Oxford Textbook of Global Public Health

The Methods of Public Health

SEVENTH EDITION
VOLUME 2

EDITED BY
Roger Detels
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Preface to Volume 2: *The methods of public health*

Volume 2 of the seventh edition of the *Oxford Textbook of Public Health* presents the methods which bring scientific rigour to the public health endeavour. With a firm and broad grounding in the methods of public health, students and practitioners will ensure that their research and practice is based on robust evidence a critically important consideration in informing decision-making. The methodology utilized is a key for assuring the strength and validity of evidence for decision-making. Randomized controlled trials, systematic reviews, meta-analyses, and economic evaluations are accepted methods for providing clinical evidence but there are difficulties in applying these in a public health context where there are large target populations and long timescales for the emergence of outcomes. While evidence emanating from the application of these techniques has become more common to inform public health decision-making, there is increasing appreciation of the complexity of public health interventions and the need to use a range of disciplinary approaches to develop and evaluate these.

The range and complexity of health problems facing populations is also increasing, and public health methodologies must evolve and expand to meet this challenge and ensure effective responses. With globalization of emerging and re-emerging infections, and demographic, nutrition, and physical activity transitions, the methods of public health must be adapted to meet the new challenges. Since the sixth edition, the effects of globalization on health including the increasing importance of global environmental changes and notably climate change, have burgeoned. These new challenges are more difficult to study than the traditional concerns of infectious and non-infectious diseases and local environmental issues. The adaptation of old methods and the development of new ones are key to ensure the continued relevance and robustness of public health research. Public health practitioners have always had to face the dilemma of balancing delays in action emanating from concern for methodological rigour with the need to act expeditiously. This dilemma is becoming increasingly complex and challenging as some of the new and emerging public health challenges are less amenable to traditional public health approaches and in some instances, are associated with ethical considerations that add to the complexity of the issue.

All the chapters in Volume 2 have been extensively revised and updated, and several new chapters added. This volume is organized into four sections: information systems and sources of intelligence; epidemiological and biostatistical approaches; social science techniques and environmental and occupational health sciences. Information systems are the foundation of all public health research and action. The lack of good information is still a barrier to effective action in much of the world. Basic information on births and deaths is not routinely available for most low-income and many middle-income countries. This gap remains a major impediment to tracking progress towards the Sustainable Development Goals. Fortunately, a concerted effort is now being made to close the gap, especially for maternal and child statistics with the support of several philanthropic foundations. Three chapters in this section (Chapters 4.1–4.3) examine the contrasting challenges facing information systems in both high-income and low- and middle-income countries. Chapter 4.2 by Zunyou Wu and Jennifer McGoogan captures the substantial advances being made in information systems and community diagnosis in low- and middle-income countries. Chapter 4.3 by Patrick Sullivan provides an insightful and contemporary overview of the impact of, and rapidly evolving new communication streams on public health.

Epidemiology and biostatistics are the core sciences of public health. Public health practice requires a firm connection to the priority health needs of populations. Epidemiological research is almost always required to establish this connection, and exceptions are few; some major acute outbreaks or overwhelming catastrophes do not allow for serious epidemiological investigation before the response is required. However, epidemiological study is still needed to assess the scope of the problem and the effectiveness of the response. Public health methods to ensure the appropriateness of inferences (Chapter 5.13) drawn from public health investigations—perhaps the most difficult and certainly the most contentious aspect of public health science—continue to evolve. This process often requires a systematic approach to ensuring that all data from all studies—published and unpublished—are synthesized into a useable summary assessment (Chapter 5.14). A critical and expanding methodological area deals with interventions and their effectiveness at a community level by Kathy Baisley et al. (Chapter 5.8). Technological advances—computers and the internet—are changing the scope of public health and opening new possibilities, from data collection and analysis for the early identification of disease outbreaks to the use of modelling of disease transmission to predict the future trends and needs (Chapters 5.3 and 5.17). The methods and special issues facing clinical epidemiology are discussed in Chapter 5.10. The final chapter in this section stresses the essential importance of surveillance to monitor public health problems and the effectiveness of intervention

programmes (Chapter 5.18). A new chapter in this section on qualitative research (Chapter 5.6) by Jennie Popay and Fran Baum covers both methodological approach and underscores the importance of understanding the voices of potential beneficiaries and Indigenous knowledge systems in the knowledge generation process.

Increasingly a more systems-based approach is being utilized to understand disease and risk. Rona Campbell provides an excellent update on new developments in the implementation of multicomponent interventions (Chapter 6.5). The completion of the human genome project is increasingly being translated to novel approaches to diseases including the use of gene therapy and leading to precision public health approaches. Of note are two new contemporary chapters in this section: Lifecourse epidemiology and analysis (Elizabeth Rose Mayeda) and Natural and quasi-experiments by Peter Craig (Chapter 5.10). The methodologies for measuring burden of disease Chapter 5.17 are particularly important as the implementation of these new methodologies is being used to provide the basis for both global and local rationing of resources and priority setting.

Social science techniques are assuming even greater importance to the practice of public health with the recognition that epidemiological information alone is not sufficient for the development and implementation of effective public health policies and programmes (Chapter 6.1). Demography is another underappreciated basic science of public health; the ageing of all populations, especially in low- and middle-income countries, will be a critical public health issue for the economic survival of these countries in the twenty-first century (Chapter 6.3). Health economics and the use of cost-effectiveness analysis (Chapter 6.6) have expanded the audience for public health research to sectors outside health, especially the finance and development sectors, nationally and globally. Health promotion expands the focus of public health from a primary concern with disease prevention and control towards an understanding of the underlying determinants of health (Chapter 6.4). These and other social science tools, including management of the health programmes (Chapter 6.8), are key for the development and implementation of effective public health policy in all countries eloquently and comprehensively covered by Wafaa el Sadr and colleagues in a new chapter on Implementation Science and translational public health (Chapter 6.9). The HIV pandemic has brought renewed interest and focus on sexuality and health that Parker et al. cover eloquently in Chapter 6.2. A novel and increasingly used approach to programme and treatment adherence is incentivizing and supporting desired behaviours which is captured in the chapter on Behavioural Economics and Health (Chapter 6.7) by Harsha Thirumurthy et al.

Environmental and occupational health sciences cover traditional public health issues, as well as the even more difficult global health challenges that are discussed in Volume 1. This section deals with both traditional and emerging environmental and occupational health hazards, many of which have been exacerbated by globalization. (Chapters 7.1–7.3). The increasingly important issues of risk assessment and management, and risk perception and communication are covered in Chapters 7.4 and 7.5. The chapter on urbanization and health by Jason Coburn highlights how increasing urbanization is impacting public health.

The importance of methodological advances in public health is illustrated by the way in which many chapters in other volumes of this Textbook consider methodological issues in considerable detail—for example, the chapters on measuring the global burden of diseases and responding to global environmental challenges. The chapters in this section illustrate the evolution and breadth of public health methods as its scope continues to expand. No doubt, this process will continue well into the future and remains a good marker of the growth and evolution of the public health sciences as sound and rigorous strategies to address emerging and ongoing public health challenges.

