

Who Counts? 1



A scandal of invisibility: making everyone count by counting everyone

Philip W Setel, Sarah B Macfarlane, Simon Szreter, Lene Mikkelsen, Prabhat Jha, Susan Stout, Carla AbouZahr, on behalf of the Monitoring of Vital Events (MoVE) writing group*

Most people in Africa and Asia are born and die without leaving a trace in any legal record or official statistic. Absence of reliable data for births, deaths, and causes of death are at the root of this scandal of invisibility, which renders most of the world's poor as unseen, uncountable, and hence uncared. This situation has arisen because, in some countries, civil registration systems that log crucial statistics have stagnated over the past 30 years. Net of debt relief, official development assistance reached US\$80 billion in 2004. Yet because of the weakness in recording vital statistics, we have little authoritative evidence that these funds have their desired effects on either mortality or poverty reduction. Sound recording of vital statistics and cause of death data are public goods that enable progress towards Millennium Development Goals and other development objectives that need to be measured, not only modelled. Vital statistics are most effectively generated by comprehensive civil registration. Civil registration has a dual function, both statistical and legal; it also helps with economic development. 30 years of stagnation will not be overcome quickly, although new efforts to develop national statistical capacities offer a unique opportunity to refocus attention on civil registration. Now is the time to make the long-term goal of comprehensive civil registration in developing countries the expectation rather than the exception. The international health community can assist by sharing information and methods to ensure both the quality of vital statistics and cause of death data, and the appropriate use of complementary and interim registration systems and sources of such data. The continued cost of ignorance borne by countries without civil registration far outweighs the affordable necessity of action.

Who counts?

By posing this question, our goal is to focus worldwide attention on the need to recommit resources to the registration of births and deaths, and to certify the causes of death in the world's poorest countries. Published fertility, mortality, and cause-specific mortality figures for rich countries are based on data from functioning civil registration systems and can sensitively monitor long-term and short-term demographic changes, and give up-to-date population counts. Fertility and mortality figures for countries without birth and death registration, however, are based on a dwindling supply of data

generated from a variety of suboptimum sources.¹ Few data for causes of death are available at all—especially for adults. Information needs in resource-poor settings can no longer be met by continued reliance on enumeration by surveys and econometric modelling. These places need to develop civil registration, and complementary, or interim sources of routinely collecting vital statistics. A holistic approach to the development of health information systems is needed,^{2–6} the centerpiece of which must be a recommitment to civil registration and to making it a sustainable source of quality information that cannot be obtained otherwise.

Key messages

- Civil registration and the resulting vital statistics are essential public goods that benefit individuals and societies. Legal documents that prove identity and citizenship not only provide access to state services or entitlements, but can also be a defence against exploitation or protracted hardship in times of emergency. If vital statistics of births and deaths are combined with accurate cause of death data, their usefulness for health decisionmaking is greatly increased. The effect of having such data for health policies and programmes can be seen across a range of countries with widely different national incomes
- The persistent failure to establish, support, and sustain civil registration systems over the past 30 years, and to ensure that causes of death are accurately known in the world's poorest countries is a scandal of invisibility, for which affordable remedies exist and need to be implemented. The scope of this scandal is enormous. Few countries in greatest need of vital events and information about cause of death have the capacity to obtain it
- Overcoming decades of stagnation will need countries to make a principled long-term commitment to comprehensive civil registration, and to make pragmatic use of complementary or alternative registration systems and sources of data for vital events and cause of death in the short term and medium term

"To make people count, we first need to be able to count people" LEE Jong-Wook, WHO Director-General, 2003–2006, address to WHO staff July 21, 2003

Published Online

October 29, 2007

DOI: 10.1016/S0140-6736(07)61307-5

This is the first in a Series of four papers about the importance of collecting data for health development

* Members listed at the end of article

MEASURE Evaluation, Carolina Population Center and Departments of Epidemiology and Anthropology, University of North Carolina at Chapel Hill, Chapel Hill NC USA (P W Setel PhD); Global Health Sciences, University of California, San Francisco, USA (S B Macfarlane MSc); History Faculty and St John's College, Cambridge, UK (S Szreter PhD); Health Metrics Network, Brisbane, Queensland, Australia (L Mikkelsen PhD); Centre for Global Health Research, St Michael's Hospital, University of Toronto, Canada (Prof P Jha DPhil); Results Secretariat, World Bank, Washington, DC, USA (S Stout DrPH); and Health Metrics Network, Geneva, Switzerland (C AbouZahr MSc)

Correspondence to:

Philip W Setel, MEASURE Evaluation, Carolina Population Center, University of North Carolina at Chapel Hill, 206 West Franklin St, Chapel Hill, NC 27516, USA
setel@email.unc.edu

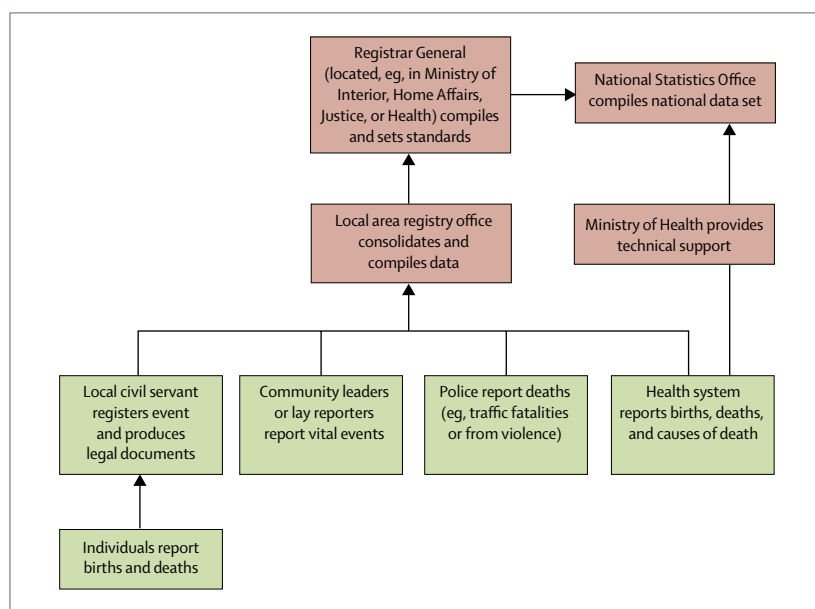


Figure 1: General structure of civil registration systems

Most people in Africa and Asia, and many in other regions, are born and die without leaving a trace in any legal record or official statistic, and without attaining the UN-proclaimed right to a recorded name and nationality.⁷ Each year, nearly 50 million newborn children are not registered,⁸ barely a third of countries outside North America and Europe have the capacity to obtain usable mortality statistics, and half the countries in Africa and Southeast Asia record no cause of death data at all.⁹ Stagnation in the maintenance of civil registration systems and the resulting failure to develop sound data for vital statistics and cause of death over the past 30 years are at the root of this scandal of invisibility, which renders most of the world's poor unseen, uncountable, and hence uncounted. Indeed, because of the insufficiencies in vital statistics no authoritative evidence is available to show whether or not billions of dollars of aid funds are having their desired effect on either mortality or poverty.³

