The Palgrave Handbook of Global Health Data Methods for Policy and Practice Sarah B. Macfarlane • Carla AbouZahr Editors

# The Palgrave Handbook of Global Health Data Methods for Policy and Practice



*Editors* Sarah B. Macfarlane Department of Epidemiology and Biostatistics School of Medicine, and Institute for Global Health Sciences University of California San Francisco San Francisco, CA, USA

Carla AbouZahr CAZ Consulting Sarl Bloomberg Data for Health Initiative Geneva, Switzerland

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#### Foreword

#### Investing in Global Health Information Systems: Learning from Nature

Countries and agencies have endorsed 17 Sustainable Development Goals and their associated 169 targets and 232 indicators. Now the global development community needs to invest—locally, nationally, and globally—to monitor and assess progress. When a potential pandemic, such as Ebola or Avian Influenza, strikes, questions are asked about the performance of public health surveillance and response systems and how much should be invested in them. It's time for us to *walk our talk*. It's time to invest adequately in our health information systems at all levels. Unless we do so, our global commitments will be just empty talk.

Those working in global public health and statistics have much to learn from nature.

The human body is one of nature's most complex systems with more than 20 organ systems and sub-systems working in a concerted manner effectively to maintain life. How can these diverse systems work together harmoniously? Only because nature invests continuously in information systems and feedback loops. Consider nature's investment in the nervous system which transmits data and information continually from conception to the last moments of life. While the human brain constitutes only 3 per cent of body weight, it consumes 25 per cent of the body's daily energy. Over 100 billion neurons connect through axons and dendrites to synapse with many other neurons, and every second the body transmits data by way of electrical signals that allow the nervous system to receive, analyse, and synthesize information, and

react accordingly. Other information systems, such as the immunological, biomedical, and hormonal systems, all contribute to maintain the functioning of the body. For example, when the immunological surveillance system senses alien pathogens, allergens, or cancerous cells, it triggers immunologic responses to remove them.

Are we ready to follow nature and direct 25 per cent of total health investments to health information systems? And if so, where should those investments be directed?

The two editors of this volume have between them decades of experience working with health information and statistics systems. Sarah Macfarlane led establishment of the Mekong Basin Disease Surveillance Network, which has built trust among disease surveillance and control experts of six Greater Mekong sub-region countries. Today these national experts share information about disease outbreaks with their peers in a prompt and timely manner, communicating information electronically and by phone and bringing together cross-border teams of experts to collect samples, identify possible contacts, and look for new cases. This immediate response is possible because of trust-based systems built through long-term collaboration that ensures reliability, credibility, and partnership based on *public*- not *self*-interests.

Carla AbouZahr, when she worked at the World Health Organization, led the start-up phase of the Health Metrics Network which, despite lasting for only eight years, has laid strong foundations for health information systems in many countries. The network created standards for national health information systems that set the foundation for ongoing efforts by multiple countries and development partners to improve health information, including the multi-partner Health Data Collaborative.

Together, the editors have mobilized the wisdom of more than 50 global experts to write and prepare the *Palgrave Handbook of Global Health Data Methods for Policy and Practice.* This handbook provides the best answer to the question about what and how to invest in generating data to inform health policy. The handbook serves three main purposes. It describes technical aspects of data sources and identifies capacity gaps for generating data. It highlights the importance of synthesizing and communicating evidence to policymakers and how to use evidence to influence policy. Finally, the handbook provides recommendations on how to improve the quality of data and information systems especially in low- and middle-income countries.

My recommendation for this book is based on my four views of global health. First, global health is the platform to make the world safer for all through global collaboration—this handbook underlines the necessity of creating country data architecture and platforms that link databases across the globe. Second, global health enables countries and non-state actors to protect their national interests—the handbook describes methods for collecting and analysing data that will support member states when they propose resolutions on the global health stage. Third, global health enables countries to showcase their best practices—this handbook covers the disciplines that enable country healthrelated data to become global health data to be used to improve people's health. Finally, global health is the process of building long-term sustainable capacity—the handbook contributes to improving skills and capacities that will ensure a shared global voice in development and implementation of evidence-based health policies and practices.

This handbook not only guides the reader to develop a health information system but, more importantly, it provides advice and examples about how to ensure that the information generated is fed into decision-making and implementation to improve health.

This is a *must read* and *must use* handbook for health systems workers, researchers, managers, and decision-makers!!!

Senior Advisor on Global Health Ministry of Public Health Bangkok, Thailand Suwit Wibulpolprasert

# Better Data for Better Health: An Ongoing Imperative

Data have driven advances in health since the early days of modern medicine. People live longer and healthier lives today because of pioneering work to collect and analyse data on the causes of disease and death and to generate evidence about interventions to prevent them. During the nineteenth century, Louis Pasteur and Robert Koch identified the pathogens involved in major infectious diseases such as anthrax, tuberculosis, and cholera. John Snow used mapping techniques to identify the sources of cholera in London. Florence Nightingale, renowned for her nursing skills, was a consummate statistician and developed innovative techniques for presenting data to elicit policy responses. Today, advances in statistical and epidemiological methods have vastly enhanced the availability and quality of health-related data. But these advances are not evenly spread. Many low- and middle-income countries have limited capacities to produce and use data to underpin decision-making. The situation within countries is worse: the data needed to identify and target marginalized and hard-to-reach population groups are not widely available.

New challenging health conditions continue to emerge, both in relation to infectious diseases but also non-communicable diseases such as cancer, diabetes, and cardiovascular conditions. Addressing the environmental, social, and economic determinants of ill-health is central to continuing improvements in health status. These developments have profound implications for the data systems needed to identify and plan remedial action and to monitor progress and effectiveness. The continuous accumulation of data and statistics creates accountability by providing evidence of what works, what does not work and, more importantly why so.

The editors of this book have brought together a diverse group of authors whose rich perspectives on the generation and use of data across the health spectrum represent the most comprehensive description of health-related information systems yet available. The core theme that unites the chapters is that reliable data and statistics are public goods, essential for the maintenance and improvement of the health of the world's peoples. Good governance and sound administration depend on reliable information, a perception that led the post-apartheid government of South Africa to overhaul the existing health information and statistical systems.

Governments are primarily responsible for creating the conditions for accessible and responsive health systems and for ensuring that the basic sources and methods of statistics and epidemiology are in place. This handbook describes the essential building blocks of information covering triedand-tested methods of data collection, such as the population census, as well as methodological innovations, such as spatio-temporal techniques and statistical modelling, and good practice such as publishing open data. It is a health imperative to adopt a systems approach to health and take full advantage of global good practices in health-related data and statistics.

The global health and statistical communities must provide countries with technical expertise and resources and support for capacity development at both individual and, critically, institutional levels. The generation and use of data for health policy—on inputs, processes, outcome, and impacts—is a human endeavour that must be collaborative, involving stakeholders across sectors locally as well as nationally and internationally. Data must be owned and used locally but also shared widely. As noted by the authors of these chapters, only through active citizenry will it be possible to improve health outcomes, health systems, health inputs, and ultimately achieve universal health care and equity. This book sets the roadmap for this glorious promise. It will be of interest to decision-makers and scholars of public policy. It is a manifesto for health activism and a source of information and knowledge that all who wish to promote health will appreciate.