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Abbreviations

AAAQ	availability, accessibility, acceptability, quality
ABI	ankle brachial index
ACA	Affordable Care Act
ACASI	audio-computer assisted self-interviewing
ACCORD	Action to Control Cardiovascular Risk in Diabetes
ACF	active case finding
ACGIH	American Conference of Governmental Industrial Hygienists
ACHPR	African Commission on Human and Peoples' Rights
ACLED	Armed Conflict Location and Event Data
ACT	artemisinin-based combination therapy
ACTG	AIDS Clinical Trials Group
AD	Alzheimer's disease
ADA	American Diabetes Association
ADAPT	Alzheimer's disease anti-inflammatory prevention trial
AED	antiepileptic drug
AF	attributable fraction
AFRINEST	African Neonatal Sepsis Trial
AGVP	African Genome Variation Project
AHA	American Heart Association
AHRQ	Agency for Healthcare Research and Quality
AI	artificial intelligence
AIDS	acquired immunodeficiency syndrome
AIIR	airborne infection isolation room
ALL	acute lymphoblastic leukaemia
ALSPAC	Avon Longitudinal Study of Parents and Children
AMD	advanced molecular detection
AMI	acute myocardial infarction
AMR	antimicrobial resistance
ANISA	Aetiology of Neonatal Infection in South Asia
ANOVA	analysis of variance
ANUG	acute necrotizing ulcerative gingivitis
APHA	American Public Health Association
ARA	American Relief Administration
ARDS	acute respiratory distress syndrome
ARI	acute respiratory infections
ARIC	Atherosclerosis Risk in Communities
ART	antiretroviral therapy
ART	atraumatic restorative treatment
ASD	autism spectrum disorder
ASEAN	Association of Southeast Asian Nations
ASFR	age-specific fertility rate
ASH	Action on Smoking and Health
ASMR	age-specific mortality rate
ATS	amphetamine-type stimulants
ATSDR	Agency for Toxic Substances and Disease Registry
BACH	Boston Area Community Health
BAL	British anti-Lewisite
BEI	Biological Exposure Index
BFP	Bolsa Familia Programme
BMGF	Bill & Melinda Gates Foundation
BMI	body mass index
BMT	buprenorphine maintenance therapy
BNP	brain naturietic peptide
BOD	Burden of Disease
BRFSS	Behavioural Risk Factor Surveillance System
BSE	bovine spongiform encephalopathy
BV	bacterial vaginosis
CABG	coronary artery bypass grafting
CAD	coronary artery disease
CBA	cost-benefit analysis
CBF	cerebral blood flow
CBR	community-based rehabilitation
CBR	cost-benefit ratio
CBS	community-based surveillance
CBT	cognitive behavioural therapy
CCA	cost-consequences analysis
CCM	community case management
CCT	conditional cash transfer
CDC	Centres for Disease Control
CDCP	Centers for Disease Control and Prevention
CDSR	Cochrane Database of Systematic Reviews
CEA	cost-effectiveness analysis
CEAC	cost-effectiveness acceptability curve
CEDAW	Committee on the Elimination of Discrimination Against Women
CER	cost-effectiveness ratio
CETP	cholesterol ester transferase protein
CFIR	Consolidated Framework for Implementation Research
CHD	coronary heart disease
CHEW	Checklist of Health Promotion Environments at Worksites
CHF	congestive heart failure
CHNA	Community Health Needs Assessments
CHP	Centre for Health Protection
CHS	Cardiovascular Health Study
CHW	community health workers
CI	confidence interval

CIDARS	China Infectious Disease Automated-alert and Response System
CIHR	Canadian Institutes of Health Research
CIMT	carotid intima medial thickness
CIOMS	Council for International Organizations of Medical Sciences
CLTS	community-led total sanitation
CM	contingency management
CMA	cost-minimization analysis
CMO	context-mechanism-outcome
COMEST	Commission on the Ethics of Scientific Knowledge and Technology
CONSORT	Consolidation of Standards for Reporting of Trials
COP	Conference of the Parties
COPD	chronic obstructive pulmonary disease
CORTIS	Correlate of Risk Targeted Intervention Study
CPAP	continuous positive airway pressure
CPE	carbapenemase-producing Enterobacteriaceae
CPG	clinical practice guidelines
CQG	cost per QALY gained
CRC	Convention on the Rights of the Child
CRE	carbapenem-resistant Enterobacteriaceae
CRE	Centre of Research Excellence
CRED	Centre for Research on the Epidemiology of Disasters
CRFA	common risk factor approach
CRIMS	Comprehensive Response Information Management System
CRISPR	clustered regularly interspaced short palindromic repeats
CRM	cross-reacting material
CROI	Conference on Retroviruses and Opportunistic Infections
CRS	congenital rubella syndrome
CRT	cluster randomized trials
CSD	community socioeconomic deprivation
CSDH	Commission for the Social Determinants of Health
CT	computed tomography
CTC	Communities that Care
CTE	chronic traumatic encephalopathy
CTS	carpal tunnel syndrome
CUA	cost-utility analysis
CVD	cardiovascular disease
DACA	Deferred Action on Childhood Arrivals
DAG	directed acyclic graphs
DAH	development assistance for health
DALE	disability-adjusted life expectancy
DALY	disability-adjusted life year
DASH	Dietary Approaches to Stop Hypertension
DBM	double burden of malnutrition
DCEA	distributional cost-effectiveness analysis
DDD	digital disease detection
DDD	Doing Development Differently
DDT	dichloro-diphenyl-trichloroethane
DHF	dengue haemorrhagic fever
DHS	Demographic and Health Survey
DiD	difference in differences
DLB	dementia with Lewy bodies
DMD	Duchenne muscular dystrophy
DOTS	directly observed treatment short
DR	drug-resistant
DRIP	Declaration on the Rights of Indigenous Peoples
DSA	demographic surveillance area
DSS	dengue shock syndrome
DTA	Declaration of Territorial Asylum
DTA	diagnostic test accuracy
DTP	diphtheria-tetanus-pertussis
EA	economic appraisal
EAE	experimental autoimmune encephalomyelitis
EASD	European Association for the Study of Diabetes
EBM	evidence-based medicine
ECDC	European Centre for Disease Prevention and Control
ECEA	extended cost-effectiveness analysis
ECHA	European Chemicals Agency
ECRHS	European Community Respiratory Health Survey
ED	erectile dysfunction
EF	error factor
EGAPP	Evaluation of Genomic Applications in Practice and Prevention
EHR	electronic health record
EIU	Economist Intelligence Unit
ELISA	enzyme linked immunosorbent assay
EMR	electronic medical records
EMRO	Eastern Mediterranean Regional Office
ENOC	essential obstetric and newborn care
EOS	early onset sepsis
EPA	European Psychiatric Association
EPHF	essential public health functions
EPI	Expanded Programme on Immunization
EPIET	European Programme for Intervention Epidemiology Training
EPOC	effective practice and organization of care
EPODE	Ensemble Prévenons l'Obésité Des Enfants
EPPI	Evidence for Practice and Policy Information
ERC	Emergency Risk Communication
ERM	emergency risk management
ERS	Economic Research Service
EU	European Union
EVD	Ebola virus disease
EWAS	epigenome-wide association studies
FAO	Food and Agriculture Organization
FAP	Food Acquisition Programme
FCA	Framework Convention Alliance
FCAC	Framework Convention on Alcohol Control
FDA	Food and Drug Administration
FDC	fixed-dose combination
FELTP	Field Epidemiology and Laboratory Training Programme
FETP	Field Epidemiology Training Programme
FH	familial hypercholesterolemia
FPG	fasting plasma glucose
FRR	familial relative risk
FVC	forced vital capacity
GA	General Assembly
GAM	generalized additive regression models

GAPPD	Global Action Plan for Pneumonia and Diarrhoea
GAR	Global Alert and Response
GATS	Global Adult Tobacco Survey
GATT	General Agreement on Tariffs and Trade
GAVI	Global Alliance for Vaccines and Immunization
GBD	Global Burden of Disease
GBS	Group B streptococcus
GBV	gender-based violence
GCM	global coordination mechanism
GCS	Glasgow Coma Scale
GDP	gross domestic product
GDPR	General Data Protection Regulation
GEE	generalized estimating equations
GETT	Genetic Testing Evidence Tracking Tool
GHO	Global Health Observatory
GHPSS	Global Health Professions Student Survey
GI	GINI Index
GIS	geographic information systems
GIV	generic inverse variance
GLASS	Global Antimicrobial Resistance Surveillance System
GM	genetically modified
GMF	global monitoring framework
GNP	gross national product
GOARN	Global Outbreak Alert and Response Network
GP	General Practitioners
GPHIN	Global Public Health Intelligence Network
GPP	Good Participatory Practice
GPS	Global Positioning System
GRADE	Grading of Recommendations Assessment, Development, and Evaluation
GRID	gay-related immune deficiency
GRR	gross reproduction rate
GSPS	Global School Personnel Survey
GST	glutathione S-transferase
GTR	Genetic Testing Registry
GTSS	Global Tobacco Surveillance System
GVAP	Global Vaccine Action Plan
GWAS	genome-wide association study
GYTS	Global Youth Tobacco Survey
HAART	highly active antiretroviral therapy
HAC	Humanitarian Action for Children
HAT	Human African trypanosomiasis
HAV	hepatitis A virus
HBOC	Hereditary Breast and Ovarian Cancer
HBSC	Health Behaviour in School-aged Children
HBV	hepatitis B virus
HCQI	Health Care Quality Indicator
HCV	hepatitis C virus
HCW	healthcare workers
HDI	Human Development Index
HDL	high-density lipoprotein
HDT	host-directed therapies
HIA	health impact assessment
HiAP	Health in All Policies
HibCV	Hib polysaccharide-protein conjugate vaccine
HIC	high-income countries
HICPAC	Hospital Infection Control Practices Advisory Committee
HIS	health information systems
HITECH	Health Information Technology for Economic and Clinical Health
HIV	human immunodeficiency virus
HLA	HLA allele
HMN	Health Metrics Network
HPS	hantavirus pulmonary syndrome
HPTN	HIV Prevention Trial Network
HPV	human papilloma virus
HRDAG	Human Rights Data Analysis Group
HRQOL	health-related quality of life
HSE	Health and Safety Executive
HTA	health technology assessment
HUS	Haemolytic uraemic syndrome
HWE	healthy worker effect
HWTS	household water treatment and safe storage
IACHR	Inter-American Commission on Human Rights
IACtHR	Inter-American Court of Human Rights
IARC	International Agency for Research on Cancer
IASC	Inter-Agency Standing Committee
IASFM	International Association for the Study of Forced Migration
IAVI	International AIDS Vaccine Initiative
ICC	International Criminal Court
ICC	intracluster correlation coefficient
ICCPR	International Covenant on Civil and Political Rights
ICD	International Classification of Diseases
ICESCR	International Covenant on Economic, Social and Cultural Rights
ICHD	International Classification of Headache Disorders
ICRC	International Committee of the Red Cross
ICT	information and communication technologies
IDF	International Diabetes Federation
IDM	intensified disease management
IDMC	Internal Displacement Monitoring Centre
IDP	internally displaced persons
IDS	integrated diseases surveillance
IDU	injection drug use
IFG	impaired fasting glucose
IFRC	International Federation of Red Cross
IGRA	Interferon-gamma release assays
IGT	impaired glucose tolerance
IHD	ischaemic heart diseases
IHME	Institute for Health Metrics and Evaluation
IHR	International Health Regulations
ILAE	International League Against Epilepsy
ILI	influenza-like illness
ILO	International Labour Organization
IMC	International Medical Corps
IMF	International Monetary Fund
IMMANA	Innovative Methods and Metrics for Agriculture and Nutrition Actions
IMNCI	integrated management of neonatal and childhood illness
IMR	infant mortality rates

