Working with people: developing a people-centred action-oriented research method in South Africa

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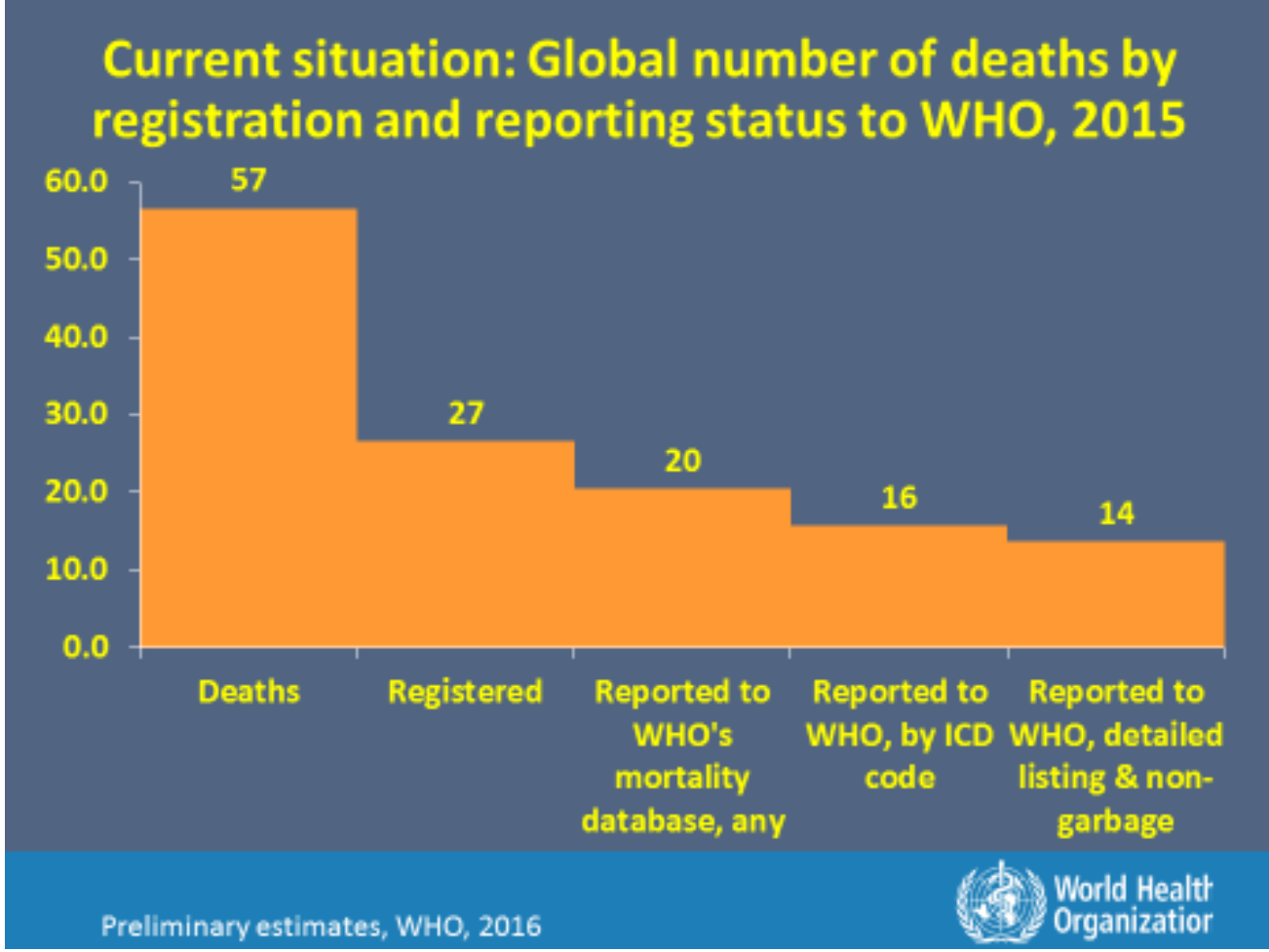
Rationale, Objectives

- 3 in 4 deaths unreported cause
- Relationship between material and data poverty
- Health systems need reliable information
- *Improved ways to record deaths*
- *Method to connect communities + authorities to assess local situations, identify priorities*



