

# Interfacing: making connections within and between states, through data dynamics, and with the international community

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*Improving data improving health: Verbal Autopsy for health systems strengthening.*

London 17 Oct 2016



**INDEPTH Network**

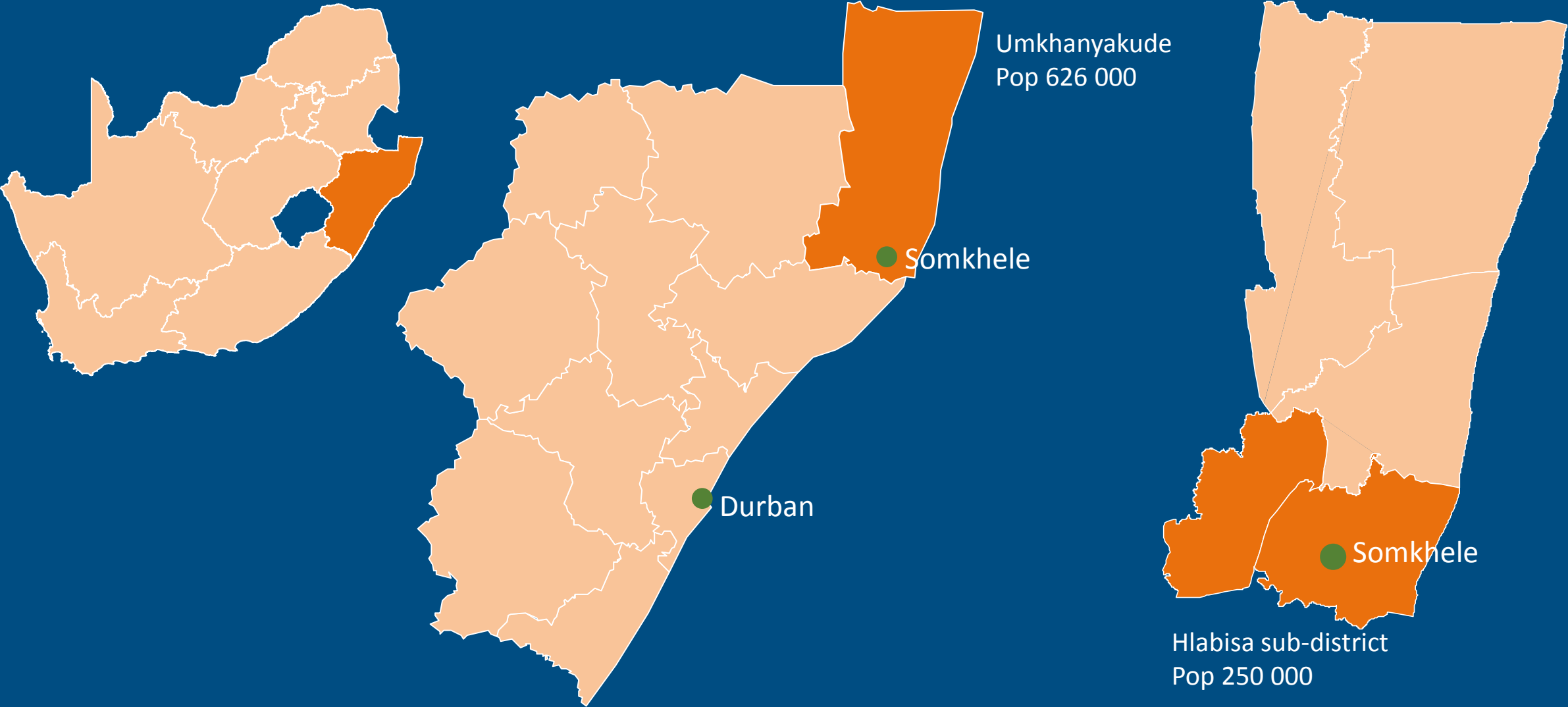
Better Health Information for Better Health Policy