INCLEN	International Clinical Epidemiology Network
IOF	Implementation Outcomes Framework
IOM	Institute of Medicine
IPAQ	International Physical Activity Questionnaire
IPCW	inverse probability of censoring weighted
IPD	invasive pneumococcal disease
IPEC	International Programme on the Elimination of Child
IPT	intermittent preventive treatment
IPT	isoniazid preventive therapy
IPV	inactivated polio vaccine
IPV	intimate partner violence
IRB	institutional review boards
IRS	indoor residual spraying
ISAAC	International Study of Asthma and Allergies in Childhood
ITC	International Tobacco Control
ITS	interrupted time series
ITU	International Telecommunication Union
JE	Japanese encephalitis
JEE	joint external evaluation
JEV	Japanese encephalitis virus
JSNA	Joint Strategic Needs Assessment
KCR	Kosova Cancer Registry
KPI	key performance indicator
LASI	Longitudinal Study of Aging in India
LAV	lymphadenopathy-associated virus
LBP	low back pain
LBW	low birth weight
LDL	low-density lipoprotein
LGBT	lesbian, gay, bisexual, and transgender
LGBTI	lesbian, gay, bisexual, transgender, and intersex
LIC	low-income countries
LMIC	low and middle-income countries
LOS	late onset sepsis
LRI	lower respiratory infections
MACS	Multicenter AIDS Cohort Study
MAI	Multilateral Agreement on Investment
MAM	moderate acute malnutrition
MAPT	microtubule-associated protein tau
MAT	medication-assisted treatment
MAV	Municipal Association of Victoria
MCAD	medium chain acyl CoA dehydrogenase
MCI	mild cognitive impairment
MCS	Millennium Cohort Study
MCU	maternal and child undernutrition
MDD	major depressive disorder
MDG	Millennium Development Goals
MDS	Model Disability Survey
MENA	Middle East and Northern Africa
MERS	Middle East respiratory syndrome
MET	metabolic equivalents of task
MI	motivational interviewing
MI	myocardial infarction
MIGS	Mediterranean Institute of Gender Studies
MIHL	minimum income for healthy living
MkV	MEMA kwa Vijana
MMA	methylated into monomethylarsonic acid
MMR	maternal mortality ratio
MMR	measles, mumps, and rubella
MMT	methadone maintenance therapy
MMT	methadone maintenance treatment
MMV	Medicines for Malaria Venture
MMWR	Morbidity and Mortality Weekly Report
MNS	mental, neurological, and substance
MOH	Ministry of Health
MOST	multiphase optimization strategy implementation trial
MOUD	medications for opioid use disorder
MPI	multidimensional poverty index
MRI	magnetic resonance imaging
MRSA	methicillin-resistant Staphylococcus aureus
MS	multiple sclerosis
MSA	multiple system atrophy
MSF	Médecins Sans Frontières
MSI	Management Systems International
MSM	men who have sex with men
MSUD	maple syrup urine disease
MTBE	methyl tert-butyl ether
MTCT	mother-to-child transmission
MTO	Moving to Opportunity
MUAC	mid-upper-arm circumference
MUSP	Mater University of Queensland Study of Pregnancy
MVPA	moderate-to-vigorous intensity physical activity
NAAT	Nucleic acid amplification tests
NAFTA	North American Free Trade Agreement
NAT	nucleic acid-based testing
NBER	National Bureau of Economic Research
NCBI	National Center for Biotechnology Information
NCD	non-communicable disease
NCEP	National Cholesterol Education Program
NCSEM	National Centre for Sports and Exercise Medicine
NDIS	National Disability Insurance Scheme
NDNS	National Diet and Nutrition Survey
NEP	needle-exchange programmes
NERC	National Ebola Response Committee
NFI	non-food item
NGO	non-government organization
NGS	Next-generation whole-genome sequencing
NHANES	National Health and Nutrition Examination Survey
NHS	National Health Service
NHSP	National Healthy Schools Programme
NIH	National Institutes of Health
NIHL	noise-induced hearing loss
NIOSH	National Institute for Occupational Safety and Health
NIPT	non-invasive prenatal testing
NK	natural killer
NMA	network meta-analysis
NMSC	non-melanoma skin cancer
NNRTI	non-nucleoside RT inhibitor
NOS	Newcastle-Ottawa Scale
NP	neck pain
NPS	new psychoactive substances
NPV	negative predictive value

NRR	net reproduction rate
NRT	nicotine replacement therapy
NRTI	nucleoside reverse transcriptase inhibitor
NSCH	National Survey of Children's Health
NSP	needle and syringe programmes
NTD	neglected tropical diseases
NZHTA	New Zealand Health Technology Assessment
OAS	Organization of American States
OAU	Organization of African Unity
OCHA	Office for Coordination of Humanitarian Affairs
ODA	official development assistance
ODF	open defecation-free
OECD	Organisation for Economic Cooperation and Development
OGTT	oral glucose tolerance test
OHCHR	Office of the High Commissioner for Human Rights
OHS	occupational health and safety
OIHP	Office International d'Hygiène Publique
OOP	out-of-pocket
OPV	oral polio vaccine
OR	odds ratio
ORS	oral rehydration salts
ORS	oral rehydration solution
ORT	oral rehydration therapy
OSD	occupational skin diseases
OSHA	Occupational Safety and Health Administration
OST	opioid substitution therapy
OTI	Office of Transition Initiatives
P&I	pneumonia and influenza
PACES	Prevent Anxiety in Children through Education in Schools
PACK	Practical Approach to Care Kit
PAF	population attributable fraction
PAHO	Pan American Health Organization
PATH	Programme for Appropriate Technologies in Health
PCA	principal components analysis
PCI	percutaneous coronary interventions
PCP	pneumocystis carinii pneumonia
PCR	polymerase chain reaction
PCT	preventive chemotherapy and transmission
PCV	pneumococcal conjugate vaccine
PCV	protein conjugate vaccine
PCV	protein-conjugated polysaccharide vaccines
PDNA	post-disaster needs assessments
PEPFAR	President's Emergency Plan for AIDS Relief
PF	prevented fraction
PHAC	Public Health Agency of Canada
PHCA	primary oral healthcare approach
PHE	Public Health England
PHEIC	Public Health Emergency of International Concern
PHM	People's Health Movement
PHN	public health nutrition
PHR	public health research
PI	protease inhibitor
PIVOT	Prostate Cancer Intervention Versus Observation Trial
PM	particulate matter
PMI	President's Malaria Initiative
PMTCT	prevention of mother-to-child transmission
POC	Point-of-care
POR	prevalence odds ratios
PPE	personal protective equipment
PPROM	Preterm premature rupture of membranes
PPV	pneumococcal polysaccharide vaccines
PPV	positive predictive value
PreP	pre-exposure prophylaxis
PRIO	Peace Research Institute in Oslo
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
ProMED	Programme for Monitoring Emerging Diseases
PSA	prostate-specific antigen
PSBI	possible serious bacterial infections
PSHE	personal, social, and health education
PTSD	post-traumatic stress disorder
PURE	Prospective Urban Rural Epidemiology
PVP	predictive value positive
PWID	people who inject drugs
PYD	positive youth development
QALY	quality-adjusted life year
QIF	Quality Implementation Framework
QUAC	Quaker Upper Arm Circumference
QUADAS	Quality Assessment of Diagnostic Accuracy Studies
R&D	research and development
RA	rheumatoid arthritis
RCS	respirable crystalline silica
RCT	randomized controlled trial
RCV	rubella-containing vaccines
RD	regression discontinuity
RDD	random digit dialling
REACH	Registration, Evaluation, Authorisation, and Restriction of Chemicals
REACT	Randomised Evaluations of Accepted Choices in Treatment
REP	Rochester Epidemiology Project
RHIS	routine health information system
ROC	receiver operator characteristic
ROI	return on investment
RP	restorative practice
RPA	rapid participatory appraisal
RR	rate ratio
RR	relative risk
RSV	respiratory syncytial virus
RT	reverse transcriptase
RTW	return to work
RVF	Rift Valley fever
SAHNA	South Asian Health Needs Assessment
SAM	severe acute malnutrition
SAR	structure activity relationship
SARI	severe acute respiratory infection
SCC	squamous cell carcinoma
SCD	sickle cell disease
SCIH	Swiss Centre for International Health
SD	standard deviation
SDC	Swiss Agency for Development and Cooperation