We argue that civil registration, vital statistics, and data for cause of death are essential public goods. They are of crucial importance to the health sector and beyond. The civil registration of births and deaths—which are our prime concern—conveys human rights to individuals and helps with economic development. Vital statistics on births and deaths, together with reliable data for cause of death, provide crucial information for policy, planning, and evaluation in all sectors of development. The health sector has a responsibility to work closely with registration authorities, national statistical offices, and other agencies to promote and support the establishment and maintenance of civil registration.

Panel 1: Glossary

In everyday use, the vocabulary of registration is often used in confused and confusing ways. For example, civil registration, vital registration, and vital statistics are often used interchangeably although they are not synonymous. The following terms are used in this paper and refer to the specific definitions provided here:

Civil registration

As defined by the UN is the continuous, permanent, compulsory, and universal recording of the occurrence and characteristics of vital events (livebirths, deaths, fetal deaths, marriages, and divorces) and other civil status events pertaining to the population as provided by decree, law, or regulation, in accordance with the legal requirements in each country. It establishes and provides legal documentation of such events. These records are also the best source of vital statistics¹³

Demographic surveillance site

The continuous registration of all demographic events, including cause of death by verbal autopsy, in a geographically defined population; usually established for the purpose of health and development intervention research

Enumeration

Distinct from registration; the means by which the presence of individuals in a household or other group is recorded; normally used in reference to a census or survey. Enumeration is anonymous and does not provide any direct benefit to the individual

Sample registration system

The longitudinal registration of demographic events, including cause of death by verbal autopsy, in a nationally representative sample of clusters such as exists in China and India

Continues on next page

Sources of vital statistics

The administrative and technical functions of civil registration and vital statistics systems can be configured in many ways, and responsibilities for maintaining the system and obtaining the vital statistics vary from country to country.^{10–13} Figure 1 shows levels and functions in civil registration and the production of vital statistics. Locally, individuals report births and deaths to civil authorities and receive legal documentation—birth and death certificates or burial permits. In many countries other parties, such as local leaders, the police, and the health system, also have a role in the reporting of events to local area registration authorities. These local authorities compile and consolidate information received and forward it on. Most commonly, the system is maintained by a national registration office in the Ministry of Interior or Justice, and sometimes, the Ministry of Health. Production of

vital statistics, on the other hand, is usually the responsibility of the national statistical office with technical support provided by the Ministry of Health. The functions and legal framework for civil registration are laid out by the UN Statistics Division in its *Principles and Recommendations for a Vital Statistics System*.¹³

Although civil registration with high and representative coverage should be the long-term goal, investment in complementary, interim sources of statistics in the short term to medium term is needed—particularly for statistics on mortality levels and causes of death.¹⁴ As noted by the UN Statistics Division: “[Although] there is no substitute for the availability of continuous information on vital events as obtained from registration of vital events in civil registration...[a]llowance is made, as appropriate, for the use of other sources of complementary or alternative data.”¹³ Panel 1 provides definitions of technical terms related to civil registration, alternative sources of routine statistics, and data for cause of death.

Health sector demands for data

Several UN and WHO reports and publications have summarised the poor state of birth and death registration in poor countries.^{9,10,15–17} The table shows the estimated proportion and number of births in each WHO region that go unregistered every year. The inequalities in registration rates are large; developing countries account for 99% of the estimated 48 million unregistered births, with South Asia and sub-Saharan Africa together accounting for 79% of all unregistered births. According to WHO (data not shown), these inequalities extend to the capacity to obtain cause-specific mortality statistics with only a third of all countries having complete data for cause of death.⁹ In Africa only the small island states of Mauritius and the Seychelles have complete registration of births, deaths, and cause of death. South Africa is the only other African country in which registration of births and deaths is high, but its cause of death data at the national level, although they have improved in recent years, still have large proportions of deaths attributed to undetermined causes. Of the remaining 43 countries in WHO’s Africa region, only Madagascar and Zimbabwe are able to obtain some data for cause of death. In southeast Asia, Sri Lanka, and Thailand have high registration coverage, but only five other countries obtain even fragmented data for cause-specific mortality. In the Americas, by contrast, 24 countries have adequate data for mortality, although not all of these have high registration coverage, and eight countries have poor data for cause of death or none at all.

In countries in which civil registration systems do not exist or do not work efficiently, the health sector usually calls for statistics on birth and death and lobbies for improved civil registration. The health sector tends to be proactive in this regard, not only because of the importance of vital statistics to health policy and planning, but also because the health system is well placed to inform and support the registration of births and deaths, and to provide

Continued from previous page

Verbal autopsy

A structured interview with caregivers or family members of households after a death occurs; used to establish probable cause of death in places where most deaths take place outside of health facilities and direct medical certification is rare

Vital event

As defined by the UN is the occurrence of a livebirth, death, fetal death (defined as the death of a fetus before birth or extraction from its mother, irrespective of the duration of pregnancy), marriage, divorce, adoption, legitimation, recognition of parenthood, annulment of marriage, or legal separation¹³

Vital registration

All sanctioned modes of registering individuals and reporting on vital events. These modes can include registration activities through complementary systems that are not done as part of the civil formal registration system and do not produce legal birth or death certificates

Vital statistics

Summary measures of vital events drawn from all of sources of vital events data. Particularly in developing country settings, where civil registration functions poorly or not at all, the UN acknowledges that many data sources and systems are used to derive estimates of vital statistics