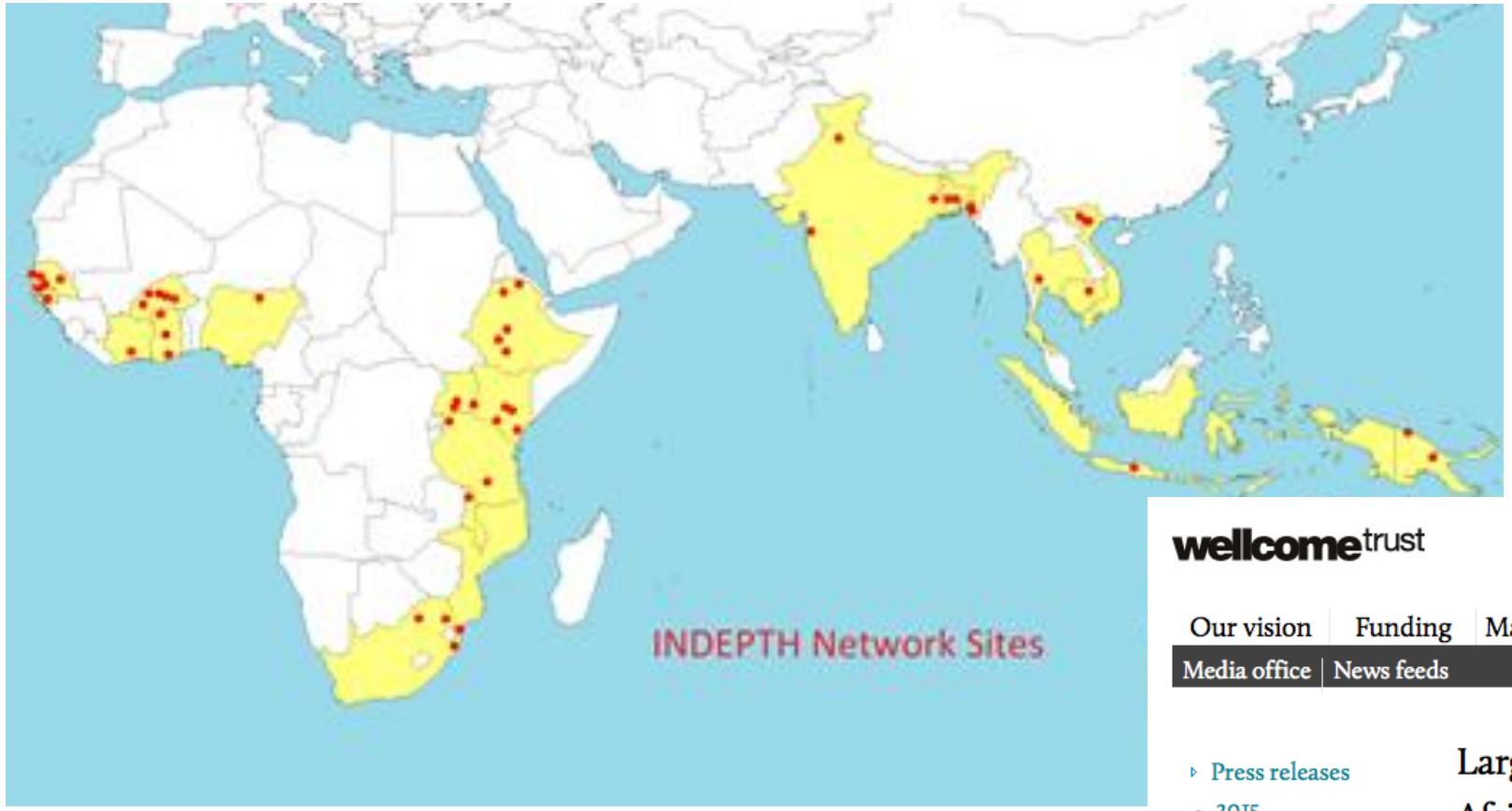
Source: Boerma, 2016

Design, 3 Phases

1. Understand levels and medical causes of death and circumstances of mortality
2. Gain local knowledge on avoidable mortality and priorities for action
3. Combine in a process that connects routine data + local knowledge to the health system

INDEPTH Network

Better Health Information for Better Health Policy



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- Press releases
  - 2015
  - 2014
  - 2013
  - 2012
  - 2011
  - 2010

Largest ever dataset on individual deaths in Africa and SE Asia reveals changing health