SDG	sustainable development goal
SDH	social determinants of health
SDIL	Soft Drinks Industry levy
SDOH	social determinants of health
SE	standard error
SES	socioeconomic status
SEYLE	Saving and Empowering Young Lives in Europe
SF	spotted fever
SG	standard gamble
SHS	second-hand smoke
SIS	Statistical Information System
SIV	simian immunodeficiency virus
SMA	spinal muscle atrophy
SMART	Sequential multiple assignment randomized implementation trial
SMD	standardized mean difference
SMR	standardized mortality ratio
SNP	single nucleotide polymorphism
SPRINT	Systolic Blood Pressure Intervention Trial
SRH	sexual and reproductive health
SRNT	Society for Research on Nicotine and Tobacco
SSB	sugar-sweetened beverage
STEM	science, technology, engineering, and mathematics
STH	soil-transmitted helminth
STI	sexually transmitted infections
SUD	substance use disorders
SUDEP	sudden unexplained death in people with epilepsy
SUDI	sudden unexpected death in infancy
SUN	scaling up nutrition
TALENS	transcription activator-like effector nucleases
TasP	Treatment as Prevention
TBA	traditional birth attendant
TBI	traumatic brain injury
TCV	typhoid conjugate vaccine
TDF	tenofovir disoproxil fumarate
TDF	Theoretical Domains Framework
TEDS	Treatment Episode Data Set
TFR	total fertility rate
THS	third-hand smoke
TIA	transient ischaemic attack
TIPS	Treatment and Identification of Psychosis Study
TLV	threshold limit values
TNT	Treat to New Targets
TPFR	total period fertility rate
TST	Tuberculin skin test
TTCV	tetanus-toxoid-containing vaccines
TTO	time trade-off
TTP	trusted third party
TTS	temporary threshold shift
UAV	unmanned aerial vehicles
UDHR	Universal Declaration of Human Rights
UHC	universal health coverage
UIS	UNESCO Institute for Statistics
UK	United Kingdom
UKPDS	United Kingdom Prospective Diabetes Study
UMV	unmanned maritime vehicles
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNGA	UN General Assembly
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
UNISDR	United Nations International Strategy for Disaster Reduction
UNMEER	UN Mission for Ebola Emergency Response
UNOCHA	United Nations Office for Coordination of Humanitarian Affairs
UNODC	United Nations Office on Drugs and Crime
UR	uncertainty range
US	United States
USAID	United States Agency for International Development
USCRI	US Committee for Refugees and Immigrants
USD	United States dollars
USDA	US Department of Agriculture
VA	verbal autopsy
VADT	Veterans Affairs Diabetes Trial
VAS	visual analogue scales
VAW	violence against women
VFD	Veterinary Feed Directive
VGDF	vapours, gases, dusts, and fumes
VIP	ventilated improved pit
VLGA	Victorian Local Governance Association
VR	vital registry
VZV	varicella zoster virus
WEA	work-exacerbated asthma
WFP	World Food Programme
WFS	World Fertility Survey
WGS	whole genome sequencing
WHA	World Health Assembly
WHAS	Worcester Heart Attack Study
WHO	World Health Organization
WRA	work-related asthma
WRMSD	work-related musculoskeletal disorders
WRSD	work-related skin diseases
WSP	Water and Sanitation Programme
WTCCC	Wellcome Trust Case Control Consortium
WTO	World Trade Organization
YLD	years lived with disability
YPLL	years of productive life lost
YSP	Youth Smoking Prevention
ZFN	zinc fingers nucleases

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SECTION 4

Information systems and sources of intelligence

4.1

Information systems in support of public health in high-income countries

Tjeerd-Pieter van Staa and Liam Smeeth

Introduction to information systems

Public health sciences have been described by a Wellcome Trust working group as follows: 'effective public health actions are based on scientifically derived information about factors influencing health and disease and about effective interventions to change behaviour at the level of the individual, the family, the community or wider society' (Public Health Sciences Working Group et al. 2004, p. 5). This field of science has made major contributions to the improvement of health such as the effects of sanitary reforms on infant mortality and, more recently, the reductions in cardiovascular disease incidence due to lipid lowering and blood pressure control. However, many challenges remain, such as how to tackle the increased prevalence of obesity and diabetes and how to relate the costs of interventions to their benefits (Public Health Sciences Working Group et al. 2004). This chapter will describe how information systems containing healthcare data can support public health research. We will first describe examples of public health information systems, followed by a description of various developments in these systems, including increased public health use of routinely collected electronic healthcare records (EHRs). More and more clinicians and healthcare professionals are using computers to store information: indeed the 'meaningful use' of electronic health records for patient care has recently been mandated in the United States (Blumenthal and Tavenner 2010). These data sources provide opportunities, among others, to test the effectiveness and impact of public health interventions. We discuss the role of randomization in public health research and conclude this chapter by highlighting the importance of an impact assessment of public health interventions.

Sources of public health information

Vital statistics

Death certificates are routinely collected in many countries in order to report on specific causes of death including, for example, alcohol-related deaths, suicides, and drug-related deaths, deaths involving methicillin-resistant *Staphylococcus aureus* (MRSA) and *Clostridium difficile*, and estimates of excess winter mortality. Trends in, for example, all-age all-cause mortality, deaths from cancer, circulatory diseases, suicide and injury of undetermined intent, and accidents are reviewed periodically as are the association of mortality rates with socioeconomic deprivation. Live and stillbirth figures are also routinely collected in many countries. The birth counts may be stratified by occurrence within or outside marriage, multiple births, mother's area of residence and country of birth, place of confinement, and father's social class (examples are given at http://www.statistics.gov.uk).

Population surveys

Population surveys are frequently used information resources. One example is the US National Health Interview Survey, which targets annually an interview with 40,000 households. Questions include health status and health services utilization and activity limitations due to ill health. The Behavioural Risk Surveillance System is a telephone survey in the US involving 150,000 people. Data are collected on health risks and behaviours, exercise, and diet. The National Health and Nutrition Examination Survey examines diet, nutrition, health behaviours, and risk factors in 5,000 randomly selected persons.

A population census provides information about the characteristics of the population and facilitates understanding of the similarities and differences in populations locally, regionally, and nationally. The results are then used to allocate public money for services including healthcare services. They are also used to identify areas with the greatest public health needs. As an example, national census data from the Strasbourg metropolitan area in eastern France were used to develop a small-area index of socioeconomic deprivation. It showed an association between increased rates of myocardial infarction and worse neighbourhood deprivation (Havard et al. 2008).

Disease surveillance

In many countries, there are systems for reporting and notification of cases of certain diseases to the public health authorities. Infectious diseases such as yellow fever and diphtheria are notifiable

on diagnosis of a suspected case and should not wait for laboratory confirmation. All notifiable cases are then reviewed and appropriate action may be taken. Analyses of local and national trends are typically published on a regular basis. Despite legal requirements to report certain infectious diseases, reporting rates for these conditions are not always optimal. To address this, for example, a New York public health institute facilitated public health reporting by creating alerts within EHRs to remind clinicians at the point of care that a particular diagnosis is reportable and providing a link to the reporting form. Patient demographics are automatically populated in the form (Calman et al. 2012).

Administrative databases

There are many administrative databases that contain information recorded for the purposes of managing the healthcare system. Several of these systems can be used for public health research. The Hospital Episode Statistics is a data warehouse containing details of all admissions to National Health Service hospitals in England. It contains clinical information about diagnoses and operations on individual patients, demographic information such as age, gender, and ethnicity, administrative information such as time waited and date of admission, and geographical information on where the patient was treated and the area in which they lived. Main procedures (such as surgical operations) are also recorded. It contains admitted patient care data from 1989 onwards, with more than 12 million new records added each year, and outpatient attendance data from 2003 onwards, with more than 40 million new records added each year (Health and Social Care Information System n.d.).