Vital statistics system

As defined by the UN is the total process of (1) obtaining information by civil registration or enumeration on the frequency or occurrence of specified and defined vital events, and relevant characteristics of the events themselves; and (2) of compiling, processing, analysing, evaluating, presenting, and disseminating these data in statistical form¹³

	Births (in thousands)	Proportion of unregistered children	Number of unregistered children (in thousands)
South Asia	37 099	63%	23 395
Sub-Saharan Africa	26 879	55%	14 751
Middle east and north Africa	9790	16%	1543
Commonwealth of Independent States and Baltic States	5250	23%	1218
East Asia and Pacific	31 616	19%	5901
Latin America and Caribbean	11 567	15%	1787
Industrialised countries	10 827	2%	218
Developing countries	119 973	40%	48 147
Least developed countries	27 819	71%	19 682
World	133 028	36%	48 276

Table: Estimated annual number and proportion of unregistered births by region, 2003⁷

information about cause of death. In such countries the health sector also usually supports demographic surveys and the establishment of demographic surveillance systems or sites. National statistical offices in these countries can contribute to collection of data for demographic and health surveys, but are often so overwhelmed with their responsibilities for conducting censuses and other national surveys, and for obtaining important economic statistics, that they have few resources to spare for the establishment and maintenance of registration systems. National registration offices might not have resources for a sufficient network of offices, or might fail to perceive the need for civil registration beyond selected urban areas.

The beneficiaries, benefits, and risks of registration

Civil registration and death certification with high and representative coverage is essential for individuals, national and sub-national authorities, and the international community. Other methods of registration and collection of data (eg, sample registration systems or research demographic surveillance sites) for cause of death address some statistical needs, but are clearly less useful than civil registration in the long term, and cannot provide the benefits that civil registration provides to individuals.

Benefits to individuals

Civil registration is the only means of establishing and protecting identities, citizenship, and property rights. Legal documents that prove identity and citizenship not only provide access to state services or entitlements, but can also be a defence against exploitation.¹⁸ Additionally, these documents (and those that prove marital status) are crucial to property rights of those who either inherit property or seek to use it as collateral to secure loans.⁷ In the context of the AIDS epidemic, legal documents and certificates are increasingly important with regard to the proper allocation of inheritances. In many countries, an inability to prove a legal relationship to a deceased spouse or father heightens the risk of alienation and deprivation of women and children. Registration can also be an instrument of social protection against forms of systemic abuse and extended hardship—whether from the exploitations of human trafficking or child labour, or that caused in times of conflict or other complex emergencies.¹⁸ For example, in the aftermath of the Asian tsunami in 2004, the availability of registration records in Thailand and Malaysia helped with the reunification of family members and the identification of those lost, compared with Indonesia in which these tasks were made much more difficult because of poor civil registration.¹⁹

Benefits to society

Data for births, deaths, and cause of death are essential for planning of services for populations. Data for mortality, particularly for cause of death, are needed to

set priorities, formulate policies, and monitor and assess such policies nationally and, increasingly, at lower administrative levels. Under sectoral reform programmes in many low-income countries, planning, budgeting, and monitoring responsibilities have been devolved to the regions, provinces, or districts. Yet few data exist at these levels—even from surveys—and the demand for such information is rapidly increasing. As completeness of civil registration and certification rises, more accurate vital statistics can be obtained by, and obtained for, small administrative areas. Additionally, continuous registration enables annual estimates of population size, and should ensure that such estimates are comparable from year to year—a challenge when many surveys use different methods, definitions, and variables.

The benefits of civil registration, alternative registration system information, and data for cause of death are evident across a range of countries with widely different gross domestic products (panel 2). At one end of the spectrum are developed countries, in which good data for mortality and cause of death have affected policy decisions and legislation. Once implemented, these policies can be effectively monitored because results can be seen in subsequent data. In middle-income, and even low-income countries, such as Chile and India, investments in civil registration, data for cause of death, and complementary sources of vital statistics have also proven useful. Birth registration and information about perinatal outcomes in Chile and India were available to policymakers and civil society, and had an important effect on population policies. In Africa, South Africa is one of the best-documented cases in which the absence of good data for cause of death allowed—for a time—poor national policies to continue, and the improved use of existing data for vital events has led to changes in policy and programme priorities.^{40–48} In the early 2000s, this country's available data for vital events pointed unambiguously at a huge increase in adult deaths. Absent information about the causes of those deaths, however, provided an opportunity for a government that was officially sceptical of AIDS to persist in casting doubt on the true effects of the epidemic in their country. Authorities in Cape Town participated in analysis of existing information about cause of death, particularly about AIDS and homicide, and gained an appreciation of the value of locally generated data for local decisionmaking. In both Uganda and Tanzania civil registration does not function as well as in South Africa, thus other sources of data for vital events have been used to set priorities, formulate essential national health intervention packages, and make decisions about resource allocation in individual districts.^{49–52}

Benefits to the international community

International commitments to fight specific diseases are now funded at levels never seen before, and their success is often intended to be assessed on the reduction of deaths due to specific causes. As demands to measure the

effectiveness of health aid have grown, so have calls for good monitoring of vital events and data for cause of death.^{46,53–57} The Millennium Development Goals (MDGs), in particular, have focused attention on this issue. Donor and development agencies, multilateral development banks, and the UN, and 189 nations committed themselves to achievement of these goals when they signed the Millennium Declaration in 2000.⁵⁸ This commitment provides new energy and focus to the development enterprise, setting eight major goals to be achieved by 2015.

As these goals were established, development agencies and national governments alike recognised a need not only to increase the overall amount of official development assistance, but also to align it well with a country's strategies and systems, and to substantially increase efforts to measure, monitor, and manage results.⁵⁹ This focus on results has brought realisation about the absence of even basic statistical capacities—especially in low-income countries.

At least six of the MDGs (ie, eradication of extreme poverty and hunger; achievement of universal primary education; attaining gender equality; reductions in child mortality; improvements in maternal health; and reductions in prevalence of HIV/AIDS, malaria, and other diseases) rely on accurate data for fertility, mortality, and causes of deaths. Within the health sector alone, eight health outcome and survival indicators and subindicators need high-quality data for births, deaths, and causes of death. Few countries in Africa have the ability to measure these indicators even nationally, and only Mauritius and the Seychelles have the information needed to measure them adequately subnationally—either by geographic area or by groupings based on socioeconomic status.