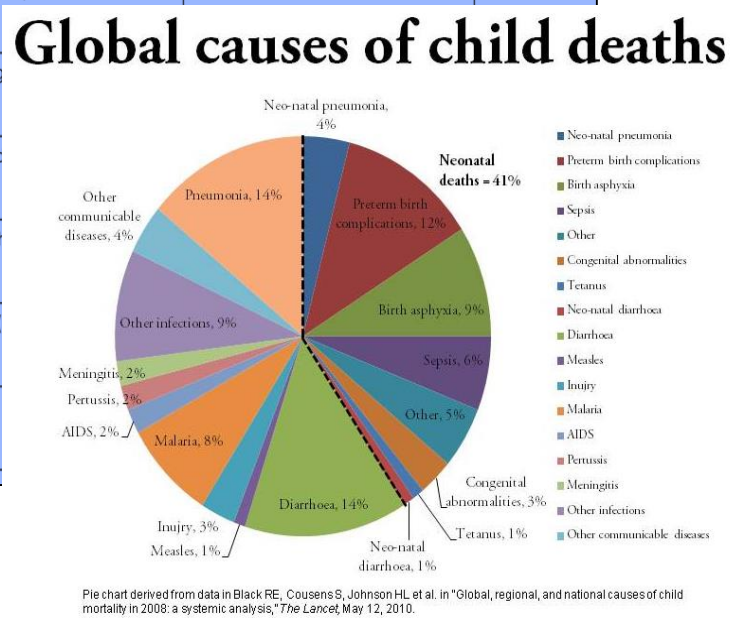
29 October 2014

An unprecedented insight into the changing health of people across Africa and Asia - including the fluctuating burdens of HIV, malaria and childhood mortality - is revealed today by the publication of the largest ever dataset of individual deaths recorded on the ground.

Phase 1 Verbal Autopsy (VA)

- Deaths outside hospitals and/or without proper registration
- Interview on medical signs & symptoms
- Interpreted to determine probable medical cause of death
- Disease burdens in unregistered populations

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
805	Did she die during labor, but undelivered?	YES ..... 1 NO ..... 2 DON'T KNOW 8	
806	Did she give birth recently?	YES ..... 1 NO ..... 2 DON'T KNOW 8	→ 818 → 818
807	How many days after giving birth did she die?	DAYS ..... [ ][ ] DON'T KNOW 9 8	
808	Was there excessive bleeding on the day labor started?	YES 1	
809	Was there excessive bleeding during baby?		
810	Was there excessive bleeding after		
811	Did she have difficulty in delivering th		
812	Was she in labor for unusually long (		
813	Was it a normal vaginal delivery?		

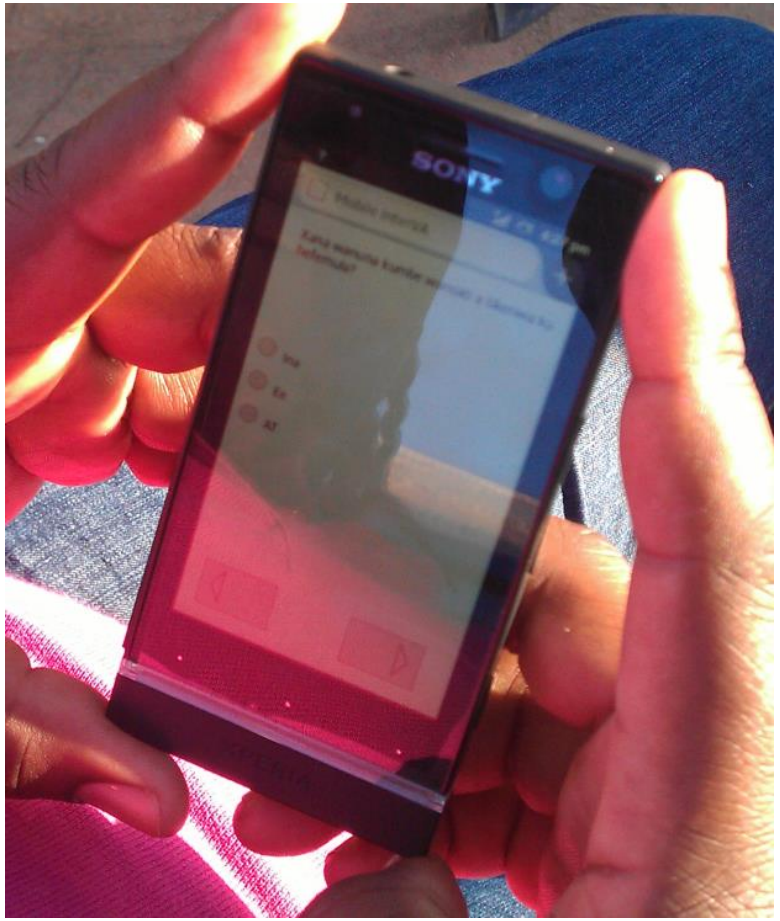


Pie chart derived from data in Black RE, Cousens S, Johnson HL et al. in "Global, regional, and national causes of child mortality in 2008: a systemic analysis," *The Lancet*, May 12, 2010.

VA Methods

- Widespread application
- Standardisation
- Scale up for health systems strengthening
- Interpret VA interviews reliably and consistently
- Automated models
- Mobile VA

InterVA



Source: Fottrell 2016

Biosocial view of VA

- VA to determine medical causes of death for people who die outside health facilities or without registration
- VA about people who do not connect to health systems
- VA is an opportunity to examine social exclusion from health systems
- In the context of the methodological transition of VA, opportunity to do this routinely

Cause of death?