# Outline

- Three vignettes
  - **Local:** Decline in HIV-related mortality in the Hlabisa health sub-district in rural northern KwaZulu-Natal
  - **National:** South Africa – Ministerial Committee on Mortality and Morbidity in Children
  - **International:** INDEPTH Verbal Autopsy Data Sharing

# HIV-related Mortality Decline in northern KwaZulu-Natal - 1



# HIV-related Mortality Decline in northern KwaZulu-Natal - 2

Fig. 2. Cause-specific SMRs for adults aged 25–49 years, KwaZulu-Natal, South Africa, 2000–2006

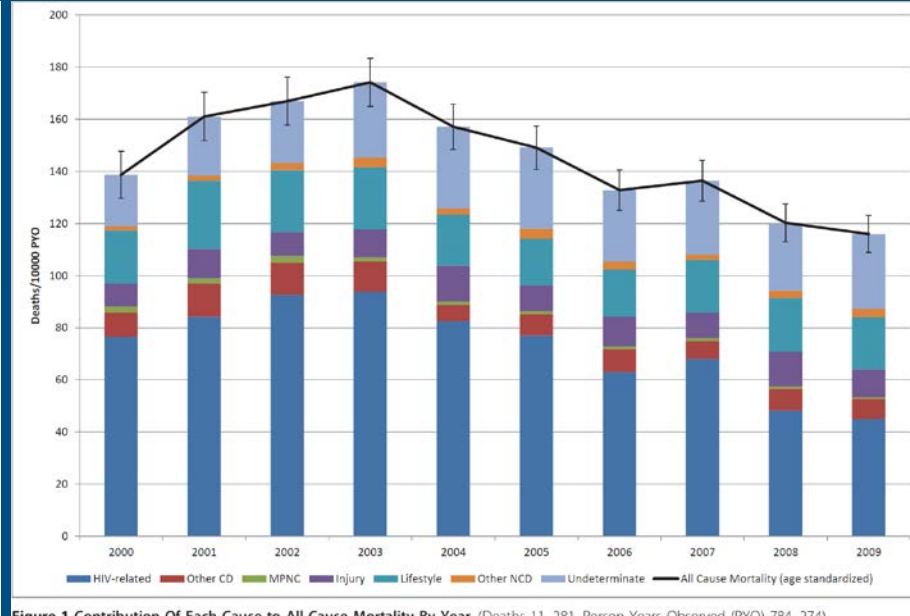
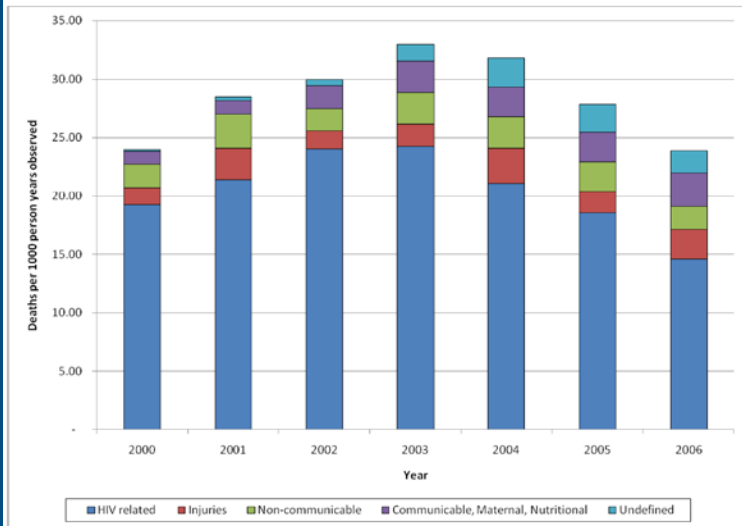


Figure 1 Contribution Of Each Cause to All-Cause Mortality By Year. (Deaths 11, 281, Person Years Observed (PYO) 784, 274).