Not only health policies, but also general economic and social policies are constrained by the simple absence of information about the distribution and characteristics of populations. The stakes cannot be overstated. In 2004, overall amounts of official development assistance, net of debt relief, reached about US\$80 billion.⁵⁹ Ensuring the effectiveness of the specific policies and programmes that are supported by this aid is clearly important to the taxpayers in those countries that provide the assistance. It is most important to citizens in developing countries who inevitably pay a deadly price if assistance intended to reach them is either badly managed or ineffective because decisionmakers are uninformed. How much longer support for efforts to expand immunisation, and confront AIDS, tuberculosis, and malaria will last is questionable if counting the lives saved, and providing direct evidence of reduction of deaths due to these causes—particularly in the poorest of the poor—remains undone.

Risks associated with registration

The undoubted benefits of civil registration systems need to be weighed against the need for effective systems to protect against inappropriate use of

Panel 2: Vital events data lead to improvements in decisions and policies

Developed countries

Information about road traffic fatalities, a leading cause of death and disability for young adults, has long been available from many countries. Steadily increasing trends in road death rates until the early 1970s eventually led to the introduction and enforcement of speed limits, seatbelt laws, and laws on alcohol use and driving. The remarkable reversal of traffic mortality trends closely followed the introduction of these measures and has been seen in many studies.²⁰

Chile

In 2001, several government departments, led by the Chilean Ministry of Health sought to improve the quality, consistency, coverage, and completeness of information about maternal and newborn health in the country. Interventions were designed to: improve guidelines for registration and reporting; cross-check data for completeness and accuracy; allow direct access to data in cases of death or questionable findings; allow free internet-based access to all information by researchers, the press, and civil society. Between 2001 and 2004, key indicators of data accuracy improved as a result of these measures and, more importantly, key outcome indicators of perinatal health improved.^{21–24}

India

The use of data for birth monitoring is highly evident in India's national family welfare programmes, and in policies and targets related to national population planning and infant and child mortality.^{25–29} These varied sources have permitted setting of evidence-based targets and the direct measurement of progress in population, and family planning and welfare. The halving of India's fertility rate in the second half of the 20th century^{28,30} would seem to be an unambiguously positive development. Many sources of birth data, however, have allowed some undesirable ramifications of population change to come to light. In India, expanded access to, and unethical use of specific medical technologies and services (namely fetal sexing by ultrasound) along with economic constraints and the cultural privilege of males has enabled prenatal sex selection of male babies. The scope and scale of the selective abortion of female fetuses in India received enormous international media attention and generated heated debate.^{31–35} It also spurred the strengthening of the 1994 Prenatal Diagnostic Techniques (Regulation and Prevention of Misuse) Act.³⁶ The mere fact that this issue has come to light so starkly—that debates are even possible about the quality, use, and interpretation of evidence in policies and the laws to back them up—speaks directly for the necessity of better data for births.

Tanzania

Beginning in the 1990s, several districts implemented sentinel demographic surveillance systems that entailed routine monitoring of vital events and data for cause of death derived from a validated set of core verbal autopsy procedures. District councils used this information for annual planning and resource allocation cycles to identify disease burdens to set programme priorities, and for the allocation of resources for cost-effective interventions.⁶⁹ district health boards and management teams reallocated funds in accordance with profiles of local mortality burden to address HIV/AIDS, malaria, and other avoidable causes of childhood and maternal mortality.^{37,38} In urban areas, they also used these data as a basis for improvement of quality of care in health facilities.³⁹

registration information. Unless identities are protected, this powerful instrument can be—and has been—used to do great harm to individuals and vulnerable minorities. Examples include the use of the Dutch population registers by the Nazi regime to locate and exterminate Jewish families,⁶⁰ and the role of identity cards in the Rwanda genocide.⁶¹ Even during peacetime, identity registration has been used by governing authorities to control the movement and liberty of

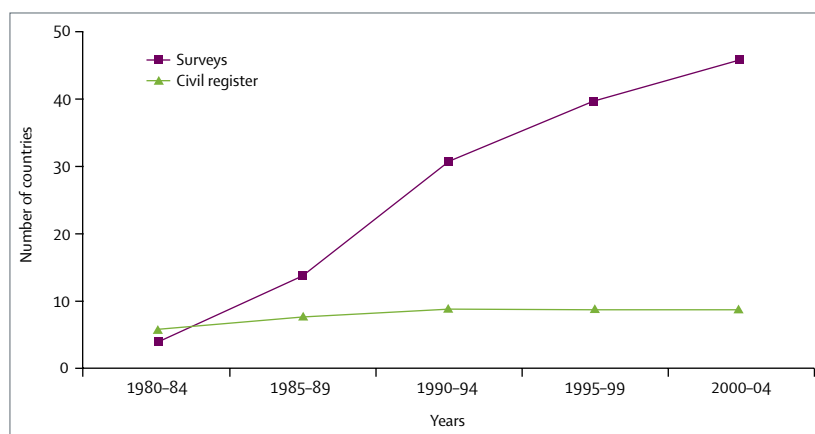


Figure 2: Collection and reporting of data for mortality by source in 50 low-income countries, 1980–2004⁴

sections of their populations, for example in communist China, apartheid South Africa, and tsarist and soviet-era Russia.

These historical lessons are warnings that careful thought should be given to the ethical dimensions and data security needs of civil registration. The ownership, administrative custody, and secure use of data are of prime importance and constitute an essential social service.⁶² If reasonable concern exists about a government's ability to implement strong measures to protect identity data, some open dialogue can be called for, in which the potential risks of collecting information about religion or ethnicity, for example, are balanced against the undoubted importance of having good information about marginalised subpopulations. The state's stewardship of the system should also include public and democratic procedures for obtaining permission to use data containing individual identifiers. At the same time, crucial protections for individuals cannot impede legitimate uses of aggregated anonymous data for the purposes of statistical analysis of social conditions and population health.