Woman gave birth at home 10am accompanied by her sister. After delivery she haemorrhaged + suffered ruptured uterus retained placenta

TBA was called but could not deliver placenta. A 2nd TBA + male traditional healer called at 1pm. The healer+ TBA delivered the placenta manually. The woman continued to bleed

The family called an ambulance but it took 2 hours to arrive. During the journey to hospital, the patient continued to bleed, became weak and died before the facility was reached

Could classification systems be improved?

Social Autopsy

Social Autopsy - A method to examine barriers to health care, risky behaviours and missed opportunities for health interventions

Karin Källander, PhD, MSc

Improving data improving health: Verbal Autopsy for health systems strengthen
17th October 2016

Kalter et al. Population Health Metrics 2011, 9:45
http://www.pophealthmetrics.com/content/9/1/45

POPULATION HEALTH METRICS

REVIEW Open Access

Social autopsy for maternal and child deaths: a comprehensive literature review to examine the concept and the development of the method

Henry D Kalter[1*], Rene Salgado[2], Marzio Babille[3], Alain K Koffi[1] and Robert E Black[1]

Abstract

"Social autopsy" refers to an interview process aimed at identifying social, behavioral, and health systems contributors to maternal and child deaths. It is often combined with a verbal autopsy interview to establish the biological cause of death. Two complementary purposes of social autopsy include providing population-level data to health care programmers and policymakers to utilize in developing more effective strategies for delivering maternal and child health care technologies, and increasing awareness of maternal and child death as preventable problems in order to empower communities to participate and engage health programs to increase their responsiveness and accountability.

Through a comprehensive review of the literature, this paper examines the concept and development of social autopsy, focusing on the contributions of the Pathway Analysis format for child deaths and the Maternal and Perinatal Death Inquiry and Response program in India to social autopsy's success in meeting key objectives. The Pathway Analysis social autopsy format, based on the Pathway to Survival model designed to support the Integrated Management of Childhood Illness approach, was developed from 1995 to 2001 and has been utilized in studies in Asia, Africa, and Latin America. Adoption of the Pathway model has enriched the data gathered on care seeking for child illnesses and supported the development of demand- and supply-side interventions. The instrument has recently been updated to improve the assessment of neonatal deaths and is soon to be utilized in large-scale population-representative verbal/social autopsy studies in several African countries. Maternal death audit, starting with confidential inquiries into maternal deaths in Britain more than 50 years ago, is a long-accepted strategy for reducing maternal mortality. More recently, maternal social autopsy studies that supported health programming have been conducted in several developing countries. From 2005 to 2009, 10 high-mortality states in India conducted community-based maternal verbal/social autopsies with participatory data sharing with communities and health programs that resulted in the implementation of numerous data-driven maternal health interventions.

Social autopsy is a powerful tool with the demonstrated ability to raise awareness, provide evidence in the form of actionable data and increase motivation at all levels to take appropriate and effective actions. Further development of the methodology along with standardized instruments and supporting tools are needed to promote its wide-scale adoption and use.

Introduction and background

In developing country settings with inadequate vital registration systems and where many deaths occur at home, verbal autopsy is the investigative method most often used to determine the prevailing biological causes of death. Health policymakers and programmers require these data to identify health priorities, allocate sparse resources, and evaluate the impact of health programs. Social autopsy consists of questions on modifiable social, cultural, and health system factors that contribute to the same deaths investigated by verbal autopsy. Because social autopsy studies are often conducted without a control group of survivors, it is important that the factors included be based on interventions of proven efficacy. Health care programmers and policymakers need these data to identify strategies for increasing health-