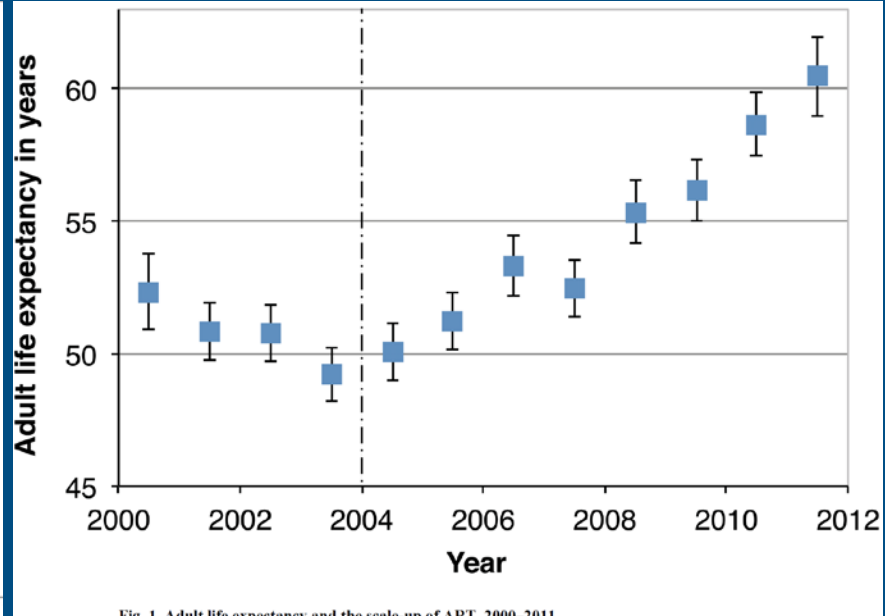


Fig. 1. Adult life expectancy and the scale-up of ART, 2000–2011

Herbst A, Cooke G, Barnighausen T, KanyKany A, Tanser F, Newell M. Adult mortality and antiretroviral treatment roll-out in rural KwaZulu-Natal, South Africa. *Bull World Health Organ.* 2009;87(10):754-62.

Herbst AJ, Mafojane T, Newell ML. Verbal autopsy-based cause-specific mortality trends in rural KwaZulu-Natal, South Africa, 2000-2009. *Popul Health Metr.* 2011;9:47.