Although the UN defines civil registration as compulsory, the reality is that many individuals who have historical reasons to fear the negative consequences or abuse of identity registration, or who have strong cultural views that might constrain them from registering infants younger than a certain age, will simply not comply and will risk the consequences. When developing a comprehensive long-term strategy to improve the measurement of vital events, the degree of democracy and the status of ethnic minorities and individual rights in the country should be taken into account. Any legacy of abuse of individual information can affect future uptake of registration even after bureaucratic obstacles are removed.^{63,64} A system that is not trusted by the population it serves is not likely to succeed in the long term. Only by serving as the legal guardians of personal, familial, ethnic, and religious identities can registering authorities engender the necessary trust, and

defend against system abuse. Once the technical and administrative safeguards are in place, they must also explicitly address cultural and behavioural sensitivities while promoting registration. Maintaining these constitutional firewalls adds a little to the cost of running the system.

Failure to support civil registration

Since 1968, the international mandate for strengthening vital statistics has been assigned to the statistical community led by the Statistical Commission. Ironically, the Statistical Commission has no authority or resources to demand the improvement of civil registration systems that are not directly under its control, and for which it has no budget. Attention has been focused on the products (ie, vital statistics) of the systems rather than on the systems themselves.⁶⁵ The health sector, too, has tended to take an instrumental view of civil registration, valuing it solely because of its potential to deliver statistics, and framing the problem as one in need of a technological fix. Alternative strategies to generate birth and death data have been developed that rely largely on survey enumeration and expensive international technical and financial assistance. As dependence on these sources has grown, national authorities have reduced incentives to further invest in civil registration systems (figure 2).⁶⁶

The International Institute for Vital Registration and Statistics, which had as one of its major objectives the coordination of efforts in this area, was forced to substantially reduce programmes in the 1990s and ceased to function entirely in 2006 because of lack of financial support. According to one of its former directors, international funding agencies decided that it was cheaper and quicker to obtain macro data through household surveys than to support the long-term development of registration systems (Robert A Israel, personal communication, May 11, 2007).

A little more than a decade later, countries are demanding financial and technical support to build statistical systems capable of monitoring development indicators. Towards this end, national statistical offices in low-income and middle-income countries are supported by several donors to develop national strategies for the development of statistics.⁶⁷

These strategies are comprehensive planning exercises that span all processes for obtaining data that make up a national statistical system. Of these strategies, few have given attention to the registration and certification of births, deaths, and causes of deaths. Countries at the early stages of the strategic planning process have a unique opportunity for their health ministries and statistical offices to coordinate their efforts to develop civil registration.

The affordable necessity of action

Civil registration systems, and the statistics they generate are intrinsic to countries' development, and not one of its

luxury byproducts.⁷ Although additional studies are needed to understand the complex relations between economic growth and social sector development on the one hand, and quality, high-coverage, and effective use of vital statistics on the other, historical and contemporary evidence suggest that they go hand-in-hand. The significance of registration systems for legal property rights has sometimes been the primary motivation for national governments to invest in creating these systems.⁶⁸

The years of disorganised, underfunded, and poorly coordinated international support; absence of national political commitment and public awareness; disorganised or weak registration infrastructures with unclear roles and responsibilities; inadequate financial and human resources; and geographic or socioeconomic isolation combined to keep complete coverage of civil registration a distant goal for many developing countries.

However daunting, each of these constraints can and should be addressed. First and foremost, the establishment of a civil registration system is an act of political will, a demonstration by national authorities of stewardship, and of reciprocal trust in their government by the registered population. For more than 200 years, systems of civil registration have been established by countries undergoing economic development (eg, the UK and Japan) or perceived as liberating by their populaces on emerging from political strife and conflict (eg, France, Cuba, or South Africa). The maintenance of civil registration needs both the trust and willing participation of citizens and ongoing political backing and commitment to long-term funding. The absence of national political commitment in low-income countries was noted nearly 30 years ago as a fundamental obstacle,⁶⁹ which remains true today.

The easiest option is to cite lack of resources as the main reason for not moving forward with registration. Although costs are certainly an important consideration, they are not the crucial barrier to improvement. Gross national income per head correlates somewhat with estimated completeness of registration, but some low-income countries do have good coverage (figure 3), showing that much can be achieved, even in low-income countries. Consideration of the costs of little investment for the past thirty years, and what the costs of not investing now will be in the future is important. A small but growing body of research about the costs of obtaining information suggests that civil registration and complementary systems are quite affordable.^{70,71} When the costs are divided by the number of people benefiting from the information generated, the costs become negligible. Vital statistics data are expensive only if they are obtained but never used.

Conclusions

The worldwide AIDS pandemic clearly shows that visibility demands accountability, which in turn generates the ability to count. In the 1990s the realities of people living with AIDS in heavily affected countries became visible,

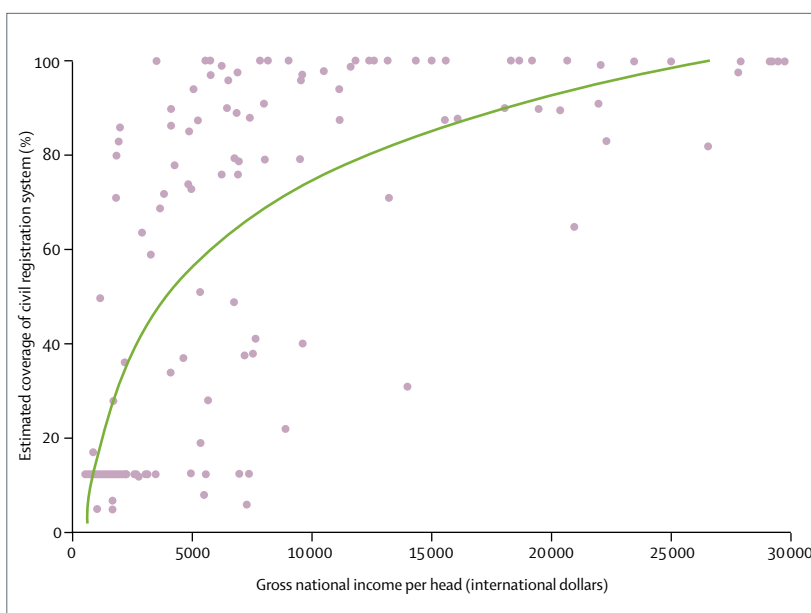


Figure 3: Association between estimated coverage of civil registration and gross national income per head, 1998–2004

and the imperative of action became irresistible. In 2001, the international community put a price-tag on action, and decided that provision of pharmaceutical care at the same standard as developed countries to as many people as could be reached in developing countries was a moral imperative.^{72,73} Setting targets and measuring progress toward those targets was central to the international response (for example, WHO's 3 by 5 initiative, which aimed to provide antiretroviral therapy to 3 million people with AIDS by 2005). By contrast, unregistered people remain unseen; no global imperative exists to make them more visible and, far from advancing into this century, the inadequate state of civil registration in developing countries remains mainly as it was three decades ago.