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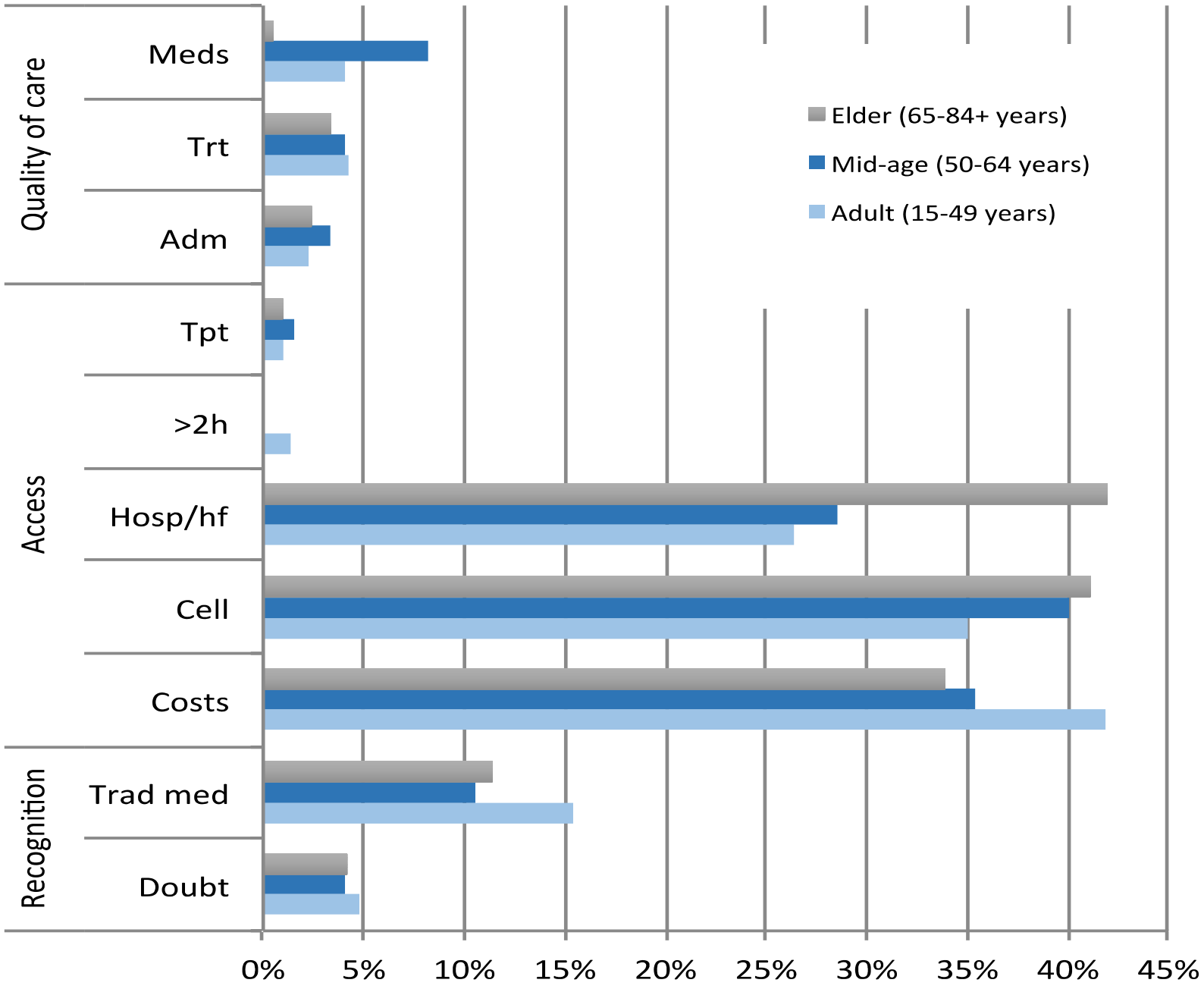
New VA indicators: 'Circumstances of Mortality'