Registries

A registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure. There are many different types of registries. An example of a product registry is the UK national registry of patients on biological therapy: patients starting such therapy are registered and followed, for example, for long-term safety issues. Healthcare service registries include patient-based individual clinical encounters, such as office visits or hospitalizations, and procedures. Examples include registries enrolling patients undergoing a procedure (e.g. carotid endarterectomy, appendectomy, or primary coronary intervention) or admitted to a hospital for a particular diagnosis (e.g. community-acquired pneumonia). These registries may be used to evaluate the processes and outcomes of care for quality measurement purposes. Disease registries use the state of a particular disease or condition as the inclusion criterion. These registries typically enrol the patient at the time of diagnosis at a routine healthcare service. Examples include cancer registries which are widely used for research (Edwards and Bell 2000).

Immunization registries have been created in order to assemble in one site a record of all immunizations and to provide reminder and recall notices when an immunization is due or late. Vaccination schedules are becoming complex due to the number of different vaccinations a child should receive. These may be further complicated by frequent changes of healthcare provider or insurance company. Immunization registries can provide a central repository of all the vaccinations given to children (Linkins 2001).

Electronic health record databases

EHRs are increasingly being used for research and public health purposes. There are currently over 300 EHR databases in 45 countries (http://www.ispor.org/intl_databases). This section describes a few examples of EHR databases that have been widely used for research. The Clinical Practice Research Datalink, previously known as the General Practice Research Database, collates the anonymized EHR information for over 5 million patients currently registered at participating general practices. General Practitioners (GPs) play a key role in the UK healthcare system, as they are responsible for primary healthcare and specialist referrals. If a patient is treated in secondary care or by a specialist, the GP is informed about major clinical outcomes, and long-term treatments are frequently handed back to the GP. Almost all GPs in the UK use computers for maintaining health records, and communications between different health providers are increasingly sent electronically (Williams et al. 2012). The Dutch PHARMO Record Linkage System collects information on patient demographics, drug dispensing, hospital morbidity, clinical laboratory and pathology results, and GP information for more than 3 million community-dwelling inhabitants of 48 geographic areas in the Netherlands (Herings and Pedersen 2012). A recent development in the Netherlands is the Mondriaan project that has developed an IT and governance infrastructure for enrichment and linkage of EHR. Privacy enhancing technology such as linkage through a trusted third party (TTP) is applied and currently data from GPs (one million), community pharmacists (12 million), and various other EHR sources are retrieved for research purposes and as feedback information to healthcare providers (www.projectmondriaan.nl). In Denmark and Sweden, each national healthcare system provides universal coverage to all residents (5.5 million inhabitants in Denmark and 9.2 million inhabitants in Sweden). Healthcare coverage includes visits to GPs, specialists, hospital admissions, and outpatient visits; drug costs are either partially or completely covered. A centralized civil registration system has been in place in each country for many years, allowing for personal identification of each person in the entire population and for the possibility of linkage to all national registries containing civil registration numbers, for example, patient registry, cancer registry, prescription databases, and registry of causes of death (Furu et al. 2010). The Rochester Epidemiology Project medical records-linkage system captures healthcare information for the entire population of Olmsted County, Minnesota in the United States. It includes a dynamic cohort of over half a million patients who received healthcare for any reason. The data available electronically include demographic characteristics, medical diagnostic codes, surgical procedure codes, and death information (including causes of death). The system covers residents of all ages and both sexes, regardless of socioeconomic status, ethnicity, or insurance status (St Sauver et al. 2012).

Recent developments in information systems

The electronic information systems in the healthcare system are evolving and increasing (Table 4.1.1). Initial use of electronic healthcare data mostly consisted of aggregate analyses of administrative data such as hospital admission data. When clinicians started to use computers for record keeping, the first research databases

Table 4.1.1 Stages in the development of EHR databases

Time period (approximate)	Development of EHR databases
1980s onwards	Data collected for administrative purposes (such as hospital admission data and death certificates); mainly used for aggregate analyses
1990s onwards	Clinicians starting to use computers for record keeping (replacing paper records) and data collated into research database. These data initially mainly used for drug safety monitoring
2000s onwards	Monitoring of clinic encounters for symptoms that may represent infectious diseases and other conditions of public health concern
2000s onwards	Linkages between various EHR databases; mainly used to obtain complementary information or to validate outcomes
2010s onwards	Enrichment of routinely collected data by prospective data collection within EHR databases (e.g. collection of blood samples for genetic analyses or patient questionnaires)
2010s onwards	Development and implementation of triage tools to guide clinicians in hospital referral of patients with, e.g. influenza; electronic alerts for eligible patients or patients prescribed unsafe combinations of medications
2010s onwards	Introduction of randomization at the point of care using the EHR database to identify potentially eligible patients and for follow-up collection of major clinical outcomes (i.e. pragmatic and cluster trials); mainly used to evaluate the effects of medicines in routine clinical practice

collating anonymized EHRs were created. One of the first of these was the VAMP research database that started in 1987. This database eventually developed into the Clinical Practice Research Datalink. The richness and completeness of many EHR databases have been increasing over time as more information is being shared electronically between different parts of the healthcare system. Laboratory data provide an example in which test results are increasingly being communicated electronically and loaded automatically into the patient's EHR.

An important development is the increased linkage between different healthcare databases. Typically, linkages are done by a TTP that collects from each data source the patient's identifiers (such as registration number in the healthcare system, patient's date of birth, gender, and postcode), and research numbers. The TTP then matches the records of the various databases retaining the linked records with the various research numbers without any patient identifiers. This approach allows the combination of different healthcare databases. Linkages between different EHR datasets are being done more frequently, benefiting both the quality and completeness of the EHR data. The UK Clinical Practice Research Datalink has been linked individually and anonymously to other healthcare datasets, including the national registry of hospital admissions, the national death certificates (with primary and secondary cause of death), and prospective disease registries, such as the cancer and cardiovascular disease registries (Williams et al. 2012).

Comparisons of the information in linked EHR databases can highlight incomplete data records and inform efforts to improve data recording in the healthcare system. In a cohort study, primary care records were linked with those from cancer registries in the UK National Cancer Data Repository. Comparison of the two datasets showed a concordance rate of 83.3%, which varied by cancer type. Cancer registries recorded larger numbers of patients with lung, colorectal, and pancreatic cancers, whereas GPs recorded more haematological cancers and melanomas (Boggon et al. 2013).

Anonymized linkages between local air pollution data, records from primary care, hospital admissions, and death certificates have been used recently to evaluate the relationships between ambient outdoor air pollution and incident myocardial infarction, stroke, arrhythmia, and heart failure. While evidence was weak for relationships with myocardial infarction, stroke, or arrhythmia, consistent associations between pollutant concentrations and incident cases of heart failure were found (Atkinson et al. 2013).

An example of a public health resource that uses linked healthcare databases is the CALIBER programme. It is linking multiple data sources including the longitudinal primary care data from the Clinical Practice Research Datalink, the national disease registry of acute coronary syndrome, hospitalization, and procedure data from hospital admission records, cause-specific mortality from death certificates, and postcode-based social deprivation. Current cohort analyses involve a million people in initially healthy populations and disease registries (Denaxas et al. 2012). A recent study that used this resource was an analysis of the effect of influenza and influenza-like illnesses on triggering acute myocardial infarction (AMI). A self-controlled case series (i.e. only cases were evaluated) identified cases of myocardial infarction from the national registry of acute coronary syndromes and looked for associations with exposure to influenza from the consultation records of GPs. It found that influenza and other acute respiratory infections can act as a trigger for AMI (Warren-Gash et al. 2012).

The Massachusetts Department of Public Health in the United States has developed a system that loads EHRs every 24 hours from clinicians' proprietary software systems. These extracts are organized into separate databases for patient demographics, vital signs, diagnosis codes, test orders and results, medication prescriptions, allergies, social histories, and provider contact details. These data provide clinically detailed surveillance data. Sensitive and specific disease-detection algorithms have been developed to overcome the limited accuracy of code diagnostic data by considering all available data. Diabetes surveillance is done using these algorithms and can provide information on, for example, the frequency of referrals for medical nutrition counselling stratified by race and locality. A comparison of this system and conventional reporting by clinicians showed a significant increase in the quantity and quality of case reports of notifiable conditions (Klompas et al. 2012).

The minimization of risk of preventable harm to patients is a priority for many healthcare organizations. In Scotland, a system has been implemented in routine primary care that provides a rapid audit method of screening electronic patient records to detect

patient harm. The objective of this tool is to support clinical improvement efforts (De Wet and Bowie 2011).