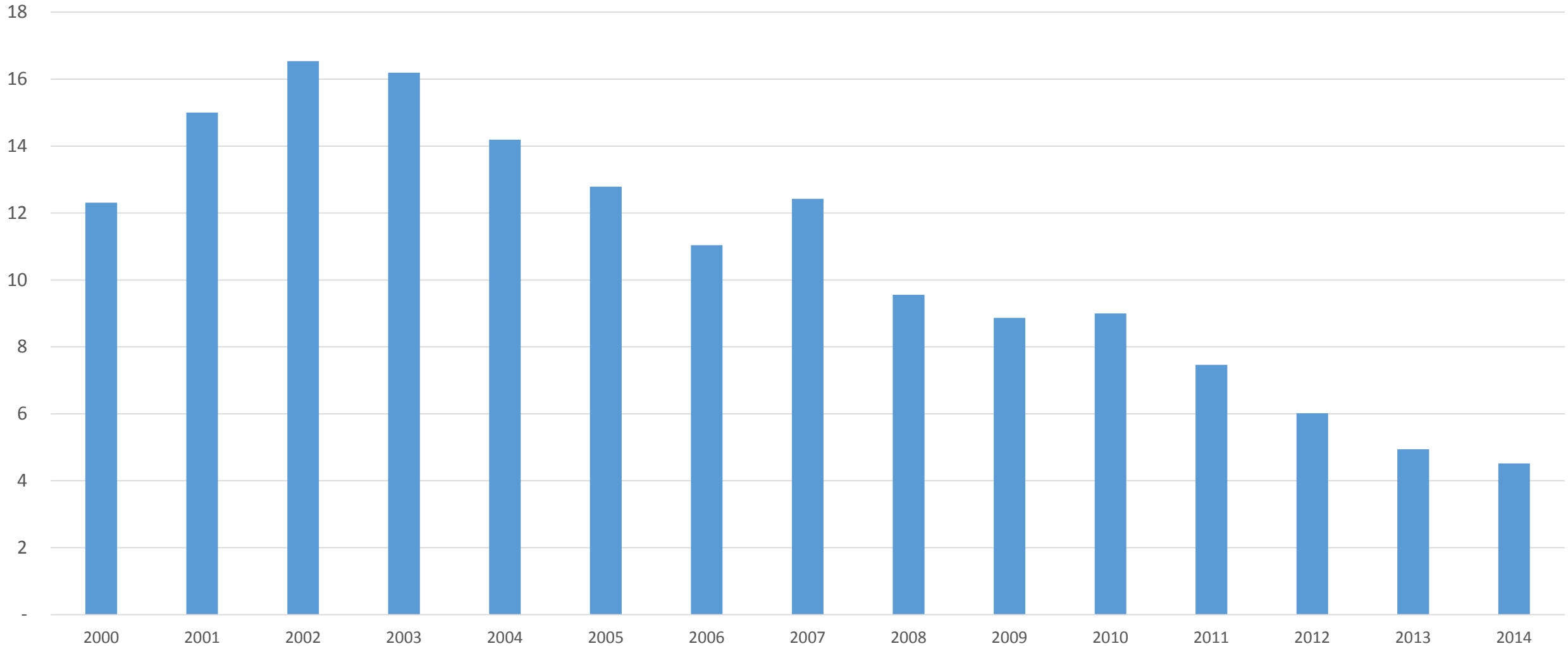
Bor J, Herbst AJ, Newell ML, Barnighausen T. Increases in adult life expectancy in rural South Africa: valuing the scale-up of HIV treatment. *Science.* 2013;339(6122):961-5.

# Local Impact

- Anne Case & Anu Garrib & Alicia Menendez & Analia Olgati, 2013. *"Paying the Piper: The High Cost of Funerals in South Africa,"* Economic Development and Cultural Change, University of Chicago Press, vol. 62(1), pages 1 – 20
  - on average, households spend the equivalent of a year's income for an adult's funeral, measured at median per capita African (Black) income.
  - Approximately **one-quarter** of all individuals had some form of insurance, which helped surviving household members defray some fraction of funeral expenses. However, an equal fraction of households **borrowed money** to pay for the funeral