Oxford Poverty and Human Development Initiative Pali Jobo Lehohla Oxford, UK

#### **Overcoming the Data Poverty Divide: Time for Structural Adjustment**

The *Palgrave Handbook of Global Health Data Methods for Policy and Practice* is a very welcome and timely source of thinking and wisdom in this rapidly changing field. While *global health* might reasonably be taken to include the entire world, in reality major differences in the quality and quantity of health data continue to follow global economic divides. Thus historically *poor* countries in many cases continue in health data poverty—at the same time as facing some of the greatest global challenges in providing health services.

While the overall scope of the handbook is huge, and can by no means be summarized here, there are three structural issues in the field of global health data that seem particularly important:

- In today's world, the agenda against infectious diseases is progressing but is by no means concluded. Life expectancy is increasing, with the consequence that more people are living to ages where non-communicable disease risks increase, just as many population-based risks such as exposure to processed foods and sugary drinks are increasing. Hence global health parameters in particular settings can change rapidly, and if local population-based data are not available, such changes cannot readily be tracked. In particular, elaborate mathematically modelled estimates of global health data can often be insensitive to short-term local changes because of inherent inertia in the underlying models.
- The technical history of data is also relevant. Until the very end of the twentieth century, computing power for handling large databases was very limited compared with today's standards. At the same time, health data expertise was typically manifested among statisticians, demographers, and epidemiologists who had no formal training in informatics and computing but who comfortably handled datasets on a few hundreds or thousands of subjects. Now desktop computers can handle datasets with many millions of records in real-time. But human capacity development for handling the

so-called *big data* on global health sensibly and effectively lags far behind, especially in Africa.

• Access to health data as a global good is an increasingly important issue. Developments such as the International Network for the Demographic Evaluation of Populations and their Health (INDEPTH) Network's public data repository, supported by the Wellcome Trust, are key to achieving an open data environment that facilitates the effective use of data for policy purposes. At the same time, such initiatives need to be balanced by capacity building for analysis and interpretation in local academic and government institutions so that data can be made to *talk* in their own contexts. Reverting to historic norms of exporting data into better-resourced but far-away analytical environments is simply unacceptable.

There is now little more than a decade to run before the 2030 endpoints of the United Nations Sustainable Development Goals. Global understanding of the preceding Millennium Development Goals was compromised to some extent by a lack of appropriate local data and analytical capacity, and the world cannot afford to repeat the same mistake. This handbook is therefore an important milestone in the quest to move the field of global health data methods forward—but substantial further investment and progress is required.

Professor of Global Health, Umeå University Umeå, Sweden Peter Byass

## Preface

On September 25, 2015, 193 countries signed the 2030 Agenda for Sustainable Development agreeing a plan of action to 'transform our world', and pledging to 'leave no-one behind'. January 1, 2016 marked the transition from the 2000–15 Millennium Development Goals (MDGs) roadmap with 8 goals, 21 targets, and 60 indicators to the 2015–30 Sustainable Development Goals (SDGs) roadmap with 17 goals, 169 targets, and 232 indicators. The first (2016) SDG report concluded: 'The data requirements for the global indicators are almost as unprecedented as the SDGs themselves and constitute a tremendous challenge to all countries' [1]. The challenge is undoubtedly real for the health sector which has 1 goal, 13 targets, and over 50 health-related indicators.

The MDGs threw a harsh spotlight on poor statistical infrastructure in many countries. Because the United Nations (UN) developed MDG indicators after the MDG Declaration, there was little or no baseline information. Many national statistical systems were not ready to collect the data required to measure progress towards the goals. Countries reported indicators based on surveys and routinely collected data, but they were sparsely distributed over time and lacked comparability. To track progress globally, international agencies estimated indicators from these country reports.

In 2015, the UN called for a *data revolution for sustainable development* to build technical capacity to manage data. The UN's vision is that all countries and people benefit from expanding opportunities provided by data technology without which the 'gaps between developed and developing countries, between information-rich and information-poor people, and between the private and public sectors will widen, and risks of harm and abuses of human rights will grow' [2]. The *Palgrave Handbook of Global Health Data Methods* 

*for Policy and Practice* is timely in addressing technical issues and capacity gaps in generating data for global health.

## About This Handbook

Many people use many approaches to collect and manage data to improve health worldwide. Data managers and analysts generate statistics using methods drawn from epidemiology, demography, statistics, social sciences, economics, anthropology, and other disciplines. Researchers develop methods for modelling and predicting, for example, the burden of disease borne by people living in different parts of the world. While field manuals and disciplinespecific textbooks describe some of these methodologies, this handbook presents for the first time a collection of approaches to gather and process data for global health. The reader—whether a student of global health or a producer or user of information, working nationally or internationally—will appreciate the descriptions of what it takes to set up systems for acquiring and sharing information to improve health globally.

We start by examining the data that national governments and their partners generate and use. Although governments are not solely responsible for setting the health agenda, they provide the context, including governance structures, within which a national or sub-national health system—public or private—operates. We argue for robust national information systems that inform and monitor local health programmes and thereby contribute to global health. Taking the country perspective, we examine how governments and many local and global partners supply data to develop and monitor their programmes. Governments share their data as indicators with the World Health Organization (WHO) and the UN system. Other institutions use the data to make global health estimates and cross-country comparisons. We also examine how academic institutions, non-governmental organizations, international agencies, and donors contribute to generating data and evidence for global health—in countries and across countries.

## Emergence of Global Health and Global Health Data

Several authors in this handbook describe the historical development of the methods they introduce. We draw on their perspectives to explain the context for the current interest in and relevance of global health and global health data.

During the nineteenth and twentieth centuries, governments began to cooperate to prevent the spread of infectious diseases resulting from increased travel and trade. European governments convened the first International Sanitary Conference in 1851 and countries of the Americas established the Pan-American Sanitary Bureau in 1902. In 1946, 61 nations signed the constitution of the WHO signalling that they intended WHO to become a global organization. WHO member states agreed to share information about epidemics of infectious diseases like cholera and yellow fever and to control their spread across borders. In 1951, member states adopted the International Sanitary Regulations, later to be known as the International Health Regulations. These regulations still require WHO's, now 194, member states to share data about outbreaks of specific conditions and emergencies.

Sovereign states continued to develop global and regional intergovernmental mechanisms, focussing more widely on public health alongside disease outbreaks. As countries in sub-Saharan Africa and South and South East Asia gained independence from colonial rule, high-income countries (HICs) provided technical and financial assistance to build their health-care systems. WHO was the normative, standard-setting agency in health. Other agencies-notably the UN International Children's Fund (UNICEF) and the World Bank-with national governments, private donors and academic institutions supported these economically and demographically *developing* countries to combat disease and build health facilities. Academic institutions, mainly in colonizing or colonized countries, and one in the US, developed the field of tropical medicine to examine and assist in the control of diseases occurring in countries in the tropics. A wealthy shipowner founded the first school of tropical medicine in Liverpool in the UK in 1898. The Rockefeller Foundation in the US led international philanthropy in public health when it established an international health division in 1914.

During the 1960s and 1970s, international concern about population growth after the Second World War dominated health and population funding to developing countries. International agencies such as the UN Population Fund (UNFPA), bilateral donors, and private philanthropies supported data collection to inform family planning activities in these countries. Demographers collected data and developed techniques to measure fertility and mortality where census data were sparse. Agencies set up population surveillance sites in South Asia and sub-Saharan Africa to monitor demographic changes resulting from interventions to promote family planning. The global discussion was about the relative stages countries had reached in the demographic transition from higher to lower fertility and reduced child mortality rates. In 1978, to address huge disparities in health status and access to health care between and within countries, 134 governments and representatives of 67 UN organizations, specialized agencies, and non-governmental organizations signed the Declaration of Alma Ata. With the vision of *Health for All*, the Declaration promoted primary health care as the vehicle 'for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world' [3]. The meeting recommended that each government monitor and evaluate its programmes to implement primary health care using the minimum of information 'with the help of a simple and relevant information system'.

