

### Umeå Centre for Global Health Research



# Making people count: the unequal world of global health data

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#### Civil registration coverage of cause of death (%), 2004-2012



The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement. Data Source: World Health Organization Map Production: Health Statistics and Information Systems (HSI) World Health Organization



Organization





### **Ratios of observations to estimated numbers:**



Figure 1 Ratio of observations used in the Global Burden of Disease model to the number of cirrhosis deaths estimated for 2010, by country.

### BMC Medicine 2014, 12:159





### Tensions between global estimates and counted data:



Proportion of vital events registered





# Verbal autopsy as the most pragmatic solution for cause-of-death data:

- Verbal autopsy (VA) interviews can be carried out by school leavers with some training
- WHO recently updated international standards for VA to the WHO 2016 version – using a tablet, interviews take around 15-20 minutes per case
- Interview findings can be processed automatically using computer models – e.g.
  InterVA – a cheap and rapid process
- What is needed to make this happen on a large scale?







# **Effectiveness of verbal autopsy:**

 Routine VAs automatically processed with the InterVA model achieve high covalidity with Global Burden of Disease cause-specific estimates for low- and middle-income countries



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Concordance correlation between GBD and INDEPTH cause-specific mortality findings in 13 low-income and middleincome countries, by six major cause of death categories. Each point represents one country, cause category, age group, and 5-year period.



Lancet Glob Health 2016; 4:785-6

# Technical barriers ? – the example of child mortality:

- There are about 670 million under-5 children in the world, and about 6 million under-5 deaths each year
- If the basic who-where-when details of every birth were recorded, the capacity needed to store a 250-character record for each of the 670 million under-5s is well within the space available on a modern laptop
- There would still be plenty of room for much more detail on each of the 6 million under-5 deaths
- No fancy modelling or estimating would be needed
- Thus IT infrastructure is not the major constraint but effective data processes on the ground particularly in Africa and Asia don't exist





# The need for worldwide vital registration:

To catch up on VR in the unregistered areas of the world, the world needs to implement:

- 1. Routine identification of deaths
- 2. A standard verbal autopsy (VA) tool
- 3. Consistent, automated cause-of-death assignment methods
- 4. Portable, robust implementations for easy field use with easy language adaptation
- 5. Transparent analyses and interpretations

### The UN needs joined-up thinking on vital registration

Universal health coverage (UHC), as described in your Editorial (Sept 8, p 859),<sup>1</sup> promises to be a major force for good in global public health. At the same time, the UN's independent Evidence Review Group on Information and Accountability for Women's and Children's Health (iERG)<sup>2</sup> reports serious shortcomings in expected progress, not least in terms of knowing how much has been achieved, because of limitations in measurement and data.

Looking back at countries that today have universal vital registration and also strong public health systems, it is clear that early public health initiatives were inextricably entwined with developments in recording births, deaths, and causes of death.<sup>3</sup> These data were then analysed in ways that directly informed public health policy, and this historic virtuous circle between vital registration and improvements in public health should not be underestimated.

Lancet 2012; 380:1643





### Generalising to global development:

- Good information systems and data, well implemented on the ground, are critical to development in general
- Epidemiologists talk about "unit of observation" the level at which things are observed (country, local area, household, individual, etc.)
- Progress in global development (and being able to document that progress) depends critically on good individual-level routine observation – not just making high-level generalisations and estimates
- *"Everyone counts so count everyone"* (Lancet 2015; 386:1313-1314)