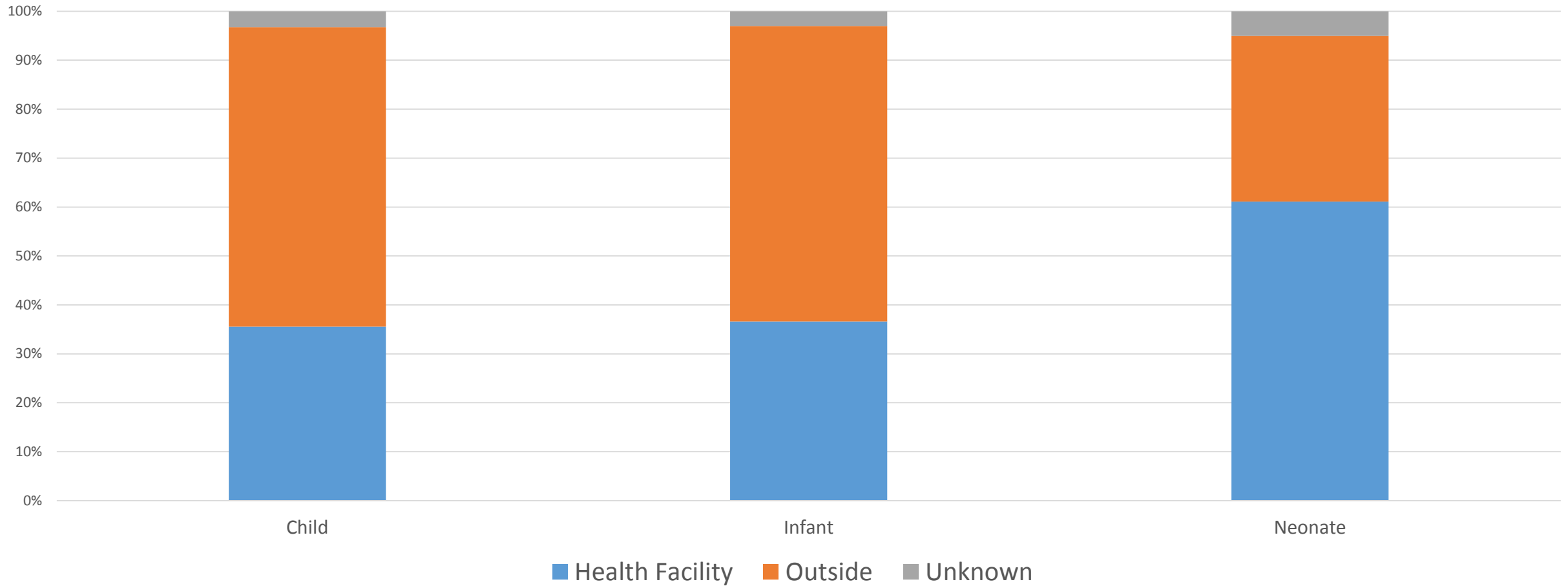
# Mortality decline re-stated

Funerals per Week

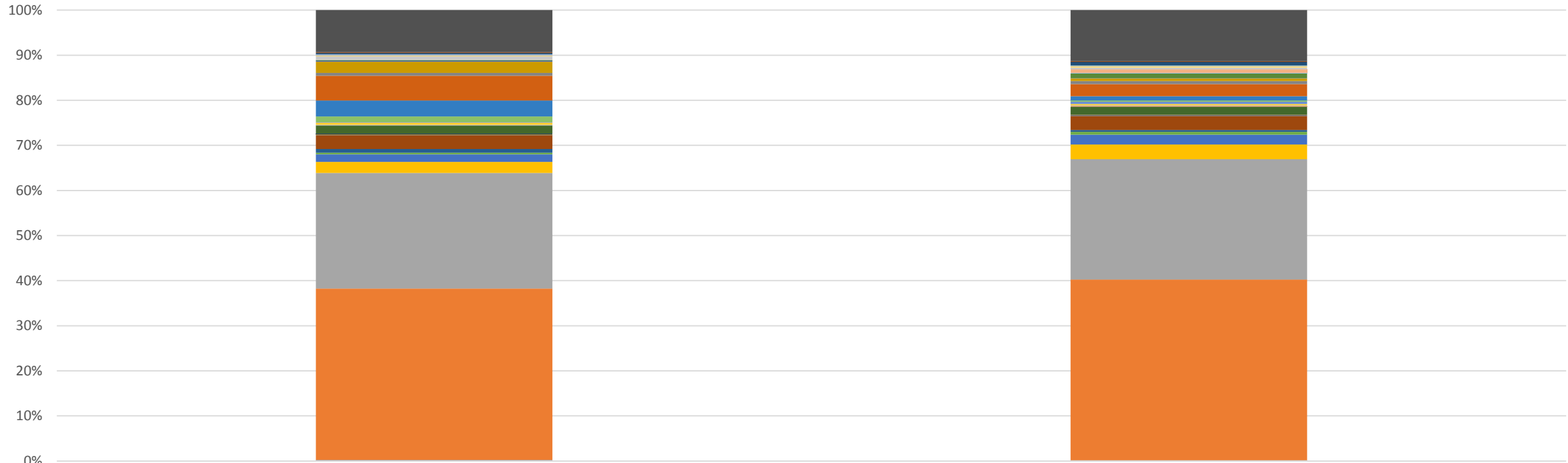


# Child Mortality - Ministerial Committee on Mortality and Morbidity in Children

Death Setting : Child (0-4yr) Deaths  
Deaths = 2083



# Cause of Death by Place of Death



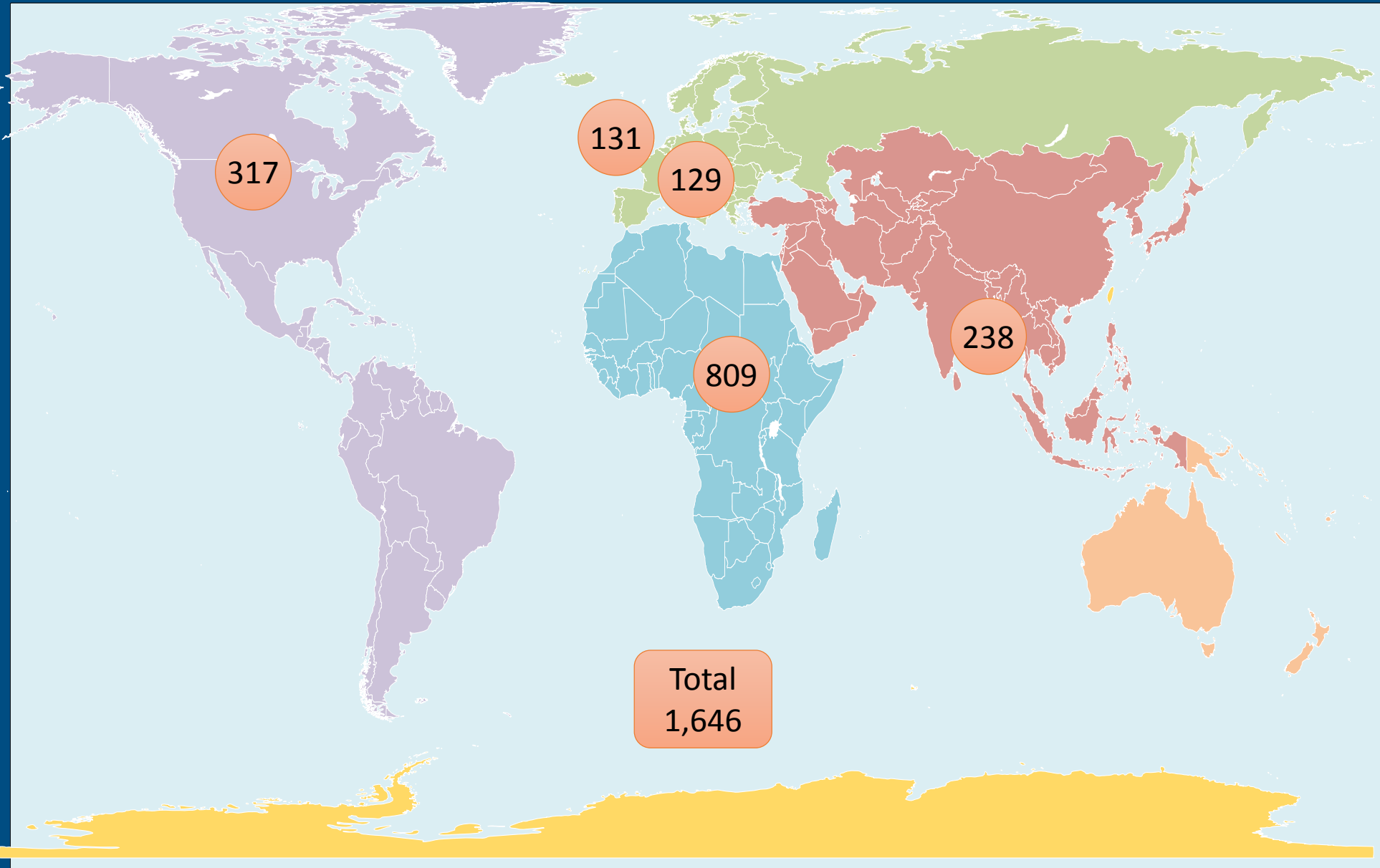
Health Facility

Outside

- 01.01 Sepsis (non-obstetric)
- 01.02 Acute resp infect incl pneumonia
- 01.03 HIV/AIDS related death
- 01.04 Diarrhoeal diseases
- 01.05 Malaria
- 01.06 Measles
- 01.07 Meningitis and encephalitis
- 01.09 Pulmonary tuberculosis
- 01.10 Pertussis
- 01.99 Other and unspecified infect dis
- 02.99 Other and unspecified neoplasms
- 03.02 Severe malnutrition
- 03.03 Diabetes mellitus
- 04.99 Other and unspecified cardiac dis
- 05.02 Asthma
- 06.01 Acute abdomen
- 08.01 Epilepsy
- 10.01 Prematurity
- 10.02 Birth asphyxia
- 10.03 Neonatal pneumonia
- 10.04 Neonatal sepsis
- 10.06 Congenital malformation
- 10.99 Other and unspecified neonatal CoD