The report of the Alma Ata meeting proposed starting by collecting qualitative rather than quantitative information since most systems were manual at that time. Nevertheless, Alma Ata marked the start of international targetsetting with measureable indicators. At the time, censuses and surveys were the prevalent sources of data. The World Fertility Survey had supported countries to collect national survey data from the early 1970s and these became Demographic and Health Surveys in 1984. Backlash against this trend to quantify people's lives led international agencies to introduce participatory approaches to development such as *rural rapid appraisal* (RRA). RRA evolved into *participatory rural appraisal* (PRA) and the World Bank used similar methods to conduct *participatory poverty assessments* (PPA) leading to their publication of *Voices of the Poor* in 1999. Tension between the value of qualitative data and information provided by people versus quantitative data collected about them is live today.

Health progress stagnated in many countries following the economic crises of the 1970s and 1980s. Demographic statistics highlighted devastatingly high levels of child and maternal mortality in developing countries. Epidemiological data demonstrated high morbidity and mortality from *tropical* diseases such as malaria, schistosomiasis, onchocerciasis, and tuberculosis (TB). Global concern led to an era of *international health* characterized by assistance from developed to developing countries to build capacity to run health and information systems. When micro-computers became available, international support began to focus on health information systems. As governments decentralized administrative authority for health and other sectors to districts, managers developed district health management information systems.

The 1993 World Bank publication, *Investing in Health*, and the 1990 Global Burden of Disease (GBD) estimates on which it was based, was a landmark in development of global health data methods. Murray, Lopez, and Jamison introduced the disability-adjusted life years (DALYs) as a comprehensive indicator to measure burden of disease and injury. Using published and unpub-

lished data and informed expert opinion, they estimated DALYs for 100 causes by age, sex, and region of the world. They intended to: address inadequate mortality data especially for adults; measure disability which had hitherto only been considered a problem for HICs; and provide a 'framework for objectively identifying epidemiological priorities which together with information on the cost-effectiveness of interventions can help when decisions on the allocation of resources have to be made' [4]. *Investing in Health* did just that, proposing packages of public health and essential clinical care that could reduce the burden of disease in developing countries by 25 percent [5]. Since that time the World Bank, WHO, and researchers at the Institute of Health Metrics and Evaluation (IHME) have evolved techniques for estimating DALYs and the data on which they are based. The 2016 GBD study included 300 diseases and injuries for more than 195 countries.

The GBD study has helped to describe countries' transitions from infectious disease-driven mortality to chronic disease-driven morbidity and mortality. Data began to show that low- and middle-income countries (LMICs) were suffering a double burden of infectious and chronic diseases such as cancer, cardiovascular disease, and obesity. Additional threats such as HIV/ AIDS, SARS, and Ebola emerged in the 1980s and 1990s and the international health community was manifestly unprepared. New global organizations with diverse partners evolved to address pressing health issues—including private and commercial enterprises, philanthropy, and academia-alongside the existing UN agencies and bilateral and multi-lateral governmental organizations. The President's Emergency Plan for AIDS Relief (PEPFAR), established in 2003, provides technical and financial support to 15 countries mainly in sub-Saharan Africa all with high HIV/AIDS prevalence rates. Entities, such as the Global Fund to fight AIDS, Tuberculosis and Malaria (2002) and Gavi the Vaccine Alliance (2010), have raised significant additional funding streams and distributed them to priority countries using a performance-based approach. Country accountability for large financial support required additional data collection and sometimes resulted in parallel disease-specific information systems.

By the turn of the twentieth century, the term global health had become ubiquitous. Global networks and entities have multiplied and academic institutions, particularly in HICs, now engage in *global health*. Although there are multiple definitions of global health, people use the term to describe activities aimed at improving people's health worldwide—acknowledging increasing complexity and diversity of health challenges that cross national boundaries, and that ill-health affects all peoples but especially the poorest and most vulnerable. While global health implies concerted action by multiple countries, institutions, and sectors, it pivots on the work of institutions that plan services and deliver quality health care directly to populations.

Often unstated, but implicit, in most definitions of global health is a necessity that institutions create and share data within and across countries to develop and evaluate policies to improve health and enhance health equity for people wherever they live. Data for global health are now omnipresent, created by growing numbers of researchers and institutions, and morphing into the emerging field of *big data*. Technology is transforming the landscape for collecting, analysing, and disseminating large volumes of data. Data collection technologies, such as computer-assisted personal interviewing, digital mapping and global positioning systems are improving data collection and field operations. Enhanced computing capacity and software permit analysis of massive quantities of data. The Internet offers access to primary and secondary data and official and unofficial publications. The ready availability of data and information challenges users to understand their integrity and veracity.

## **Defining Global Health Data**

*Global health* then is an umbrella term that encapsulates the contributions of all countries and multiple institutions to developing policies and implementing interventions to improve all people's health equitably worldwide. Interestingly, the term encompasses both activities and their goal, that is, people work *in* global health *to achieve* global health. In this handbook, we examine the data and methods policymakers and practitioners use to achieve global health.

But what are *global health data*? We haven't found a definition but, after speaking with colleagues and reading the literature, we realize that people use the term in different ways—just like its parent term, global health. The fundamental question is: when do health-related data become global health data?

We continued our discussion with colleagues and came up with the following argument and definition of global health data on which we base this handbook.

Health-related data may originate from any sector, and may be collected and analysed:

• *by* governmental and non-governmental organizations within health systems, public and private providers, researchers undertaking dedicated studies, or international agencies

- *to* manage health systems, evaluate interventions, manage preventive and clinical care, inform other sectors, develop global and local policy, or to advance research
- *as* primary data through formal and informal data collection systems or as independent research, using openly available secondary data, or by harvesting big data
- *through* observing, interviewing or examining populations using administrative systems or at the point of delivery
- *using the methods* of several disciplines including demography, statistics, epidemiology, social sciences, and economics
- *and managed* manually or by using information technology and specialized software
- *and disseminated* as management indicators, official national and international statistics, or in peer-reviewed journals

Health-related data are collected where people live, and should inform policy and practice to address local health challenges.

Health-related data become *global health data* when—aggregated, synthesized, and exchanged—they form the basis of estimates and evidence that drive international debate and collaborative efforts to improve health status and reduce disparities across populations, borders, and geographies. Numerous people and agencies create and use global health data, but national governments are obliged to maintain essential infrastructures to produce quality data to address their health priorities, and they share these data as indicators for international benchmarking against agreed targets.

Global health data must be trustworthy and represent populations fairly. Ideally, producers collect and manage these data consistently, economically, efficiently, ethically, and transparently, and disseminate them widely.

Global health data methods describe how governments and other agencies use traditional and new technologies to collect, clean, aggregate, synthesize, and disseminate health-related data; and transform them into indicators, estimates, and evidence that inform efforts to improve health status and reduce disparities across populations, borders, and geographies.