This Series focuses on the need for investment in obtaining civil registration and data for mortality in a large part of the world. After decades of working with the limitations of incomplete data, the fundamental problems of absent and deficient civil registration have remained unaddressed. Now is a time for action. The continued costs of ignorance borne by countries without firmly founded vital statistics far outweigh the affordable necessity of action. So, who counts? Everyone. And the international community should set a future date for ensuring that everyone is counted.

Contributors

PWS, SBM, SSz, LM, PJ, SSz, and CAZ wrote, edited, and reviewed the manuscript.

MoVE writing group

In addition to the authors of this article are: Robert N Anderson (National Center for Health Statistics, Centers for Disease Control and Prevention, Hyattsville, MD, USA); Ayaga A Bawah (INDEPTH Network, Accra, Ghana); Ana Pilar Betrán (Department of Making Pregnancy Safer, WHO, Geneva, Switzerland); Fred Binka (INDEPTH Network, Accra, Ghana);

Kanitta Bundhamcharoen (International Health Policy Program, Bangkok, Thailand); Rene Castro (Ministry of Health, Chile); John Cleland (London School of Hygiene and Tropical Medicine, London, UK); Francesca Coullare (United Nations Statistics Division, New York, USA); Timothy Evans (Information, Evidence and Research, WHO, Geneva, Switzerland); Ximena Carrasco Figueroa (Department of Health Statistics and Information, Ministry of Health, Chile); Chakkalackal Korah George (Institute of Health Systems, Hyderabad, India); Laragh Gollogly (Department of Knowledge, Management and Sharing, WHO, Geneva, Switzerland); Rogelio Gonzalez (Ministry of Health, Chile, and Center for Perinatal Diagnosis, Hospital Dr Sotero del Rio, Pontificia Universidad Catolica de Chile, Santiago, Chile); Danuta Rajs Grzebień (Department of Health Statistics and Information, Ministry of Health, Chile); Kenneth Hill (Harvard Center for Population and Development Studies, Cambridge, MA, USA); Zhengjing Huang (National Center for Chronic and Non-communicable Disease Control and Prevention, Chinese Center for Disease Control and Prevention, Beijing, China); Terence H Hull (Australian Demographic and Social Research Institute, Australian National University, Canberra, Australia); Mie Inoue (Department of Measurement and Health Information Systems, WHO, Geneva, Switzerland); Robert Jakob (Department of Measurement and Health Information Systems, WHO, Geneva, Switzerland); Yong Jiang (National Center for Chronic and Non-communicable Disease Control and Prevention, Chinese Center for Disease Control and Prevention, Beijing, China); Ruy Laurenti (Department of Epidemiology, School of Public Health, University of Sao Paulo, Brazil); Xiaoyan Li (National Center for Chronic and Non-communicable Disease Control and Prevention, Chinese Center for Disease Control and Prevention, Beijing, China); Denise Lieveley (International Statistical Institute, London, UK); Alan D Lopez (School of Population Health, University of Queensland, Brisbane, Australia); Doris Ma Fat (Department of Measurement and Health Information Systems, WHO, Geneva, Switzerland); Prasanta Mahapatra (Institute of Health Systems, Hyderabad, India); Mario Meriardi (Department of Making Pregnancy Safer, WHO, Geneva, Switzerland); Jyh Kae Nien (Center for Perinatal Diagnosis, Hospital Dr Sotero del Rio, Pontificia Universidad Catolica de Chile, Santiago, Chile); Francis C Notzon (National Center for Health Statistics, Centers for Disease Control and Prevention, Hyattsville, MD, USA); Chalapati Rao (School of Population Health, University of Queensland, Brisbane, Australia); Keqin Rao (Center for Health Statistics Information, Ministry of Health, Beijing, China); Osman Sankoh (INDEPTH Network, Accra, Ghana); Kenji Shibuya (Department of Measurement and Health Information Systems, WHO, Geneva, Switzerland); Nadia Soleman (Health Action in Crises, WHO, Geneva, Switzerland); Viroj Tangcharoensathien (International Health Policy Program, Bangkok, Thailand); Paul J van der Maas (Erasmus University Medical Center, Rotterdam, The Netherlands); Fan Wu (National Center for Chronic and Non-communicable Disease Control and Prevention, Chinese Center for Disease Control and Prevention, Beijing, China); Gonghuan Yang (Chinese Center for Disease Control and Prevention, Beijing, China); Siwei Zhang (National Center for Cancer Registry, Beijing, China); Maigeng Zhou (Chinese Center for Disease Control and Prevention, Beijing, China).

Conflict of interest statement

We declare that we have no conflict of interest. The views expressed in this manuscript are not necessarily those of the Health Metrics Network or USAID.

Acknowledgments

Funding for the preparation of this manuscript was provided, in part, by the Health Metrics Network and MEASURE Evaluation, Phase 2, a USAID cooperative agreement (GPO-A-00-03-00003-00), implemented by the Carolina Population Center, University of North Carolina at Chapel Hill. The authors thank Luong Nguyen, Dan Williams, and Robert Mswia for research assistance in the preparation of the manuscript.