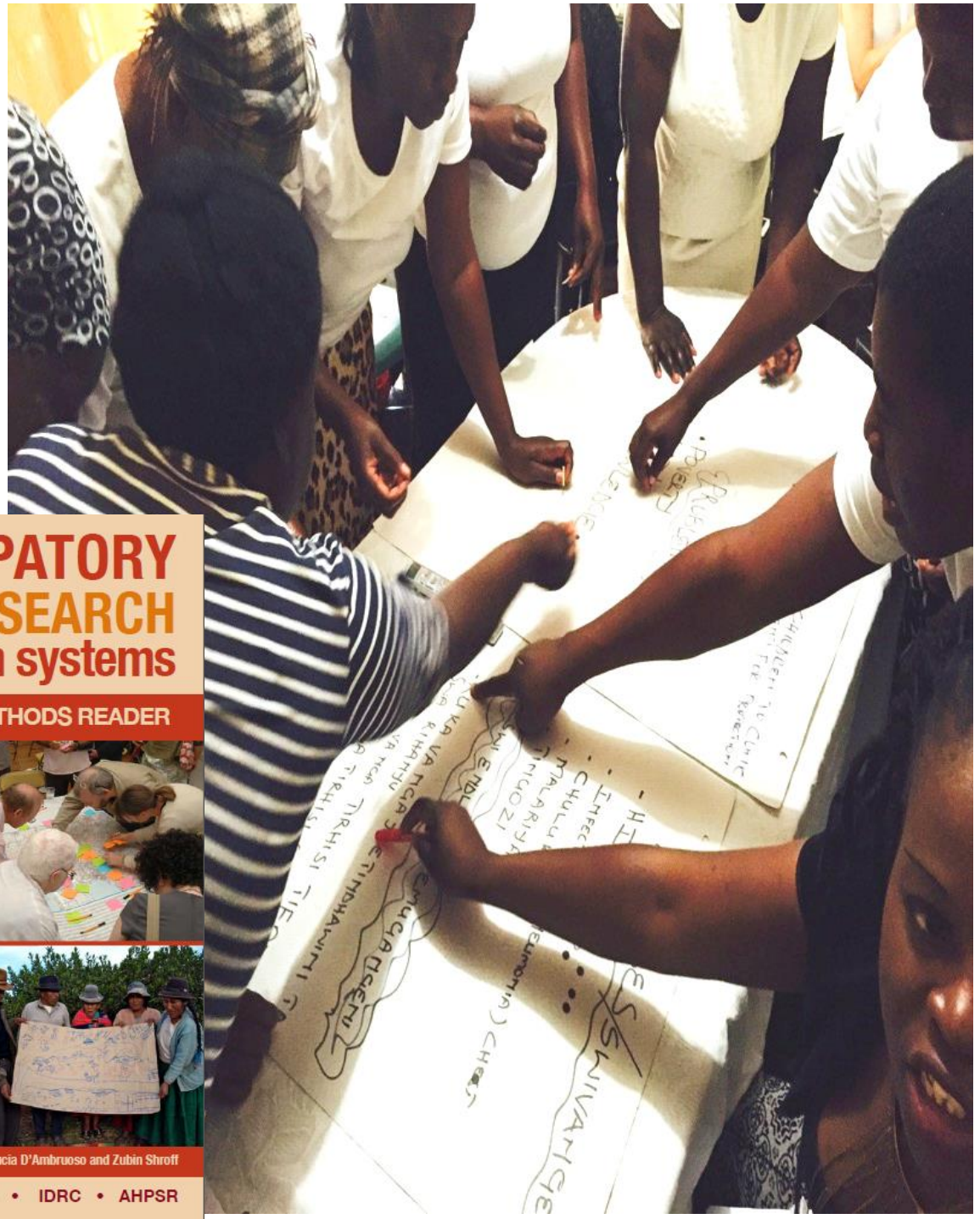
Structure	Theme	VA Question/Indicator
↓ Care Pathway Home To Hospital ↓	Recognition	Were there any **doubts** about whether care was needed?
		Was **traditional medicine** used?
	Access	Did anyone use a **telephone**/cell phone to call for help?
		Did (s)he use **motorised transport** to get to the hospital/facility?
		Did (s)he **travel to a hospital/facility**?
		Does it take **>2 hours** to get to the nearest hospital/facility?
		Did the total **cost of care** prohibit other household payments?
	Quality	Were there problems during **admission**?
		Were there problems with the way (s)he was **treated** in the hospital/facility?
		Were there problems with getting **medications**, tests or treatments?

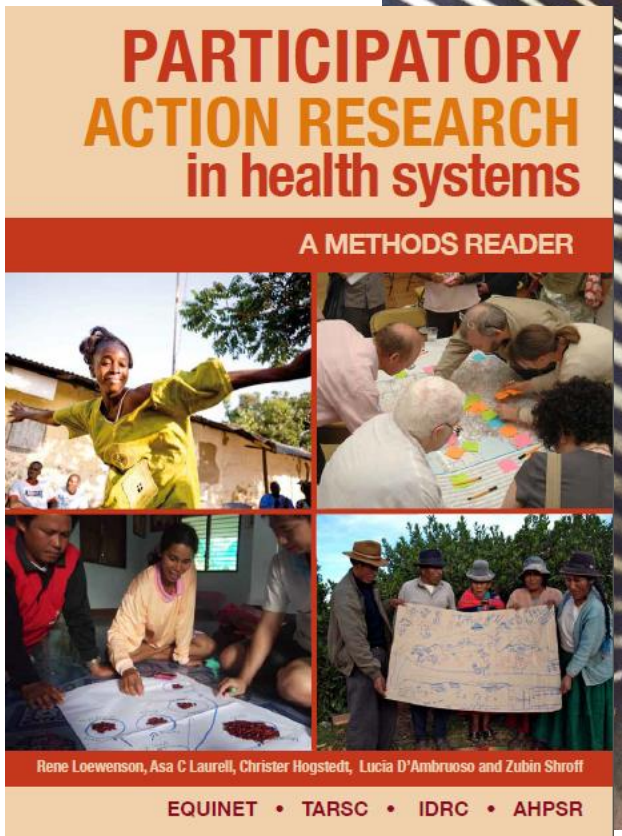


- Problems with access
  - Not calling for help
  - Not going to facility
  - Overall costs (incl. travel, transport, meds, food etc.)
- Traditional medicine
- Lower/no problems with quality (for those going to facilities)
- Varied by COD