#### **Organization and Contents of the Handbook**

Such an ambitious definition of global health data made editing this handbook a daunting task. We decided to bring together the strands of global health data methods knowing that the result would be indicative rather than comprehensive. We invited an exceptional group of colleagues—with a formidable range of experience in handling data in different contexts and countries—to provide the technical content of the handbook. We, as editors, have attempted to frame their contributions and to fill gaps in topics to include those we think necessary. We began by making a list of chapter topics but the list changed as some authors became too busy to write and others offered new and exciting suggestions. The combination of topics has matured over time and we are pleased with the end result. We also know there are other issues and perspectives we could have included. We hope that by bringing at least these themes together, we will stimulate others to continue to frame and enhance global health data and methods.

We made some hard decisions. First about data: we decided not to ask authors to provide data per se but only to illustrate the issues they introduce. Second about methods: we invited authors to give an overview—indicating where the reader might obtain additional resources—but not to delve deeply into any particular technique. Third about examples: we wanted to show how practitioners use the same methods in different contexts, so we asked authors to choose their examples from around the world. We have divided the contributions into five parts covering essential themes underpinning global health data and methods.

Part I: Lays the Foundations of Global Health Data for Policy and Practice With Tangcharoensathien (Chap. 1), we, as editors, examine the data sources that comprise a national health information system. We also trace the flow of locally generated data from communities and facilities as they translate into information through administrative levels to reach a central ministry of health-situated within a national statistical system-which then reports indicators internationally to WHO and other UN agencies. With Frank (Chap. 2), we explore the escalation in global demand for indicators and the tensions this creates for collecting enough relevant and reliable data. Brindis and Macfarlane (Chap. 3) examine the fragile interplay between data and policy and offer insights into how to maximize policymakers' use of data at any level from national to global. Macfarlane, Lecky, Adegoke, and Chuku (Chap. 4) follow the transformation of data into evidence of effective and efficacious interventions that contribute to health system performance. Finally, Karpati and Ellis (Chap. 5) lay out some principles for using quality data to inform government policy.

*Part II: Presents the Major Sources of Global Health Data* MacDonald (Chap. 6) introduces the census as the most long-standing source of population data which is as relevant to planning services today as it was for the ancient Greeks. AbouZahr, Mathenge, Brøndsted Sejersen, and Macfarlane (Chap. 7) explain the civil registration system that records vital events in people's lives from birth to death and how this process generates continuous population and health statistics. Macfarlane (Chap. 8) follows the evolution of national household surveys to provide a cross-sectional picture of a population's health and its access to and use of health services. Lippeveld, Azim, Boone, Dwivedi, Edwards, and AbouZahr (Chap. 9) examine the role of health management information systems in processing routine data from communities through district to national level. Finally, Ungchusak, Heymann, and Pollack (Chap. 10) demonstrate how surveillance systems collect data to monitor and protect people from disease and other unwanted public health events and conditions.

*Part III: Provides Examples of Specialized Systems of Global Health Data* Maina and Mwai (Chap. 11) introduce systems of National Health Accounts (NHA) which collect and analyse data on who pays and how much they pay for health services—providing a case study from Kenya. Siyam, Diallo, Lopes, and Campbell (Chap. 12) explain the importance of data to planning and organizing the health workforce. Silva and Mizoguchi (Chap. 13) examine challenges in obtaining mortality data in situations of armed conflict. Thomson, Lyon, and Ceccato (Chap. 14) explain the unique value of incorporating climate data in health information systems. Finally, Geraghty (Chap. 15) describes how geographic information systems guide resource allocation in health.

Part IV: Introduces Methods for Collecting and Analysing Global Health Data Singh, Krishan, and Telford (Chap. 16) show the value of qualitative data for gaining insights into health policy and practice particularly to target interventions towards vulnerable populations. Bawah and Binka (Chap. 17) provide the essentials of demography, the discipline that describes and predicts how population structures change over time, whether across the world or in a small geographic area. Lansang, Dennis, Volmink, and Macfarlane (Chap. 18) review epidemiological principles and methods, and offer some practical considerations in designing studies to inform policy and programme management. Kahn, Mwai, Kazi, and Marseille (Chap. 19) introduce methods of health economics as tools to assist policymakers choose intervention strategies that will maximize health gains with available resources. Diggle,

Giorgi, Chipeta, and Macfarlane (Chap. 20) explain spatial and spatiotemporal modelling to describe, predict, and map the distribution of health outcomes in space and over time to assist public health planners. Finally, Mathers, Hogan, and Stevens (Chap. 21) introduce statistical models that bring together sparse, diverse, and sometimes inaccurate country data to generate global health estimates of health indicators to facilitate cross-country comparisons over time.

Part V: Highlights Some Principles and Policies for Managing Global Health Data We, as editors (Chap. 22), provide some tools for data producers and users to address issues of data quality, integrity, and trust. Laessig, Jacob, and AbouZahr (Chap. 23) outline best practices for organizations to adopt to disseminate data openly for others to use. They demonstrate the significance of unlocking vast amounts of data generated from multiple sources. Thomas and McNabb (Chap. 24) explore ethical issues associated with collecting and using data for public health, emphasizing the importance of ensuring data confidentiality, establishing principles for sharing data, determining availability and ownership of data, maintaining transparency, and using routine data to monitor health equity. Finally, we as editors (Chap. 25) return to the theme of global health data and methods. We reflect on authors' contributions and endeavour to frame the many activities they have described and lay out how national and international stakeholders collaborate to strengthen the data environment. In looking to the future, we emphasize the need for strong governance and ethical frameworks, long-term investments in institutional capacity development, and much improved collaboration and cooperation across sectors, stakeholders, countries, and development agencies.

## Levelling the Playing Field

Our short review of the history of global health and global health data shows that countries once referred to as developing, and now as LMICs, spent the last century catching up with the latest technical developments proposed by wealthy countries but without the human or financial resources to fully implement them. Big data provide the biggest opportunity and the biggest threat to the health information systems of LMICs. Unless the international community supports them to consolidate their information and surveillance systems, LMICs may learn their health data from others. Individuals or organizations anywhere in the world can anticipate the next global epidemic by searching the Internet and they might even identify the village or household at its epicentre. Data scientists can extrapolate trends in people's opinions and choices about their health care; they can also estimate global health indicators by building large databases drawing on data from many sources. Independent researchers obtain funding to conduct dedicated surveys to describe the health conditions in a country or region of countries. We argue for strong global collaboration and investment to support LMICs maintain health information and surveillance systems to identify priorities and monitor interventions especially at the granular level of districts and communities—while introducing appropriate technologies.

Authors of chapters in this handbook demonstrate remarkable advances in data methods and in harnessing these methods for global health. They also demonstrate immense disparities in technical and human resources to apply the methods to support local decision-making and to contribute global knowledge. We hope that, by describing traditional alongside innovative approaches, this handbook will inspire readers to share and build as well as to estimate and innovate.

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We thank all authors for their valuable contributions and for their patience in working with us to ensure that the chapters complement each other. As their short bios indicate, they represent a community of experts with years of experience working with global health data in many countries and global institutions. Several colleagues supported us through the journey of editing this book. We single out Wayne Enanoria, Hugo López-Gatell, Patrick Gerland, Robert Hiatt, Pavana Murthy, Janet Myers, Poonam Patel, Sara Seims, Vivek Singh, Stefaan Verhulst, and Andrew Young for their welcome advice and contributions. We thank Kerstin Svendsen for designing most of the figures and Geetha Raayanker for working on the references.