References

- Walker N, Bryce J, Black RE. Interpreting health statistics for policymaking: the story behind the headlines. *Lancet*. 2007; **369**: 956–63.
- Bchir A, Bhutta Z, Binka F, et al. Better health statistics are possible. *Lancet* 2006; **367**: 190–03.
- Jamison DT, Breman JG, Measham AR, et al, eds. Disease control priorities in developing countries. Part 1. Summary and cross-cutting themes. Washington and New York: The World Bank and Oxford University Press, 2006.
- Boerma JT, Stansfield SK. Health statistics now: are we making the right investments? *Lancet* 2007; **369**: 779–86.
- WHO. World health statistics 2007. Geneva: World Health Organization, 2007.
- Evans T, Stansfield S. Health information in the new millennium: a gathering storm? *Bull World Health Organ* 2003; **81**: 856.
- Szreter S. The right of registration: development, identity registration, and social security—a historical perspective. *World Dev* 2007; **35**: 67–86.
- UNICEF. The ‘rights’ start to life. A statistical analysis of birth registration. New York: United Nations Children’s Fund, 2005.
- Mathers C, Ma Fat D, Inoue M, Rao C, Lopez AD. Counting the dead and what they died of: an assessment of the global status of cause of death data. *Bull World Health Organ* 2005; **83**: 171–77.
- Powell NP. Organizational arrangements for a vital registration system. Working paper No 1. Bethesda, MD (USA): International Institute for Vital Registration and Statistics; 1977.
- UN Department of International Economic and Social Affairs Statistics Division. Handbook on civil registration and vital statistics systems. Preparation of a legal framework. New York: United Nations, 1998.
- Rao C, Bradshaw D, Mathers CD. Improving death registration and statistics in developing countries: Lessons from sub-Saharan Africa. *S Afr J Demogr* 2004; **9**: 81–99.
- UN Department of Economic and Social Affairs Statistics Division. Principles and recommendations for a vital statistics system. Revision 2. New York: United Nations, 2001.
- AbouZahr C, Cleland J, Coullare F, et al, on behalf of the Monitoring of Vital Events (MoVE) writing group. The way forward. *Lancet* 2007; published online Oct 29. DOI: 10.1016/S0140-6736(07)61310-5.
- Mathers C, Inoue M, Lopez A, Shibuya K. Overview of global mortality data sources. Geneva: World Health Organization, 2003.
- WHO. World health report 2005. Making every mother and child count. Geneva: World Health Organization, 2005.
- Lawn JE, Cousens S, Zupan J. 4 million neonatal deaths: when? Where? Why? *Lancet* 2005; **365**: 891–900.
- UNICEF. Birth registration. Right from the start. Innocenti Digest No 9. Florence, Italy: United Nations Children’s Fund and Innocenti Research Centre, 2002.
- UNICEF. Birth registration: the record in tsunami-affected areas. Bangkok: United Nations Children’s Fund, 2005.
- Lopez AD. Competing causes of death: a review of recent trends in mortality in industrialized countries with special reference to cancer. *Ann N Y Acad Sci* 1990; **609**: 58–76.
- Szot J. Mortalidad infantil e indicadores económicos en Chile: 1985–1999. *Rev Med Chil* 2002; **130**: 107–12.
- Donoso E, Villaruel L. Mortalidad neonatal precoz. Chile 1991–97. *Rev Chil Obstet Ginecol* 1999; **64**: 286.
- Morgues M, Henríquez MT, Tohá D, Vernal P, Pittaluga E, Vega S, et al. Sobrevida del niño menor de 1500 g en Chile. *Revista Chilena de Obstetricia y Ginecología* 2002; **67**: 100–05.
- Gonzalez R, Meriardi M, Lincetto O, et al. Reduction in neonatal mortality in Chile between 1990 and 2000. *Pediatrics* 2006; **117**: e949–e54.
- Ministry of Health and Family Welfare. Annual report of the Ministry of Health and Family Welfare, Government of India, New Delhi, 1996–97. New Delhi: Government of India, 1997.
- Ministry of Health and Family Welfare. Annual report of the Ministry of Health and Family Welfare, Government of India, New Delhi, 1997–98. New Delhi: Government of India, 1998.
- Ministry of Health and Family Welfare. Annual report of the Ministry of Health and Family Welfare, Government of India, New Delhi, 1998–99. New Delhi: Government of India, 1999.
- Department of Family Welfare. National Population Policy 2000. New Delhi: Ministry of Health and Family Welfare, Government of India, 2000.

