

Counting for health



"The single most critical failure of development over the past 30 years".¹ This judgment comes from the team leading Who Counts?, a Series beginning today in *The Lancet* on the status of country and global efforts to register every birth and death, and to certify every cause of death. This "scandal of invisibility"² means that millions of human beings are born and die without leaving any record of their existence. Over three-quarters of them are to be found in sub-Saharan Africa and south-east Asia.

Why does civil registration matter? Tracing the imprint of a person's existence not only confirms their citizenship, but also represents the first step in securing their right to life, freedom, and protection. Registration enables access to services and provides crucial data to policymakers charged with designing and planning health systems. Most fundamentally of all, registration is proof that a state recognises and respects the lives of those it has a responsibility to defend and develop.

Counting human lives and deaths is a pressing priority. Resources invested into global health have been scaled up massively in recent years. Without proper systems in place to monitor and track the impact of these new financial flows, donors will do a poor job of holding themselves accountable for their investments.

Sadly, there has been, in the words of the Who Counts? team,³ "widespread neglect" of this issue. Little progress has been achieved during the past four decades. Countries and global institutions have paid only limited attention to vital registration. Today, less than a third of the world's population is covered by accurate data on births and deaths. Far greater global urgency needs to be injected into this challenge. UN agencies, such as WHO, must do a better job of coordinating their efforts and supporting countries. The Who Counts? team reaches the verdict that WHO "has made little progress".³ This conclusion is all the more hard hitting since the team includes senior WHO scientists.

At country level, robust and effective national statistics systems are essential if registration is to become a reality. An independent national statistics service requires strong government ministries, a functioning legal system and civil service, devolved local

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information networks to collect registration data, and a vocal civil society to press governments to act. The health sector can be an important catalyst in this effort.

Globally, there is a gap. No single UN agency currently has responsibility for registering births and deaths. This absence has led the Who Counts? team to call for a new international body to improve civil registration efforts. But they concede that the likelihood of a new organisation being inaugurated is low. In the interim, they urge donors to encourage countries and global partners to do more to promote and support registration systems. Ultimately, this campaign is about how much each of us values the life of every other human being. It is a test of our humanity.

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- 1 Setel PW, Macfarlane SB, Szreter S, on behalf of the Monitoring of Vital Events (MoVE) writing group. A scandal of invisibility: making everyone count by counting everyone. *Lancet* 2007; published online Oct 29. DOI:10.1016/S0140-6736(07)61307-5.
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- 3 Mahapatra P, Shibuya K, Lopez AD, 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.

Keeping count: births, deaths, and causes of death



The four papers in this Series called *Who Counts?* describe the state of the world's vital statistics, and the fact that few countries derive these from routine compulsory measures through civil registration. However, every country in the world has the capacity to produce useful economic data. Because of its particular interest in, and requirements for, demographic and epidemiological data, the health sector should raise similar expectations of national capacity to produce vital statistics.

Unrepresentative, biased, incomplete, and often out-of-date, the world's vital statistics compare poorly with the detailed information available on every country's economy. The effort and expense of gathering and interpreting data on national income and trade balances are accepted costs of monitoring economic prospects in an international market. Health is arguably as important as economics, and establishing their mutual interdependence has made a big difference to the funding and attention that health attracts. Sen proposes mortality as an indicator of economic success or failure,¹ but many countries are still making patchy and incomplete efforts to count lives and deaths, and to document how their people die.

Data collection in health is often focused on specific diseases. Compared with economic data, systematic compilation of health indicators is the exception rather than the norm, both within and between countries. With the sole exception of child mortality, mortality statistics for the developing world are in a deplorable state. We live in a time of increasing demand for health care, of rapid epidemiological transition, and of greater accountability for achievement of results and the effective use of resources. The world has an acute and a chronic need for reliable, timely, and relevant information on the health of its population. Yet the absence of reliable and continuous data on deaths by age, sex, and cause has failed to elicit a coherent response from development agencies and donors, or the global public-health community.

Who Counts? was written to answer three questions. Why are the data so limited and of such poor quality? What can we do in the meantime? How can we improve matters? The first paper serves as a reminder that birth and death registration have important

implications and uses beyond the health sector and at all levels of human development.² The second shows that there has been virtually no progress over the past 40 years in the proportion of global deaths that are registered and certified as to cause.³ The third explains how demographers and epidemiologists use alternative data sources and estimation methods to make the best of what there is, especially for overall levels of child mortality.⁴ The fourth describes the legal, technical, and managerial infrastructure needed to create and run a vital statistics system.⁵

The Series touches briefly on the fact that the associated benefits of getting information on vital statistics are also those that render it problematic. Civil registration both secures basic human rights, and facilitates the worst violations of those rights: segregation, discrimination, and genocide. An individual's right to be counted, at both extremes of life, is fundamental to social inclusion. Civil registration acknowledges that each of us has an identity and that the collective of those identities is the basis for community wellbeing and human development. To live and die without being counted is to be denied many personal and societal benefits. Without the legal status that birth registration confers, education, health care, international travel, and property rights are not assured. Full and equal protection under the law is not possible. Even in the absence of insurance or inheritance, death registration and certification are often prerequisites for burial, remarriage, or the resolution of criminal cases.