Phase 2 VA + PAR

- Participatory action research (PAR) process to elicit local knowledge on the causes of mortality and priorities for action
- PAR seeks to overcome conventional subject-object distinctions to shift power towards those affected to know, problematize, understand, act and transform





- 3 village based discussion groups
- 8 weeks - series of meetings
- 2 conditions selected on the basis of high prevalence and community and health authorities priorities

- Subjective perspectives elicited and systematised into collective accounts

- Photovoice, visual method
- Directly representative of people’s perspectives
- Images of physical environment as an input to the discussions

Housing, unemployment

Unclean water

Unsafe environments
Perceived neglect

Quality of Care

- **Poor quality care**
  - Long waiting times, overcrowded clinics
  - Delays in treatments, lack of medications
  - Lack of confidentiality
- **Blame + negativity towards nurses despite lack of autonomy**

Priorities for Action

- Reduce unemployment
- Provide clean water
- Expand clinics
- Improve accountability and responsiveness of staff
- Engage with communities for health education

Phase 3 Health Systems Appraisal

- Provincial stakeholders - interpret data, identify actions, critique method
  - *Flexible waiting times in clinics*
  - *Re-organisation of ambulance services*
  - *Health education and information*
  - *Multi-level inter-sectoral collaboration in policy and planning*
- Continuum of action - no/low cost to more substantial
- Beyond the clinic - connecting actors at different levels
- Robust, innovative partnerships approach, acceptable and relevant for use in health systems

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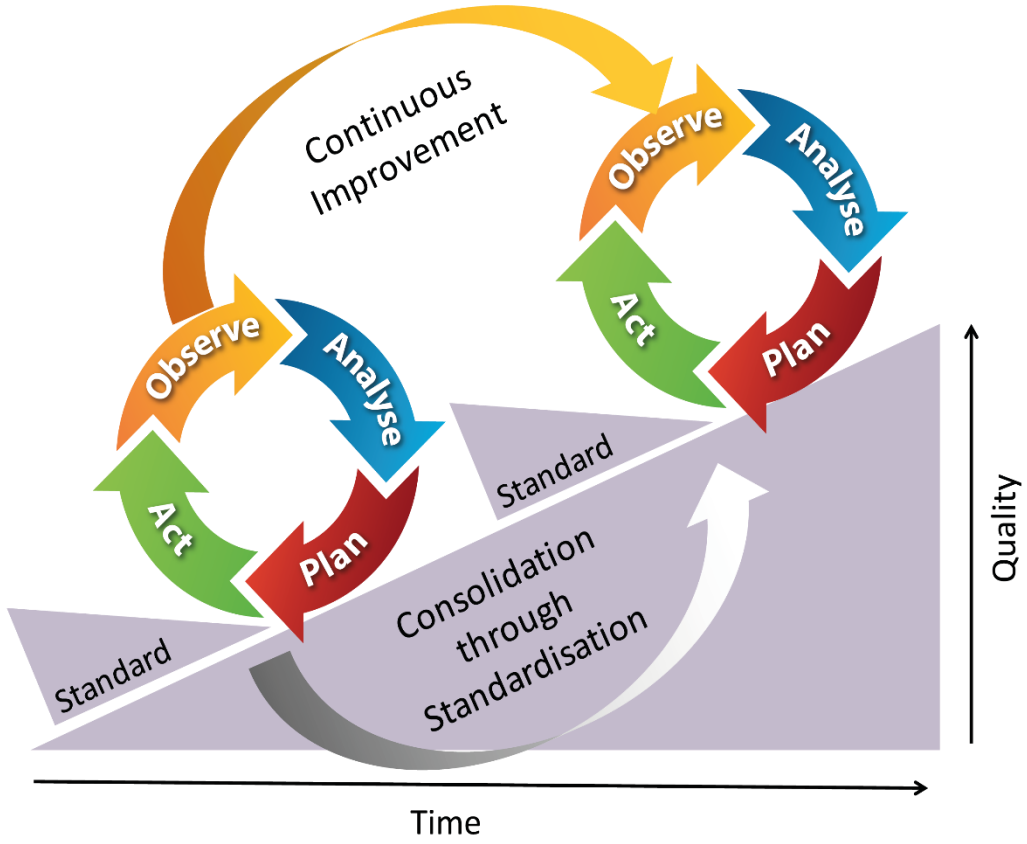
Outputs + Next Steps

- **HSR method**: based on core standards, contextually relevant Piloted suitable for application in other sites
  - New ways to understand deaths in VA
  - PAR with communities
  - Embedded in health system
- **Co-produced evidence**: practical knowledge built from multiple perspectives (services users, providers) + embedded in local policy context. Promotes capacity building + evidence-based advocacy
- **Knowledge partnerships**: Planning for extending into an ongoing process of reflection and action



Whose voices count?