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San Francisco, CA, USA Geneva, Switzerland Sarah B. Macfarlane Carla AbouZahr

#### References

- 1. The Demographic and Health Surveys Program. [cited 2018 26th April]. Available from: https://dhsprogram.com/
- 2. Data Revolution Group. A world that counts. Mobilising the data revolution for sustainable development. 2014 [cited 2018 26th April]. Available from: http://www.undatarevolution.org/report/
- 3. International Conference on Primary Health Care. Alma-Ata USSR 6–12 September 1978. Declaration of Alma Ata. 1978 [cited 2018 26th April]. Available from: http://www.who.int/publications/almaata\_declaration\_en.pdf
- 4. Murray CJ, Lopez AD, Jamison DT. The global burden of disease in 1990: summary results, sensitivity analysis and future directions. Bulletin of the World Health Organization. 1994;72(3):495–509. [cited 2018 26th April]. Available from: https://www.ncbi.nlm.nih.gov/pubmed/8062404
- 5. The World Bank. World development report 1993. Investing in health. New York, USA: Oxford University Press; 1993. Available from: http://dx.doi. org/10.1596/0-1952-0890-0

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## **Notes on Contributors**

**Carla AbouZahr** has academic qualifications from the London School of Economics and Political Science and the London School of Hygiene and Tropical Medicine. She is a senior technical advisor on civil registration and vital statistics (CRVS) to the Bloomberg Data for Health Initiative, at the University of Melbourne, Australia. Previously, she worked at the WHO, Geneva, where she was the coordinator for health statistics and information systems. She was responsible for the annual flagship publication World Health Statistics and for technical support to countries on health information systems.

**Olufemi Adegoke** gained academic qualifications in population and international health at Harvard University and in human nutrition at University of Ibadan, Nigeria. In a career focussed on public health and nutrition, he has extensive experience conducting, monitoring, and evaluating health programmes. He has worked with Oxford Policy Management, the World Bank's Development Impact Evaluation (DIME) team, the Independent Monitoring and Evaluation Program (IMEP), FHI 360, Columbia University, Pact, and the Carter Center.

**Tariq Azim** is a senior technical advisor with John Snow, Inc., MEASURE Evaluation. He has over 30 years of experience in the development and scale-up of routine health information systems in Bangladesh, Pakistan, and Ethiopia and in health system reconstruction and capacity building in Afghanistan. He has contributed to the development of global tools such as a curriculum for assessment and training in routine health information systems and enhancing data use.

**Ayaga A. Bawah** is a demographer and senior lecturer at the Regional Institute for Population Studies, University of Ghana, and a research affiliate of the Population Studies Center (PSC) at the University of Pennsylvania in the US. He has been an assistant professor at Columbia University in New York, senior research associate at the INDEPTH Network, and scientist of the Navrongo Health Research Centre in

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northern Ghana. His research interests are in child health, health equity, fertility and reproductive health, and research methodology.

**Fred N. Binka** is Professor of Epidemiology and the foundation vice-chancellor of the University of Health and Allied Sciences, in Ho, Ghana. He founded the acclaimed research group, the INDEPTH Network. As a specialist in the epidemiology and control of malaria, he has served on numerous advisory and expert committees for WHO, the Gavi Alliance, the African Medical and Research Foundation (AMREF), the Malaria Consortium, and the Innovative Vector Control Consortium (IVCC). He is an associate editor of the *International Journal of Epidemiology* and recipient of several prestigious awards, including the Rudolf Geigy Award, the Ronald Ross Medal, and Member of Order of the Volta, awarded in 2016 by the President of Ghana for service to the nation.

**David Boone** is an epidemiologist with extensive experience in international and US domestic public health. He works with the MEASURE Evaluation Project at John Snow, Inc. His areas of expertise include disease control and surveillance, health information system strengthening, and monitoring and evaluation for HIV/AIDS, malaria, tuberculosis, and maternal and child health. He has worked with WHO and the Global Fund to Fight AIDS, Tuberculosis and Malaria to develop tools and methods to improve data quality in routine health information systems.

**Claire D. Brindis** is a professor and director of the Philip R. Lee Institute for Health Policy Studies and co-director of the Adolescent and Young Adult Health Information Center, both at the University of California San Francisco. Her research focusses on ameliorating the impact of social, health, and economic disparities among a wide variety of multi-ethnic and multi-racial populations, with a focus on adolescents and young adults. As a policy advisor to public sector policymakers and private foundations, and a bi-lingual, bi-cultural Latina researcher, she is committed to shared data for research and accelerated learning for improved health outcomes and to the translation of evaluation findings for community groups, providers, policymakers, and other stakeholders.

**Tanja Brøndsted Sejersen** has academic qualifications in demography, statistics, and political science. She is a statistician at the United Nations Economic and Social Commission for Asia and the Pacific. She is the focal point for the Asia-Pacific CRVS initiative to 'Get Every One in the Picture', as well as for the Asia-Pacific CRVS Partnership and the Regional Steering Group for CRVS in Asia and the Pacific. Her work involves capacity-building activities and collaboration with partners to support country action to improve national CRVS systems.

**Peter Byass** is Professor of Global Health at the Umeå University, in Northern Sweden, and director of the Umeå Centre for Global Health Research. He holds honorary professorships at the University of Aberdeen, Scotland, and the University of the Witwatersrand, Johannesburg, South Africa. For over 25 years, he has worked on population health measurement issues in Africa and Asia, contributing to evidence and methodologies. He is a deputy editor of Global Health Action and on the editorial boards of *PLoS Medicine* and *Population Health Metrics*. One of his specialist research interests has been the development of probabilistic models for interpreting verbal autopsy material, initiating the now widely used InterVA model.

**Jim Campbell** is the director of the Health Workforce Department at World Health Organization Headquarters. He oversees the development and implementation of global public goods, evidence, and tools to inform national and international investments in the education, development, and retention of the health and social sector workforce. This work is in pursuit of universal health coverage, healthy lives, global health security, and the SDGs. He coordinates the Global Health Workforce Network, engaging member states and relevant partners across technical streams of work.

**Pietro Ceccato** is a senior research scientist and lead in the Environmental Monitoring Program at the International Research Institute for Climate and Society, Earth Institute, Columbia University, New York, US. His research activities include the development and integration of remote sensing products to monitor climate and the environment into early warning systems for human health, agriculture, pest management, and natural disasters.

**Michael Chipeta** is a geospatial epidemiology researcher at the Big Data Institute, University of Oxford, UK. His research interests are in spatial statistics (geostatistical designs) with applications to disease mapping, spatial data analysis, statistics for public health, spatiotemporal modelling, tropical disease epidemiology and health surveillance (monitoring and evaluation).

**Nkata Chuku** obtained his medical degree from the University of Lagos in Nigeria and a master's degree in health policy, planning and financing from the London School of Economics and London School of Hygiene and Tropical Medicine. He has over 15 years of experience in health systems strengthening in Nigeria and other African countries. He is a Founding Partner of Health Systems Consult Ltd. and has worked as KMPG's pioneer Healthcare Lead for West Africa, FHI 360's director for health systems strengthening in Nigeria, senior monitoring and evaluation advisor for the PEPFAR \$415 million GHAIN project, and as a clinician in different locations.