The combination of routinely collected EHRs with prospectively collected data is an important development in improving the quality of information resources. A study in the Clinical Practice Research Datalink recruited about 8,000 persons aged 50–64 year for a survey about working life. Study participants completed questionnaires about their work and home circumstances and the EHRs will be used to analyse health outcomes over time. The inter-relationship between changes in employment (with reasons) and changes in health (e.g. major new illnesses, new treatments, mortality) will be examined. This study will contribute to the evidence base as to whether working beyond the traditional retirement age is feasible for those with major health problems associated with ageing and the effect of occupational and personal circumstances (e.g. savings, retirement intentions, domestic responsibilities, whether work is arduous or rewarding) (Palmer et al. 2015; D'Angelo et al. 2016).

Syndromic surveillance is the practice of monitoring clinic encounters for symptoms that may represent infectious diseases and other conditions of public health concern. There are several examples in which EHRs are used to conduct this surveillance. An example is QSurveillance which provides weekly information on the consultation rates of flu-like illness in general practices covering a total population of almost 22 million patients (QSurveillance n.d.). A comparable system has been developed in New York State, United States, in which routinely collected EHRs from health centres are transferred daily to the research database. Respiratory illness, fever, diarrhoea, and vomiting are the key symptoms monitored, with analysis to determine when the incidence of these syndromes exceeds expected thresholds (Calman et al. 2012).

The EHRs can also be used to guide clinicians in hospital referral of patients with influenza-like illness during a pandemic. During pandemics of novel influenza and outbreaks of emerging infections, surge in healthcare demand can exceed capacity to provide normal standards of care. In such exceptional circumstances, triage tools may aid decisions in identifying people who are most likely to benefit from higher levels of care. A recent study (called FLU-CATs) developed a system for real-time capture of symptoms in patients presenting in primary care with influenza-like illness. GPs were prompted by a pop-up box to provide symptoms when a diagnosis of influenza-like illness was entered into the EHR. The collected data can then be used to refine and update the triage tools for predicting hospital admission and measure clinical outcomes such as hospital admission or death and GPs' clinical assessments and management decisions. Such a system is also potentially adaptive, since with ongoing data collection, triage tools can be regularly adapted to changes in virus, human behaviour, and models of healthcare provision in the community (Venkatesan et al. 2015).

Pandemic preparedness is a major public health activity in many countries, including the United Kingdom. The major objectives of the UK strategy are, in case of an influenza pandemic: to identify key clinical, epidemiological, and virological features of the new influenza virus; to count severe cases, and identify risk groups affected, to describe the evolving pandemic and its impact at the population level (e.g. by age-group) particularly in relation to hospitalizations and mortality; and to measure the uptake and safety of various pharmaceutical countermeasures. Several information systems would be used to collect the data to be used for this, including primary care consultations, records of calls to telephone help-lines and web-based advisory services relating to influenza-like illness, virological 'sentinel' surveillance schemes in primary care, laboratory analysis of a sample of cases to identify the genetic features of the virus, and analysis of death records (Department of Health 2011).

Future developments in information systems

There is an increasing need to perform studies across different EHR systems and across different countries mainly because of the need for a larger sample size. The healthcare systems in most countries consist of multiple healthcare providers who often use different systems to store data, either on paper or electronically. Furthermore, physicians often record data differently and inconsistently, both on paper and electronically. Various international initiatives have used different approaches to combine heterogeneous EHR databases. One approach focuses on IT aspects with the aim to develop EHR systems that are interoperable and allow seamless transfer of data (http://www.transformproject.eu/; http://www.ehr4cr.eu/). All the information in the various databases is mapped together with a detailed understanding of the content of each of the data elements and use of a single coding dictionary across the different databases. An alternative approach is to maintain the EHR data structure as collected by the participating health professionals but to develop a common protocol across the different databases. The operational definitions of how the data are classified will vary by individual EHR database but the research questions will be kept similar. This model is currently used by the Innovative Medicines Initiative PROTECT project (http://www.imi-protect.eu/). The third approach is used by the OMOP initiative in the United States: all EHR data from the different databases are integrated into a central research database according to a common data model (http://omop.fnih.org/). A distributed network model where basic analyses are run on federated datasets generating common input data and subsequent local aggregation and central pooling of results, constitutes the fourth approach to dealing with heterogeneous EHR databases. The EU-ADR project uses this approach. In one of their studies, data from eight European healthcare databases (administrative claims, medical records) were combined. This data set included over 1.9 million individuals (59,594,132 person-years follow-up) who used 2,289 different drugs. It found for a frequent event such as AMI, there were 531 drugs (23% of total) for which an association with relative risk ≥2, if present, can be investigated. For a rare event such as rhabdomyolysis, there are 19 drugs (1%) for which an association of same magnitude can be investigated. It concluded that even larger databases would be required to detect signals for less frequent exposures and outcomes (Coloma et al. 2012).

A recent development is the use of EHRs to measure the quality of clinical care and provide financial incentives through 'pay-for-performance' programmes (Campbell et al. 2009). EHRs are used to evaluate clinician and system performance with the goal of making healthcare safer and more efficient. The adoption of computerized clinical records itself may be associated with improved care and outcomes (Cebul et al. 2011) although some doubts remain (Classen and Bates 2011). There are several different dimensions in which quality of healthcare can be measured. Examples of different quality measures include the number of patients with diabetes seeing an

ophthalmologist, clinical outcomes in patients with hypertension, percentage of clinicians reviewing out-of-range laboratory results with a certain number of hours, and the percentage of patients receiving incorrect medications (Weiner et al. 2012). The quality and completeness of the EHRs are of course critical in achieving the goals of the 'pay-for-performance' programmes.

Internet postings, blogs, and social media postings may provide another source of information for the early detection of new infectious disease epidemics. A recent study analysed the queries to online search engines, which are used by millions of people around the world each day. It concluded that this approach accurately estimated the level of weekly influenza activity in each region of the United States, with a reporting lag of about 1 day. The use of search queries could detect influenza epidemics in areas with a large population of web search users (Ginsberg et al. 2009). This potential use of Internet searches was tested in a US study that compared Internet searches with rates of outpatient visits for influenza-like illness and of confirmed laboratory tests. It was found that Internet searches were highly correlated with rates of outpatient visits for influenza-like illness but less correlated with rates of laboratory-confirmed influenza (Ortiz et al. 2011). The main limitation of these analyses of unstructured Internet data is that it may be difficult to separate activities by concerned healthy people from those with the disease of interest. Healthcare seeking behaviour, physician testing practices, and Internet search behaviour can be influenced by high levels of media coverage (Ortiz et al. 2011).

The information on the Internet can also be evaluated for the monitoring of side effects of medicines. A study evaluated the text on Internet message boards dedicated to drug abuse in order to compare different prescription opioids. Over 48,000 posts were analysed and the unstructured text was coded. It was found that the number of posts on these drug abuse message boards varied between the different opioids (Butler et al. 2007). While this approach is interesting, one cannot conclude that these differences in drug abuse messages were caused by the pharmacological differences between the opioids. Different levels of information provision by, for example, the clinicians or in the information sheet or prescribing to different patient populations could also lead to different levels of Internet activities.

Randomization in public health research

The present allocation of healthcare interventions is often inconsistent. Clinicians will be influenced in their prescribing behaviour, not only by clinical considerations, but also by other issues including drug preferences, exposure to marketing materials, and guidance from the local healthcare funders, which will vary considerably between practices and clinicians (Adamson et al. 2012). Clinicians will respond differently to uncertainties in the evidence base. The prescribing of antibiotics to patients with mild to moderate exacerbations of chronic obstructive pulmonary disease provides an example of this. A review of EHRs found major differences in the rate of antibiotics prescribing to these patients. Very few patients received an antibiotic in some clinics while antibiotics were routinely prescribed in other clinics. This variability in care (due to a lack of randomized trials conducted in these patient groups) produces a potentially unfair lottery for the receipt of healthcare interventions. Treating patients in this inconsistent manner generates no new evidence to improve clinical practice. On the other hand, randomization with structured data collection would provide the evidence to guide clinicians in selecting treatments. A possible model would be to offer randomization to all willing patients as part of routine clinical care in every situation where there is genuine uncertainty about which of two or more widely accepted treatments is best. The EHRs could be used to measure major clinical outcome and follow progress (van Staa et al. 2012). An analysis of the trial evidence for medicines used by millions of patients and with blockbuster sales showed that only one of the 24 top blockbusters in 2011 had a randomized trial including more than 10,000 participants and few of the blockbusters had evidence of beneficial effects on mortality (Ioannidis 2013). A mega-trial with mortality as an outcome could address concerns about side effects and also provide evidence of effectiveness of medicines in routine clinical practice.