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Editorial

OXFORD

Privilege and inclusivity in shaping Global Health agendas

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Northern voices dominate Global Health discussions. Of recent Lancet Commissions, excluding representatives from international organizations, 70% of commissioners on the Women and Health commission came from the global North, and likewise, 71% of the Health and Climate Change commission, 72% of the Global Surgery commission and 73% of the Global Health commission (Lancet 2016). Only two out of the 16-member Board of Directors of the Consortium of Universities of Global Health come from the global South (CUGH 2016). No current or past president and only one current member of the World Health Summit's scientific committee is from the global South (WHS 2016). Only one of the 17 advisory board members of the journal Global Health Governance is based in a low/middle income country (LMIC) institution (GHG 2016).

Only 15% of the world's population lives in high-income countries. Yet Global Health conferences continue to be dominated by invited Northern speakers and important committees on Global Health composed mainly of Northerners. The words of a few from the global North wield a disproportionate power that carries well beyond their own boundaries. How can it be acceptable that these groups continue to dominate in deciding what problems we think about in Global Health and how we approach them?

The lack of inclusivity in Global Health carries major risks for the field. The most excellent research study or Global Health program risks failure unless it is informed by and contextualized by the people close to where change is sought. The Ebola crisis starkly illustrated the follies of a top-down system of global response to local health problems, and the crying need to develop local institutions and systems, access the experiential and tacit knowledge of local and country actors and listen more closely to voices from the ground (Wilkinson and Leach 2014). It is neither conscionable nor accurate to make the excuse that there is not enough technical know-how or expertise in LMICs to accommodate more such voices. Widening the breadth of participation in key discussions is critical to accessing different forms of knowledge, capacity and intelligence.

How then can discussions in Global Health begin to embrace global diversity? Social media initiatives such as the recent list of 300 influential women in Global Health and the campaign to reject men-only panels (#allmalepanels) have had some success (Graduate Institute 2015; Twitter 2016). Perhaps a new hashtag to protest how northern elites shape development debates would have an impact, but it will only be a start.

The question of inclusivity calls for multiple approaches. Intersectionality—the study of how privilege and disadvantage are linked to overlapping social identities—holds promise in deepening our understanding of inclusivity. Understanding how one axis of disadvantage (e.g. gender) may operate contiguously with others (e.g. working in a low income country, non-Anglophone, young), helps us better conceptualize complex social hierarchies that more accurately mirror real-life experience (Larson *et al.* 2016).

Action to promote inclusivity and diversity is not free of pitfalls. One relates to the politics of representation, where particular individuals or groups become associated with specific constituencies and are repeatedly invited to represent the interests of that constituency. This is linked to homogenization—when the views of so-called representatives become conflated with the needs of an entire group or country, however heterogeneous in reality. We need to push towards real inclusion so that diverse voices are not just brought to the table but are empowered to shape the debate and set the agenda.

What practical steps might be taken to improve inclusivity in Global Health? Codes of conduct for Boards and Commissions concerned with Global Health could be framed to encourage inclusion of individuals from the global South (as well as other underrepresented groups), and provide standards to judge inclusivity. Global meetings could be held more frequently in LMICs and support more participation from poorly represented regions and groups through financial scholarships. Conference programmes can ensure the inclusion of LMIC-based and non-elite speakers. Innovative session formats that maximize participation help make conferences less inhibiting and hierarchical, and can promote different styles of intervention and dialogue. The top Global Health journals should be more open than they currently are to qualitative research—the recognized scientific approach for listening to diverse voices and accessing diverse experiences (Daniels *et al.* 2016). Initiatives such as fee

"Global Health community needs to reflect on whom it is seeking to serve

- promote involvement of marginalized people
- reflect on how benefits distributed
- work with introspection and humility

(Sheikh et al 2016)

Further information

D'Ambruoso, L. et al (2016). 'Moving from medical to health systems classifications of deaths: extending verbal autopsy to collect information on the circumstances of mortality'. Global Health Res Policy, 1:2.

Hullur, N. et al (2016). 'Community perspectives on HIV, violence and health surveillance in rural South Africa: a participatory pilot study'. J Global Health, 6:010406.

Worldwide, 65% of deaths go uncounted – here's how to change that http://tinyurl.com/j4hk98e

When communities help authorities tally births and deaths, health care equalises http://tinyurl.com/zn25272

Engaging with communities can help tackle poverty linked health problems http://tinyurl.com/zh89dag

Acknowledgements

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