**Rodolfo J. Dennis** is Professor of Medicine in the Department of Clinical Epidemiology and Biostatistics at Pontificia Universidad Javeriana in Bogotá, and head of the Research and Clinical Medicine Departments at Fundación Cardioinfantil, Instituto de Cardiología, also in Bogotá, Colombia. He has more than 30 years of experience in the practice and teaching of clinical epidemiology.

**Khassoum Diallo** is a statistician/demographer with extensive experience in statistics, monitoring and evaluation, research, and knowledge management. Over the last 25 years, Diallo has provided technical support and capacity building to governmental and non-governmental organizations, and to the UN in more than 50 countries in Africa, Asia, and Latin America. He has occupied various positions in UN agencies (UNICEF, UNHCR, UNFPA, and WHO) and academia in Africa, North America, and Europe. He is the coordinator of the Data, Evidence and Knowledge Management Unit in the Health Workforce Department at World Health Organization Headquarters.

**Peter Diggle** is a distinguished university professor at CHICAS, Lancaster University, Lancaster, UK. He also holds adjunct appointments at Johns Hopkins University, Columbia University, and Yale University. His research interests are in the development and application of statistical methods for the biomedical and health sciences. His particular methodological research interests are in spatial statistics and longitudinal data analysis.

**Vikas Dwivedi** is a public health professional involved in improving metrics, use of data, and data integration and interoperability, working for John Snow, Inc. He promotes institutionalizing innovations, digital health, engagement of private sector, and performance management. Over the past 18 years, he has worked with health systems in Asia and Africa. His approach seeks to empower health workers to translate data into action, with a focus on the application of business principles and processes in the design and use of health information systems.

**Michael Edwards** has been a biostatistician and senior health informatics advisor for the John Snow, Inc. International Division and the MEASURE Evaluation Project since 1999. He has over 30 years of experience in statistical analysis and in the design of health and geographic information systems, particularly in the areas of health and HIV/AIDS programme monitoring and disease surveillance. He has designed and supported the development of national health information systems that allow decision-makers to visually analyse programme indicators in tables, graphs and maps, and multi-level configurations, so that the systems are functional at national, regional, district, and even service delivery levels.

**Jennifer Ellis** gained her academic qualifications at Columbia University and Occidental College. She was an adjunct assistant professor for the City University of New York where she taught biostatistics and research methods and served five years as technical deputy editor for the *American Journal of Public Health*. At the Bureau of Tobacco Control in the New York City Department of Health and Mental Hygiene she oversaw research, evaluation, and epidemiology. She joined Bloomberg Philanthropies in February 2008 where she directs epidemiology and data use across public health programmes, overseeing partner activities that monitor global health progress and trends and leads the Bloomberg Philanthropies Data for Health Initiative.

**John Frank** has undergone training in family and community medicine at the universities of Toronto and McMaster, and in epidemiology at the London School of Hygiene and Tropical Medicine. From 1983 to 1991, he was a professor at the University of Toronto and was the founding director of research at the Institute for Work & Health in Toronto from 1991 to 1997. In 2000, he was appointed inaugural scientific director of the Institute of Population and Public Health at the Canadian

Institutes of Health Research. He took on the role of director of the Scottish Collaboration for Public Health Research and Policy (SCPHRP) in 2008. He holds a chair in public health at the University of Edinburgh and is a fellow of the Royal Society of Edinburgh.

**Estella Geraghty** is the chief medical officer and health solutions director at Esri, developer of the world's most powerful mapping and analytics platform. She leads business development in Health and Human Services and is passionate about delivering value through a geographic approach. Formerly she was the deputy director of the Center for Health Statistics and Informatics with the California Department of Public Health where she led the state vital records and public health informatics programmes, engaging in initiatives in meaningful data use, health information exchange, open data, and interoperability. She also served as an associate professor at the University of California Davis, conducting research on geographic approaches to health policy and community development.

**Emanuele Giorgi** is Medical Research Council Fellow in Biostatistics at CHICAS, Lancaster University, Lancaster, UK. His expertise is in the development of statistical methods and their application to public health problems, with a special focus on the spatial and spatio-temporal epidemiology of tropical diseases. He has also developed open source statistical software for disease mapping.

**David Heymann** is Professor of Infectious Disease Epidemiology at London School of Hygiene and Tropical Medicine, head of the Centre on Global Health Security at Chatham House, London, and chairman of Public Health England, UK. Previously he was the WHO assistant director-general for health security and environment, and representative of the director-general for polio eradication. From 1998 to 2003, he headed the WHO Communicable Diseases Cluster and led the global response to SARS. Before joining WHO, he worked for 13 years as a medical epidemiologist in sub-Saharan Africa, on assignment from the US Centers for Disease Control and Prevention (CDC), where he participated in the first and second outbreaks of Ebola haemorrhagic fever. He is an elected fellow of the Institute of Medicine of the National Academies, US, and the Academy of Medical Sciences, UK.

**Dan Hogan** has academic qualifications in health policy and decision science from Harvard University and is head of Corporate Performance Monitoring & Measurement at Gavi the Vaccine Alliance. Between 2013 and 2018, he was a statistician in the Department of Information, Evidence and Research at the World Health Organization where he led the monitoring of service coverage for universal health coverage and coordinated WHO data inputs for SDG monitoring. He has developed and produced a variety of global health estimates, including for indicators of HIV, child and maternal health, and injuries, as well as health-state valuations.

**Bryon Jacob** is, with Matt Laessig, co-founder and the chief technical officer at *data.world, Inc.*, a public benefit corporation with the mission to build the most meaningful, abundant, and collaborative data resource in the world by democratizing

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access to data and accelerating the open data movement. He is a recognized leader in building large-scale consumer Internet systems and an expert in data integration solutions. His academic and professional experience spans artificial intelligence research at Case Western Reserve University, enterprise software at Trilogy, and consumer web experience at Amazon.

James G. Kahn is a professor in the Philip R. Lee Institute for Health Policy Studies, the Institute for Global Health Sciences and the Department of Epidemiology and Biostatistics at the University of California San Francisco (UCSF). He is the founder and director of the UCSF Global Health Economics Consortium (GHECon). He is an expert in cost-effectiveness analysis and associated methods of decision analysis, systematic review, meta-analysis, and costing. He is the principal investigator for the Consortium for the Assessment of Prevention Economics (CAPE) and the UCSF component of a National Institute on Drug Abuse (NIDA)-funded modelling consortium. He is a co-founder and UCSF principal investigator for the Global Health Cost Consortium, a project to increase the availability and quality of cost data for treatment and prevention programmes for HIV, TB, and other diseases.

Adam Karpati has medical qualifications from McGill University's Faculty of Medicine in Montreal and New York University Medical Center. He served in the Epidemic Intelligence Service at the CDC and holds a master's degree in public health from the Harvard School of Public Health. He is the senior vice president for Public Health Programs at Vital Strategies, a global public health organization, where he oversees programmes to strengthen public health systems and addresses leading causes of morbidity and mortality in low- and middle-income countries. These include the Bloomberg Philanthropies Data for Health Initiative. Prior to joining Vital Strategies, he worked at the New York City Department of Health and Mental Hygiene, most recently as executive deputy commissioner for the Division of Mental Hygiene.