- 29 Department of Family Welfare. Reproductive and child health programs: schemes for implementation. New Delhi: Ministry of Health and Family Welfare, Government of India, 1997.
- 30 Registrar General of India. Compendium on India's fertility and mortality indicators: 1971–1997. Vital Statistics Publication, Sample Registration System. New Delhi: Vital Statistics Division, Office of the Registrar General of India, 1999.
- 31 Jha P, Kumar R, Vasa P, Dhingra N, Thiruchelvam D, Moineddin R. Low female[corrected]-to-male [corrected] sex ratio of children born in India: national survey of 1.1 million households. *Lancet* 2006; **367**: 211–18.
- 32 George SM. Sex ratio in India. *Lancet* 2006; **367**: 1725.
- 33 Bhat M. Sex ratio in India. *Lancet* 2006; **367**: 1725–26.
- 34 Bhopal R. Sex ratio in India. *Lancet* 2006; **367**: 1728–29.
- 35 Sen A. Missing women. *BMJ* 1992; **304**: 586–87.
- 36 Supreme Court of India. The Supreme Court Judgment dated May 4, 2001 in the PNDT Act, 1994. *Ind J Medical Ethics* 2001; **9**: 91. <http://www.ijme.in/093do7.html> (accessed June 15, 2007).
- 37 de Savigny D, Setel P, Kasale H, et al. Linking demographic surveillance and health service needs—the AMMP/TEHIP experience in Tanzania. Multilateral Initiative on Malaria; 1999 March 15–19; Durban, South Africa, 1999.
- 38 Mkusa V, Hemed Y, Masuki G, Setel PW. Setting priorities in health care: use of diverse information perspectives at the district level in Tanzania. 4th International Conference on Priorities in Health Care; 2002 18–22 Sept; Oslo, Norway, 2002.
- 39 Setel P, Kitange H, Alberti K, Moshiri C. The policy implications of adult morbidity and mortality in Tanzania: from data analysis to health policy—preliminary experiences. Global Forum for Health Research (Forum 2); 1998 June 25–26; Geneva: World Health Organization, 1998.
- 40 Robins S. Long live Zackie, long live': AIDS activism, science, and citizenship after apartheid. *J S Afr Stud* 2004; **30**: 651–72.
- 41 Bradshaw D. What do we know about the burden of cardiovascular disease in South Africa? *Cardiovasc J S Afr* 2005; **16**: 140–41.
- 42 Bradshaw D, Dorrington RE, Sitas F. The level of mortality in South Africa in 1985—what does it tell us about health? *S Afr Med J* 1992; **82**: 237–40.
- 43 Bradshaw D, Kielkowski D, Sitas F. New birth and death registration forms—a foundation for the future, a challenge for health workers? *S Afr Med J* 1998; **88**: 971–74.
- 44 Bradshaw D, Nannan N, Groenewald P, et al. Provincial mortality in South Africa, 2000—priority-setting for now and a benchmark for the future. *S Afr Med J* 2005; **95**: 496–503.
- 45 Bradshaw D, Schneider M, Dorrington R, Bourne DE, Laubscher R. South African cause-of-death profile in transition—1996 and future trends. *S Afr Med J* 2002; **92**: 618–23.
- 46 Bradshaw D, Groenewald P, Bourne DE, et al. Making COD statistics useful for public health at local level in the city of Cape Town. *Bull World Health Organ* 2006; **84**: 211–17.
- 47 Groenewald P, Bradshaw D, Dorrington R, Bourne D, Laubscher R, Nannan N. Identifying deaths from AIDS in South Africa: an update. *AIDS* 2005; **19**: 744–45.
- 48 Groenewald P, Nannan N, Bourne D, Laubscher R, Bradshaw D. Identifying deaths from AIDS in South Africa. *AIDS* 2005; **19**: 193–201.
- 49 Global Forum for Health Research Secretariat. The 10/90 Report on health research 1999. Forum 2. Geneva: World Health Organization, 1999.
- 50 Kapiriri L, Norheim OF, Heggenuhougen K. Using burden of disease information for health planning in developing countries: the experience from Uganda. *Soc Sci Med* 2003; **56**: 2433–41.
- 51 de Savigny D, Kasale H, Mbuya C, Reid G. Fixing health systems. Ottawa, Canada: International Development Research Centre, 2004.
- 52 Ministry of Health. The policy implications of Tanzania's mortality burden: mortality burden profiles from sentinel sites, 1994–2002. AMMP-2 Final Report Volume 4. Dar es Salaam: Adult Morbidity and Mortality Project, Tanzania Ministry of Health, University of Newcastle upon Tyne, and UK Department for International Development, 2004. http://research.ncl.ac.uk/ammp/site_files/public_html/finrep/index.html (accessed June 16, 2007).
- 53 Tollman SM, Zwi AB. Health system reform and the role of field sites based upon demographic and health surveillance. *Bull World Health Organ* 2000; **78**: 125–34.
- 54 Diaz T, Loth G, Whitworth J, Sutherland D. Surveillance methods to monitor the impact of HIV therapy programmes in resource-constrained countries. *AIDS* 2005; **19** (suppl 2): S31–37.
- 55 Setel PW, Sankoh O, Mathers C, et al. Sample registration of vital events with verbal autopsy: innovative approaches to measuring and monitoring vital statistics. *Bull World Health Organ* 2005; **83**: 611–17.
- 56 Baiden F, Hodgson A, Binka FN. Demographic Surveillance Sites and emerging challenges in international health. *Bull World Health Organ* 2006; **84**: 163.
- 57 Murray CJ. Towards good practice for health statistics: lessons from the Millennium Development Goal health indicators. *Lancet* 2007; **369**: 862–73.
- 58 UN. The Millennium Development Goals Report 2006. New York: United Nations, 2006.
- 59 World Bank. Global monitoring report 2006: strengthening mutual accountability—aid, trade, and governance. Washington DC: The World Bank Group, 2006.
- 60 Moore B. Victims and survivors: the Nazi persecution of the Jews in the Netherlands 1940–1945. London: Arnold, 1997.
- 61 Longman, T. Identity cards, ethnic self-perception and genocide in Rwanda, in Caplan J, Torpey J, eds. Documenting individual identity. The development of state practices in the modern world Princeton NJ: Princeton University Press, 2001: 345–57.
- 62 UN Department of Economic and Social Affairs Statistics Division. Handbooks on civil registration and vital statistics systems, series F, No 70. Policies and protocols for the release and archiving of individual records. New York: United Nations, 1998.
- 63 Lewando-Hundt G, Abed Y, Skeik M, Beckerleg S, El Alem A. Addressing birth in Gaza: using qualitative methods to improve vital registration. *Soc Sci Med* 1999; **48**: 833–43.
- 64 Jewkes R, Wood K. Competing discourses of vital registration and personhood: perspectives from rural South Africa. *Soc Sci Med* 1998; **46**: 1043–56.
- 65 UN Statistical Commission. ECOSOC resolution 1307 (XLIV), adopting the “1970 world programme for the improvement of vital statistics”. UN Statistical Commission Report, 1968: 1968.
- 66 Mahapatra P, Shibuya K, Lopez AD, et al, on behalf of the Monitoring of Vital Events (MoVE) writing group. Civil registration systems and vital statistics: successes and missed opportunities. *Lancet* 2007; published online Oct 29. DOI:10.1016/S0140-6736(07)61308-7.
- 67 PARIS21 Secretariat. A guide to designing a national strategy for the development of statistics (NSDS). Paris: OECD/PARIS21, 2004.
- 68 Higgs E. Life, death, and statistics. Civil registration, censuses, and the work of the General Register Office, 1836–1952. Hatfield, UK: Local Population Studies, 2004.
- 69 Powell NP. Major obstacles to achieving satisfactory registration of vital events and the compilation of reliable vital statistics. Technical papers of the International Institute for Vital Registration and Statistics, No 15. Bethesda MD: International Institute for Vital Registration and Statistics, 1981.
- 70 Rommelmann V, Setel PW, Hemed Y, Mponezya H, Angeles G, Boerma T. Costs and results of information systems for poverty and health indicators in the United Republic of Tanzania. *Bull World Health Organ* 2005; **83**: 569–77.
- 71 Stansfield SK, Walsh J, Prata N, Evans T. Information to improve decision making for health. In: Jamison DT, Breman JG, Measham AR, et al, eds. Disease control priorities in developing countries. Part 3. Strengthening health systems. Washington and New York: The World Bank and Oxford University Press, 2006: 1017–30.
- 72 Schwartzlander B, Stover J, Walker N, et al. AIDS. Resource needs for HIV/AIDS. *Science* 2001; **292**: 2434–36.
- 73 Lange JM, Perriens J, Kuritzkes D, Zewdie D. What policymakers should know about drug resistance and adherence in the context of scaling-up treatment of HIV infection. *AIDS* 2004; **18** (suppl 3): S69–74.