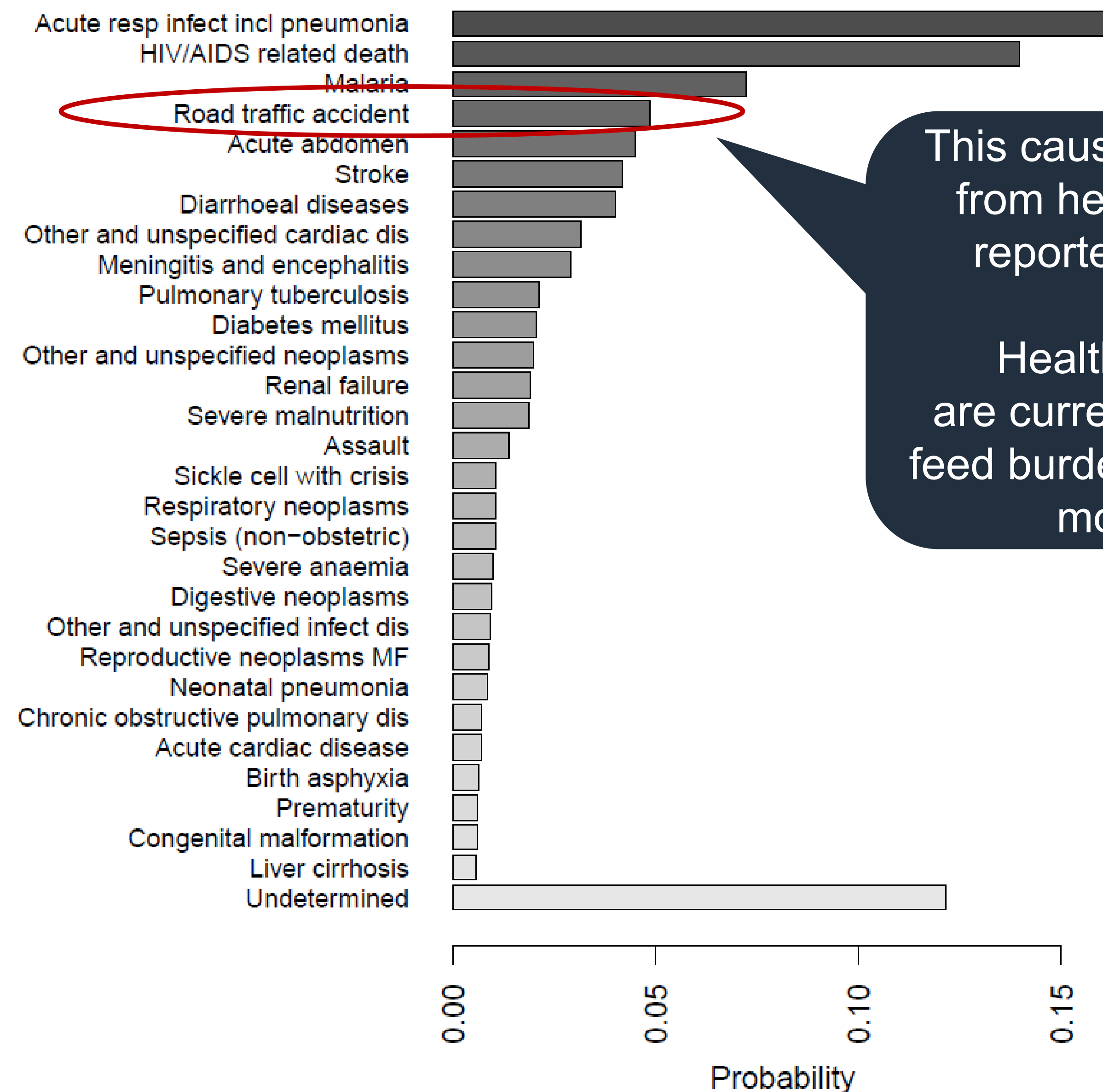
# Participatory refinement of CRVS VA process maps

# A result: CRVS VA cause specific mortality fractions for community deaths – Anonymous Sub-Saharan African country

**Community deaths constitute ~ 70% of all deaths**



This cause is missing from health facility reported deaths;

Health facility data are currently used to feed burden of disease models.

# Some take homes

- Global health in the SDG era cannot continue its dependency on global estimates and models for monitoring and forecasting progress;

- Countries are starting to use systems thinking to radically re-engineer their CRVS systems and integrate game changing approaches;

- For the first time countries have causes of deaths in the community from automated verbal autopsy to complement health facility data;

# Some take homes

- There is a growing research agenda to innovate in real-time data production and analytic methods for the key metric of mortality surveillance.

- Increased investments in national CRVS systems as part of health information systems are essential to provide timely and reliable data and information on national trends in rates and the causes of deaths;

Civil Registration & Vital Statistics

Data for Health Initiative

Thank you