**Dhruv Kazi** is a cardiologist, researcher, and health economist at the Beth Israel Deaconness Medical Center. He trained in India, Kenya, the UK (London School of Economics and Political Science), and the US (Baylor College of Medicine, UC San Diego, and Stanford University). His work focusses on improving long-term clinical outcomes among patients with cardiovascular disease in resource-scarce settings. He has worked on the evaluation of health policies, novel diagnostic approaches, medical devices, drug therapy, and genetic testing using simulation modelling and the application of advanced statistical techniques to large observational datasets. He has examined the economics of the health-care workforce in the US and in India, China, and sub-Saharan Africa.

**Anjali Krishan** holds a master's degree in urban planning from the University of Illinois-Urbana Champaign, US. She has conducted research on development topics such as gender, security, and public health, using qualitative and ethnographic methods in conjunction with quantitative tools. Between 2014 and 2016, Anjali was a research associate at Amaltas Consulting Pvt. Ltd.; in this role, she was the principal

investigator on several mixed method studies in the global health sector. She is pursuing her doctorate in international development at University of Oxford, UK.

**Matt Laessig** gained academic qualifications at the Wharton Business School and the Lauder Institute of International Studies and Management, University of Pennsylvania. He is the chief operating officer and co-founder, with Bryon Jacob, of *data.world, Inc.*, a public benefit corporation with the mission to build the most meaningful, abundant, and collaborative data resource in the world by democratizing access to data and accelerating the open data movement. He has been an entrepreneur and executive in the technology industry for the last 20 years and served as Vice President of Business Development at Bazaarvoice, the global leader in social commerce solutions.

**Mary Ann Lansang** is a clinical professor at the Department of Clinical Epidemiology, University of the Philippines Manila, and an infectious diseases specialist at The Medical City in Pasig City, Philippines. She has more than 30 years of experience in global health, with technical expertise in the epidemiology, prevention, control, and management of infectious and tropical diseases; policy development for public health programmes; monitoring and evaluation of public health programmes; health policy research and knowledge translation; and health systems strengthening.

**Muhammed M. Lecky** has academic qualifications from the University of California Berkeley and was a MacArthur Foundation Post-Doctoral Research Fellow at the Harvard School of Public Health. He is a Federal National Electoral Commissioner with the Nigeria Independent National Electoral Commission. He worked as the executive secretary/CEO of the Health Reform Foundation of Nigeria and prior to that served as a senior policy and strategic advisor to the International Development and Research Center (IDRC), Canada. He was the executive secretary/CEO of the Nigeria National Health Insurance Scheme, and a director of Health Policy, Planning, Research, Statistics and Monitoring and Evaluation at the Nigeria Federal Ministry of Health.

**Pali Jobo Lehohla** gained academic qualifications in population studies, economics, and statistics from the universities of Lesotho and Ghana. He served as statisticiangeneral of South Africa from 2000 to 2017. He was co-chair of PARIS21, chair of the UN Statistics Commission, founding chair of the Statistics Commission of Africa, and chair of the African Symposium for Statistical Development. He was the vice president of the International Statistics Institute and a member of the United Nations panel on the Data Revolution. He is a consultant to the Oxford Poverty and Human Development Initiative and a member of the United Nations Secretary-General's Independent Accountability Panel for the Global Strategy for Women's, Children's and Adolescents' Health. He has honorary doctorates from the universities of Stellenbosch and Kwazulu Natal and is a forceful advocate for improving data systems in Africa.

**Theo Lippeveld** is a public health physician with in-depth experience in health policy analysis and health services planning in low- and middle-income countries. For the past 25 years, he has worked with John Snow, Inc., on the design and implementation of national routine health information systems. He is director of the Data Use

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Partnership supporting the Ethiopia Federal Ministry of Health (FMOH) for better use of information at all levels of the health system. He is a co-founder and the president of the Routine Health Information Network (RHINO).

**Sofia Lopes** is a graduate nurse, with postgraduate training in health and development from the Institute of Hygiene and Tropical Medicine, University of Lisbon. She has developed her work on public health, focussing on health systems and human resources for health, particularly for women's health. She contributed to the States of the World Midwifery 2014 and to the development of the WHO Global Strategy on Human Resources for Health Workforce 2030. She is a PhD student at the University of Cape Town in the Public Health doctoral programme. Her research interests are women's health and empowerment, health systems, and research methodologies.

**Bradfield Lyon** is an associate research professor at the University of Maine and an adjunct research scientist at the IRI, Earth Institute, Columbia University, New York. He is a climate scientist interested in understanding what drives climate variability and change, particularly in East Africa.

**Alphonse L. MacDonald** gained academic qualifications in social sciences at Radboud University of Nijmegen, the Netherlands. He started his career as a scientific officer at the Institute for Sociology, Radboud University, Nijmegen. Throughout his career he has provided methodological and technical assistance to population censuses and household surveys. He is an honorary professor of the Universidad Nacional San Antonio Abad, Cusco, Peru, and a senior advisor to the General Bureau of Statistics of Suriname. He is the first vice president (2018–2020) and president elect (2020–2022) of the Inter-American Statistical Institute (IASI).

**Sarah B. Macfarlane** is 2017 Edward A. Dickson Emerita Professor in the Department of Epidemiology and Biostatistics at the University of California San Francisco (UCSF). She is a founding member of UCSF Global Health Sciences and a visiting professor to the Aga Khan University in East Africa. She worked for many years at the Liverpool School of Tropical Medicine in the UK where she headed the Unit for Statistics and Epidemiology. She served for six years as associate director for Health Equity at the Rockefeller Foundation where she supported public health and research programmes in Africa and Asia. She is especially interested in building capacities and collaboration across health information and statistical systems.

**Thomas Maina** is a health economist with over 15 years of experience in the fields of health-care financing, policy, planning, and budgeting. He is an expert in health systems strengthening, health resource tracking, and economic evaluation of health programmes. He has extensive experience in public policy, planning and budgeting, and health resource tracking using tools like National Health Accounts, Public Expenditure Tracking Surveys, and Public Expenditure Reviews. He is a consultant to the World Bank in Nairobi.

Elliot Marseille is the principal of Health Strategies International in Oakland, California, a firm that specializes in the economic evaluation of global health

programmes. He has over 30 years of senior public health management and research experience with a focus on the empirical and modelled assessment of the cost and cost-effectiveness of services, programmes, and policies related to HIV/AIDS. He was the director of UCSF's 'PANCEA' study of the unit costs of HIV prevention strategies in five countries. He is a consultant to the University of California San Francisco Center for Global Surgical Studies. He teaches decision analysis, and leads the HIV and school health modelling activities for a cooperative agreement designed to extend CDC's modelling capacity for HIV, HCV, school health, STIs, and TB.

**Gloria Mathenge** has qualifications in demography and public health and is social statistician at the Pacific Community where she provides technical assistance and advice to governments of the Pacific Islands in the development of CRVS systems and the analysis of administrative data. She serves on the International Union for the Scientific Study of Population (IUSSP) Scientific Panel on Innovations for Strengthening CRVS Systems.

**Colin Mathers** led the Mortality and Health Analysis Unit at the World Health Organization in Geneva, from 2002 until 2018, and was responsible for official statistics on global health trends and burden of disease, and more recently, monitoring progress towards the health-related targets of the UN SDGs. His principal research interests are in the measurement and reporting of population health and its determinants, summary measures of health, and projections of human life expectancy and causes of death.

**Sarah McNabb** has academic qualifications in international and public health from Georgetown University and the University of Washington. She is a project lead for information systems and population health at NewYork-Presbyterian Hospital. Her research interests include: health policy; programme evaluation; and the application of health information technology to improve care coordination, increase patient engagement, and reduce health disparities. She was a 2016 Margaret E. Mahoney Fellow at the New York Academy of Medicine and is a member of Alpha Sigma Nu National Jesuit Honor Society.