EHR databases could offer an ideal platform to undertake large pragmatic trials, with randomization at the point of care and collection of follow-up data using the EHR (van Staa et al. 2012). Such an approach would allow the assessment of effectiveness of healthcare interventions in everyday clinical practice among representative populations. A recent study developed and evaluated the methods to implement simple pragmatic trials in primary care, identified the barriers and facilitators for clinicians and patients, as well as the experiences of trial participants. As part of this study, patients with high cardiovascular risk were randomized between simvastatin and atorvastatin (van Staa et al. 2012). Potentially eligible patients were identified in the EHRs using risk prediction tools. Outcome data such as continuation of statin treatment and occurrence of heart attacks were collected using the routinely collected data from primary care, linked data from hospital admissions, a prospective disease registry, and death certificates. This study concluded that EHR point-of-care trials are feasible, although the recruitment of clinicians is a major challenge owing to the complexity of trial approvals. These trials will provide substantial evidence on clinical effectiveness only if trial interventions and participating clinicians and patients are typical of usual clinical care and trials are simple to initiate and conduct (van Staa et al. 2014).

Discontinuation and non-compliance with medication over time can be an important outcome measurement in pragmatic trials. For example, if patients preferentially use e.g. atorvastatin for a longer period of time, this could mean a substantially lower number of patients suffering a heart attack. In most trials, study participants are regularly monitored and instructed how to take their medicines. But the rates of persistence are often considerably lower in routine clinical practice, as stringent monitoring procedures do not apply. Pragmatic trials that collect follow-up information unobtrusively (e.g. from EHR databases) would provide the answers that decision makers need: that is, will this intervention make a difference in routine clinical practice compared to alternative strategies (Tunis et al. 2003).

The TRANSFoRm project developed an approach to embed trial functionalities within the EHRs including the pre-population of electronic Case Report Forms directly from the EHRs and the potential to record trial-specific data at the point of care. In addition, it also implemented data standards which allowed users to query the EHRs without a detailed understanding of how data were originally recorded and stored in the EHRs and what coding system was used (i.e. interoperable data systems) (Ethier et al. 2017). The

(TRANSFoRm) clinical trial tools were then used for automated identification, recruitment, and follow-up. A small feasibility study was conducted in three general practices in Poland. Participants were physicians and patients with gastro-oesophageal reflux disease. It found that physicians were satisfied with the usefulness of the system, as it enabled easier and faster identification, recruitment and follow-up of patients compared with existing methods (Mastellos et al. 2016).

Cluster trials randomly allocate entire areas or health service organizational units to intervention or control groups, with outcomes evaluated for individuals within each cluster. They facilitate pragmatic evaluation of the effectiveness of interventions delivered in routine practice settings. Public health interventions could be tested in cluster trials as one can, for example, implement the novel intervention in one set of randomly selected clinics and the old intervention in the remaining clinics. The effectiveness of screening programmes could also be tested in cluster trials, with half of the clinics conducting the screening and the other half not. An example of a study that used EHR data is a study that tested the effectiveness of providing clinicians with the guideline recommendations on antibiotic prescribing in respiratory illness. Electronic prompts are activated during a patient's consultation for upper respiratory illness. The EHRs are used to measure the outcomes of interest, which include the rate of antibiotic prescribing (Gulliford et al. 2011).

Phased access to new interventions has been proposed as a method to measure effectiveness and safety. Practices or regions would be randomized to early or late access and the EHR data would be used to measure the outcomes of interest. Because practices are randomly chosen for each new intervention, a practice will have access to some of the new interventions (Adamson et al. 2012).

Impact assessment of public health interventions

The measurement of outcomes of public health interventions in routine clinical practice should be considered a major public health activity. This impact assessment can inform the extent of uptake but also identify any issues with the implementation of the public health activity. However, this impact assessment is not consistently done. For example, measurements of outcomes are lacking in a major UK programme that targeted the use of statins in patients with high cardiovascular risk. Following a detailed review of evidence, the UK National Health Service introduced a population-wide vascular risk assessment programme. This consists of a systematic approach to assessing risk of vascular diseases for everyone between 40 and 74 years who is not yet diagnosed with cardiovascular disease or treated for risk factors. Statin treatment should be initiated if a patient has a high risk (20% or greater 10-year risk) of cardiovascular disease (National Health Service Health Check Programme 2008). However, a recent analysis of the EHRs found that many healthy patients were prescribed a statin despite having a below-threshold cardiovascular risk and that there was wide variation between practices in the extent of statin prescribing to patients at high risk.

Another example of the difference between intended use according to guidelines and actual use in clinical practice concerns the selective cyclooxygenase-2 inhibitors (coxibs). These drugs ranked, before September 2004, among the most commonly used medications in the world. They were developed to minimize the upper gastrointestinal side effects of conventional non-steroidal anti-inflammatory drugs. A large number of cost-effectiveness analyses were conducted in order to provide clinicians with guidance on which patient groups should be treated with coxibs. These analyses were based on mathematical models that took into account the higher prescription costs and lower incidence of gastrointestinal side effects of coxibs. The assumptions that were used in these models were obtained from the main coxibs randomized trials. However, an analysis of EHRs found that the vast majority of coxib users in routine clinical practice would not have been eligible for the main coxibs randomized trials, as they did not have osteoarthritis or rheumatoid arthritis and only used coxibs intermittently or short term. Thus, the many cost-effectiveness analyses that were conducted for coxibs lacked external validity and were of limited value in guiding clinicians on how to treat patients in routine clinical practice. The authors of the EHR analyses concluded that the field of health technology assessments should move from evaluating cost-*efficacy* in ideal (hypothetical) populations with ideal interventions, to cost-*effectiveness* in real populations with pragmatic interventions (van Staa et al. 2009). The clinicians were not provided with any guidance on how to use coxibs in the vast majority of patients who could be treated with coxibs. Public health interventions should be developed with a focus on who could be targeted in routine clinical practice rather than on who had been included into randomized trials. It has been proposed that public health programmes should be preceded by a systematic review of the research evidence assessing the likely effects of these programmes followed by an impact evaluation after launch (Oxman et al. 2010).

Scientific challenges in research with electronic healthcare data

Data quality is of course very important for research that uses EHR data. There are several dimensions of data quality. The accuracy and validity of the information in EHR databases will depend on the level and specificity of the coding of medical data at the clinics. A clinic that mostly records data using unstructured free-text or using non-specific codes will provide data that are less useful for research. Data quality also depends on the completeness of information. A clinic that is not routinely informed about, for example, hospitalizations of their patients will not provide complete data, even if the clinic codes the medical data to highest standards. Reliability of information includes the level of changes in data collection over time. As an example of secular changes, the Quality and Outcomes Framework introduced in England in 2004 resulted in a substantive increase of the data included in this framework. Relevance of the collected data for the desired use is another component of data quality. An EHR database that is based on records from GPs may not contain all the data considered relevant by a specialist for making a diagnosis. Timeliness of information processing is also critical for data quality (Audit Commission 2007). Studies that use EHR data for public health research will need to consider these different aspects of data quality.

There are many different EHR systems and similar information may be recorded and stored differently, making it difficult to extract information in a standardized manner or to share information between different partners. Complex systems may need to be built

in order to make computer systems interoperable and to exchange EHR data with public health agencies. An example of such a system is the US National Electronic Disease Surveillance System. This is a web-based infrastructure for public health surveillance data exchange between the Centers of Disease Control and the 50 US states. Forty-seven states had in 2010 fully operational general communicable disease electronic surveillance systems, of which 39 states had systems that were interoperable and 42 states had the capacity to receive electronic laboratory reports (Centers for Disease Control and Prevention 2011).

Ethical aspects of research with electronic healthcare data

Healthcare data contain sensitive information about individuals. Adequate protection of individuals' privacy and data security are very important requirements for researchers to adhere to. EHR databases typically remove patients' identifiers (such as name, address, and postcode) from the research database. In some databases, researchers will never be able to contact the clinician or patient; these data are considered fully anonymized. In other databases, researchers will not know the patients' identifiers but they are able to contact the clinician or patients through a gatekeeper; these data are considered pseudo-anonymized. In the Clinical Practice Research Datalink, the patient's clinician can be contacted (following approval by an ethics committee), who can then review the request and contact the patient, if appropriate.