- 12.01 Road traffic accident
- 12.03 Accid fall
- 12.04 Accid drowning and submersion
- 12.05 Accid expos to smoke fire & flame
- 12.06 Contact with venomous plant/animal
- 12.07 Accid poisoning & noxious subs
- 12.08 Intentional self-harm
- 12.09 Assault
- 12.99 Other and unspecified external CoD
- 99 Cause of death unknown



# INDEPTH Data Repository Downloads



# INDEPTH Network Cause-Specific Mortality

- Most popular download – 320 downloads to date
  - User feedback – age categories in dataset inflexible
- Solution – link to individual level micro-data
  - Individual identity disclosure risk – revealing date of birth and date of death
  - Risk manifests itself at local community level

**Table 1 Evidence for barriers to sharing of routinely collected public health data**

Category	Barrier	Peer-reviewed		Non peer-reviewed
		Empirical data	Non-empirical*	
<b>Technical</b>	1. Data not collected	[6,21,24,31]	[2,4,7,18,22,14,26-28,30]	[3,23,25]
	2. Data not preserved		[33]	[3,32,34,35]
	3. Data not found		[45]	[3,34]
	4. Language barrier			[36]
	5. Restrictive data format		[40]	[3,34,36-39,41]
	6. Technical solutions not available		[42]	[37]
	7. Lack of metadata and standards	[21,24,43]	[40,44,45]	[1,35-37,39,41,46]
<b>Motivational</b>	8. No incentives		[27,45,49]	[35]
	9. Opportunity cost	[51,52]	[13,33,50,53]	[35]
	10. Possible criticism		[33]	[32]
	11. Disagreement on data use	[21]	[49]	
<b>Economic</b>	12. Possible economic damage		[7,26,27,30]	[55]
	13. Lack of resources	[56,21]	[13,27,28,30,42,53,57]	[3,23,34-36,39,37]
<b>Political</b>	14. Lack of trust	[19,59,60]	[33,61]	[34-37]
	15. Restrictive policies		[30]	
	16. Lack of guidelines		[45,62,65]	[37,41,63,64]
<b>Legal</b>	17. Ownership and copyright		[62,65,66,69]	[37,63,64,67]
	18. Protection of privacy	[12,19,59,73,75]	[44,57,62,66,72,74]	[36,37,64,67,68,70,71]
<b>Ethical</b>	19. Lack of proportionality			[76]
	20. Lack of reciprocity	[51,52]	[50,77,78]	
Number of unique documents (% of total)		14 (21.5%)	30 (46.2%)	21 (32.3%)

\*No or little original data presented.