Governments, multilateral organisations, and health initiatives cannot monitor how population health is changing without reliable vital statistics. We must be careful not to interpret bold efforts to estimate the global burden of disease as suggesting that the job is done and that we reliably know the cause-of-death pattern in each country.⁶ Far from it. A cause of death is assigned for no more than one in three deaths worldwide, and even for these deaths there is often considerable uncertainty about the diagnosis.⁷ Epidemiological estimates have given a better understanding of probable levels of key health indicators in countries. Despite their utility, these estimates are no substitute for reliable civil registration

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data with competent medical certification of the cause of death.

UN agencies, including WHO, have not advocated effectively for better national mortality statistics, in part because of structural and funding constraints. National statistics are therefore often disseminated with few caveats about reliability.⁸ Moreover, the health field is characterised by vertical disease-focused programmes that yield separate and poorly coordinated data-collection efforts. The many vertical disease-control programmes and initiatives promote a culture of competition for resources which leads to fragmentation, and a lack of investment in comprehensive health-information systems capable of tracking births, deaths, and causes of death. Without the routine, representative, and continuous mortality data that civil registration generates, disease-specific programmes cannot validate estimates of progress towards their disease-control targets. Linking funding to monitoring of specific disease-control programmes has thus distorted priorities and meant lost opportunities for civil registration systems. As a result, there is a very limited evidence base for much health and social policy.

Technical assistance in health is alone not sufficient and its effect has been limited.³ Just as in countries, no single development agency has sole responsibility for national development of vital statistics. Joint efforts by development partners to monitor key fertility and mortality indicators have yielded uncertain results, and had the unintended consequence of encouraging

governments not to invest in civil registration systems. International development agencies ensure continued non-investment on the part of governments by profligate spending, to monitor progress towards particular development goals.

What do we learn from this series of papers and what would constitute an appropriate response? To begin with, civil registration is a long-term investment. It took three centuries for the UK to develop a functioning reliable system for civil registration. Whether civil registration is a byproduct of economic and social development, or a necessary precursor, the good news is that it need not take three centuries to build a system. South Africa has shown that even a decade of concentrated effort can result in sizeable gains.⁹

Countries first need to get the right legislation in place, making it a requirement to register births and deaths. Global development partners, civil society, media, parliamentarians, and health and development advocacy groups can call for such legislative change. Establishing the infrastructure of a vital statistics system requires careful planning, strategy, and resources, and sustained political commitment, with broad support from all sectors. If sectoral responsibilities for civil registration and vital statistics are sensibly coordinated, the effort as a whole costs less. Many governments remain to be convinced that it is in their interest to know who they govern, how their populations are changing, and the nature and extent of the health threats that they face; and that civil registration is an indicator of effective governance.

All countries need to train their physicians in applying the International Statistical Classification of Diseases and Related Health Problems, to reliably certify the underlying cause of death.¹⁰ This is a neglected area in the medical curriculum, and WHO needs the resources to ensure that one of its most widely distributed standards is applied correctly. Cause of death tends to fall between the medical profession's understandable bias towards the living patient, and the public-health profession's lack of interest in individual outcomes, with the result that one of the most informative pieces of public-health information is lost. Without rigorous procedures to correctly certify and code data on causes of death, civil registration systems are of little value for health policy.

The UN and development banks must make a case for civil registration, backed by commensurate resources, while recognising that they cannot carry these systems for countries. WHO and its technical partners can systematically evaluate the completeness and quality of countries' civil registration systems.^{3,5} These agencies can also provide pointers on how to improve particular country's situations. For example, some countries might be best advised to initially strengthen their urban cause of death information, gradually extending coverage to more rural or remote populations.

Health policies ought to be more effective if they are guided by reliable information on levels, patterns, and causes of death in a population, and how these are changing. The tools and resources exist to test this assumption on a routine basis, as long as critical evidence that what happens in health policy actually results in people living longer and healthier lives. The health sector is best placed to promote the benefits of civil registration for all sectors of society, and to lead intersectoral collaboration in establishing routine mechanisms for gathering population and health data. These measures permit the health sector to function, and provide the evidence for evaluating global efforts to accelerate health development.

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