**Nobuko Mizoguchi** earned her doctorate in demography from the University of California Berkeley, where her research focussed on crisis mortality. She is a senior demographer for International Programs, Population Division, US Census Bureau. She teaches demographic analysis and population projections globally and specializes in mortality measurement and estimation.

**Daniel Mwai** is a health finance specialist working for the Health Policy Plus and a lecturer in health economics at the University of Nairobi and the School of Global Health, Strathmore University. He is a recognized thought leader with over 12 years of experience in health financing; health policy; economic evaluation (costing, efficiency, effectiveness, and equity analysis); economic research; and planning, budgeting and resource mobilization for health sector in Africa. His work spans the public and private

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sectors, not-for-profit, and international development. He has worked extensively to apply health resource tracking using tools in low- and middle-income countries such as National Aids Spending Assessment (NASA), NHA, PERs, and PETS.

**Marjorie Pollack** qualified from the Medical College of Pennsylvania and is American Board of Internal Medicine (ABIM) certified in internal medicine. After completing Epidemic Intelligence Service (EIS) training and a preventive medicine residency at CDC, she has worked as a consultant medical epidemiologist for over 35 years in over 50 countries, with WHO, Pan American Health Organization (PAHO), USAID, UNICEF, the World Bank, and the Asian Development Bank. Since 1997 she has worked with ProMED-mail (Program for Monitoring Emerging Diseases) of the International Society for Infectious Diseases, of which she is the deputy editor. She has developed a curriculum for training field epidemiologists in the use of nontraditional information sources as an adjunct to routine disease surveillance and runs training workshops for field epidemiologists and other health-care personnel.

**Romesh Silva** holds academic qualifications in demography from the University of California Berkeley. He is a technical specialist at the UNFPA headquarters in New York. He is UNFPA's global technical lead in population data/estimation in humanitarian settings and in CRVS. He serves on the IUSSP Scientific Panel on Innovations for Strengthening CRVS Systems and the editorial board of the journal *Conflict and Health*.

**Suneeta Singh** is a medical doctor with postgraduate qualifications in paediatrics and public health from the Lady Hardinge Medical College, Delhi. In more than 30 years of experience in the global health sector, she has worked as an academic, and in bilateral and multi-lateral funding organizations. She founded the Delhi-based Amaltas Consulting Pvt. Ltd., a research and consulting organization devoted to developing intellectual capital to accelerate improvements in the lives of people. The organization's work on over 55 projects in the past ten years has helped bring about programmatic and policy changes in low- and middle-income countries.

**Amani Siyam** has postgraduate training in medical statistics and demography and several years of experience in the design, implementation, and evaluation of population and health development programmes. She is a technical officer at the Information, Evidence and Research Department at the World Health Organization. Her work focusses on improving health data measurement and metrics for national planning, monitoring and evaluation, and the attainment of the health-related SDGs. She contributes to the development of normative guidance in strengthening health workforce strategic information to support countries institute evidence-based human resources for health policy and planning.

**Gretchen Stevens** is an epidemiologist in the Department of Information, Evidence and Research at the World Health Organization in Geneva. She led the development of the Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER), which define and promote best practices in reporting health estimates. She has carried out global analyses of the prevalence of overweight and obesity, hearing and vision impairment, infertility, child growth, and anaemia and has published comparative analyses of mortality data.

**Viroj Tangcharoensathien** qualified in medicine from Mahidol University, Thailand, and in health planning and financing from the London School of Hygiene and Tropical Medicine. He is an advisor on Global Health to Ministry of Public Health and is the secretary general of Thailand's International Health Policy Program Foundation which he co-founded in 1998. He was awarded the Edwin Chadwick Medal in 2011 for his contributions to improve health systems in the interests of the poor. From 2011 to 2015, he was the director of the IHPP Research Hub. He is the co-lead of the University of Tokyo-IHPP research hub for the Asia Pacific Observatory. He chaired the negotiations of the WHO Global Code of Practice on the International Recruitment of Health Personnel.

**Myriam Telford** holds a masters in international development from the University of Bath, UK. She has carried out research looking at the use of qualitative methods in NGO evaluations, considering the gap between aspirations and reality in the delivery of evaluations. From 2015 to 2016, she was program lead at Amrit Foundation of India, an NGO that uses research and advocacy to promote the wellbeing of children with intellectual challenges. In this role, she organized a mixed methods study looking at the barriers that children with challenges in New Delhi face when trying to access services for health, education, and wellbeing.

**James Thomas** is Associate Professor of Epidemiology at the Gillings School of Global Public Health, University of North Carolina and director of MEASURE Evaluation at Carolina Population Center, at the University of North Carolina. MEASURE Evaluation is USAID's flagship project for strengthening health information systems in low- and middle-income countries. Thomas' areas of expertise include social epidemiology, network analysis, public health ethics, and digital health data ethics. He was the principal author of the Public Health Code of Ethics, and served as an ethics advisor to the director of the Centers for Disease Control and Prevention.

**Madeleine Thomson** trained as a medical entomologist and is a senior research scientist at the International Research Institute for Climate and Society, Earth Institute, Columbia University, New York. She leads the health work at the IRI as the director of the IRI-WHO Collaborating Center (US-406) for Early Warning Systems for Malaria and Other Climate-Sensitive Diseases. She is a senior research scholar in Department of Environmental Health Sciences at the Mailman School of Public Health, Columbia University and a visiting professor at the Medical School, Lancaster University, UK. She has over 30 years of experience in operational health research in Africa with a focus on use of climate information by health sector decision-makers.

**Kumnuan Ungchusak** gained academic qualifications from Siriraj Medical School and Mahidol University, Thailand. He is a member of the board of the Thai Health Promotion Foundation and oversees prevention and control programmes related to

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non-communicable diseases, tobacco, alcohol, drug abuse, and traffic injuries. Previously, he served as the director of Thailand Field Epidemiology Training Program and became the director of Bureau of Epidemiology from 2001 to 2008, where he was involved in the establishment of the Surveillance Rapid Response Team.

**James (Jimmy) Volmink** has academic qualifications from the universities of Cape Town, Harvard, and Oxford. He is Professor of Clinical Epidemiology and Dean of the Faculty of Medicine and Health Sciences at Stellenbosch University, South Africa. He was the founding director of Cochrane South Africa and director of research and analysis of the Global Health Council in Washington DC. His interests include evaluating the effects of health-care interventions, promoting evidence-based decisionmaking, addressing health inequalities, and fostering research capacity building. He is an elected member of the Academy of Science of South Africa and an elected fellow of the Royal College of Physicians of Edinburgh.

**Suwit Wibulpolprasert** is a general practitioner, public health specialist, administrator, and policy advocate. From 1977 to 1985, he was a director/practitioner in four rural district hospitals in Thailand. He has served as director of the North Eastern Public Health College, director of Technical Division of the FDA, director of the Bureau of Health Policy and Planning, deputy permanent secretary and senior advisor at the Thai Ministry of Public Health. He is the vice chair of the IHPP Foundation and the Health Intervention and Technology Assessment Foundation, and senior advisor on global health to the Ministry of Public Health. He is a member of the National Health Security Board, Health Systems Research Institute Board, and the National Research and Innovation Policy Council.

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