There is considerable debate about whether (pseudo)anonymized healthcare data should be made available for research. In an opt-in system, data can only be made available to researchers dependent on their informed consent. In an opt-out system, patients can refuse to have their data used for research. In other systems, anonymized data are considered exempt from consent or dissent requirements and can be used for research as long as the data do not contain patient identifiers. The use of health data for research raises complex ethical questions of privacy. One interesting approach to evaluating public acceptability of different approaches to challenging ethical questions like this is the use of citizens' juries. They are based on the premise that, given time, opportunity, support and resources, ordinary people can make decisions about complex matters. A project in the North of England explored what control informed citizens would seek over the use of EHRs for research after participating in a deliberative process using citizens' juries. They addressed the question of to what extent should patients control access to EHRs for research use? At the end of several days of deliberation, 33 out of 34 jurors voted in support of the secondary use of data for research, with 24 wanting individuals to be able to opt out, 6 favouring opt in, and 3 voting that all records should be available without any consent process. All jurors thought that public benefit was a key justification for access (Tully et al. 2018).

The critical question is whether the right of data privacy trumps all other rights and duties or whether there is a balance between different considerations. There is the right of patients to receive proper treatments and the duty of the healthcare to, for example, monitor treatments for effectiveness and safety, and be cost-effective. A healthcare system that generates and applies the best evidence for collaborative healthcare choices of each patient and provider has been defined as a learning healthcare system (McGinnis 2010). Such a system would continuously test interventions and collect data on the outcomes and then use the results to inform and improve clinical practice. Scientific research including public health requires high-quality data, and a learning healthcare system that aims to continuously improve cannot be achieved without such data. It has been proposed that data governance should be viewed as a matter of weighing up the value accruing to individuals, such as privacy and consent, against the value that the research may generate for the public (Rumbold et al. 2011).

The discussion about rights of data privacy and the research use of EHRs should not be restricted to abstract legal notions but also consider the likelihood of data privacy breaches and how these can be minimized. Staff training and standard procedures are essential, but the skills and attitudes of staff are also very important to ensure that data are treated with appropriate care. Regular audits of data security by external experts can also help to maintain a culture of continuous improvement (MacKenzie et al. 2011). With appropriate data security procedures, the risk of breaches of data privacy could be minimized. Also, the standards and quality of research are important considerations in the balancing of rights of data privacy and the research use of EHRs. Registration of the study prior to the start of the analyses and external access to protocols after completion of the analyses have been advocated strongly for randomized trials (Chan et al. 2006). External access to protocols and the possibility for independent researchers to replicate the study findings could help to improve research standards. A public health system that uses EHRs for high-quality and transparent research and with minimal risk of privacy breaches is clearly ethically superior to a system that applies few standards.

Conclusion

Information systems are critical for public health activities with information being exchanged between public health agencies, clinicians/healthcare providers, individuals, and communities. The EHRs can provide information on diseases and healthcare activities and electronic alerts within the EHRs can be used to remind clinicians of necessary or required public health activities. The effectiveness of some public health interventions can be monitored and also tested using the EHRs. Better data on risks and benefits of healthcare interventions can also help to improve decision-making and informed consent by individuals (Calman et al. 2012). The increasing computerization of the healthcare system will offer many important opportunities to improve public health activities.

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4.2

Community diagnosis and health information systems in low- and middle-income countries

Zunyou Wu and Jennifer McGoogan

Introduction

Broad recognition of health as a basic human right began with the formation of the World Health Organization (WHO) in 1946 (see **Box 4.2.1**), as a specialized agency within the United Nations (UN) (WHO 1946). Twenty years later in 1966, the International Covenant on Economic, Social and Cultural Rights was ratified by the UN General Assembly (GA). Article 12 of the Covenant reinforces international commitment to protecting health as a natural human right, recognizing *'the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'* (UN GA 1966). Since then, these agreements have been followed by other similar commitments; for example, the Declaration of Alma-Ata (1978), the Health For All goals (1981), the World Medical Association Declaration of Ottawa (1998), and the Abuja Declaration (2001).

In 2000, the UN Millennium Declaration, with the support of 189 of its member states as well as 22 international organizations, launched the Millennium Development Goals (MDGs)—eight international development goals meant to be achieved by 2015 (UN GA 2000). MDG 4 (Reduce Child Mortality), MDG 5 (Improve Maternal Health), and MDG 6 (Combat HIV/AIDS, Malaria and Other Diseases) were meant to directly influence health. This helped to galvanize national and international health organizations by bringing awareness to these issues and pushing them to the forefront of political agendas worldwide. It also helped to provide renewed momentum, as considerable funds, earmarked for initiatives aimed at achieving the MDGs, became available through international aid organizations such as the United States President's Emergency Plan for AIDS Relief (PEPFAR), the President's Malaria Initiative (PMI), the GAVI Vaccine Alliance, The Bill & Melinda Gates Foundation, and The Global Fund to Fight AIDS, Tuberculosis and Malaria (The Global Fund).

The aspirations that the MDGs embodied were ambitious, but the tactical work that would be required to achieve them fit neatly into the usual purview of public health, which had already long been doing the work of elevating average health status and reducing burden of disease, combatting health inequity and inequality, ensuring provision of basic services, and improving health system efficiency, all at the community level. Thus, one of the near-immediate

Box 4.2.1 Constitution of the World Health Organization (WHO)

WHO founding principles (WHO 1946):

- Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.
- The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.
- The health of all peoples is fundamental to the attainment of peace and security and is dependent on the fullest co-operation of individuals and states.
- The achievement of any State in the promotion and protection of health is of value to all.
- Unequal development in different countries in the promotion of health and control of diseases, especially communicable disease, is a common danger.
- Healthy development of the child is of basic importance; the ability to live harmoniously in a changing total environment is essential to such development.
- The extension to all peoples of the benefits of medical, psychological, and related knowledge is essential to the fullest attainment of health.
- Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people.
- Governments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.

positive outcomes of the MDGs was the recognition of the human race itself as a community and hence, 'global health' or 'global public health' as a concept (Marten 2019), a movement which had first begun in the mid-1990s with a refocusing of efforts at the WHO (Brown et al. 2006).

While overall, the MDGs were generally considered successful—development was accelerated, lives were saved, people were lifted out of poverty (UN 2015)—nearly every aspect of the MDGs were also heavily criticized (Fehling et al. 2013; Marten 2019). For example, the MDGs were written primarily by the United States, Europe, and Japan, with the heavy influence of large international aid organizations. Neither the citizens nor the governments of the developing nations the MDGs were meant to help were involved in their creation. Moreover, although the MDGs were written as global goals, assessments of performance against the goals were repeatedly applied at the individual country level. The mismatch between global-level goal setting and country-level performance measurement meant that many countries struggled and some were, arguably unfairly, labelled as 'off-track'. Furthermore, the sense of futility felt in countries where the MDGs were not realistically feasible was harmful and, in some cases, counterproductive to growth and development of local public health infrastructure, governance, and accountability (Cohen et al. 2014; Easterly 2009; Easterly 2013; Fehling et al. 2013; Vandemoortle 2009).

This problem was further exacerbated by insufficiencies in data availability, quality, timeliness, and potential for aggregation and disaggregation, in statistical methodologies and capacity, and in national (and international) information systems. Although over the course of the MDG era (2000–2015), more and better data became available, coordination with statistical systems improved, and new statistical methodologies were developed, these issues were serious obstacles to progress in the MDG era (2000–2015) (UN 2015), and remain so today.

Not surprisingly, it was low- and middle-income countries (LMIC; see **Box 4.2.2**), in particular, that faced unreachable standards for success. These nations generally did not have the data collection infrastructure and information management systems to support measurement of current state, much less evaluation of achievement over time. For instance, some countries' civil registration systems were inefficient and ineffective, leading to large gaps in vital statistics and related data. Consequently, governing bodies at local, subnational, and national levels relied on incomplete, outdated, and/or low-quality evidence for policy development and planning purposes. Thus, experience gained in monitoring progress toward the MDGs underscored the power of effective use of data for setting appropriate targets, focusing efforts, successfully implementing interventions, assessing performance, and increasing accountability (UN 2015).

Fundamentally, this activity of describing the current state, setting goals for a future state, and measuring progress against those goals is the basis of community diagnosis. Careful and deliberate selection of health indicators, or metrics, is important to the planning, execution,

Box 4.2.2 Low- and middle-income countries (LMIC)

List of LMIC defined by the World Bank as having a gross national income per capita of less than 12,236 United States dollars (USD) in 2018 (World Bank 2018). Studies conducted in countries listed in bold font highlighted as examples within the chapter.

Afghanistan
Albania
Algeria
American Samoa
Angola
Argentina
Armenia
Azerbaijan
Bangladesh
Belarus
Belize
Benin
Bhutan
Bolivia
Bosnia & Herzegovina
Botswana
Brazil
Bulgaria
Burkina Faso
Burundi
Cabo Verde
Cambodia
Cameroon
Central African Rep.
Chad
China
Colombia
Comoros
Congo, Dem. Rep.
Congo, Rep.
Costa Rica
Cote D'Ivoire
Cuba
Djibouti
Dominica
Dominican Rep.
Ecuador
Egypt, Arab Rep.
El Salvador
Equatorial Guinea
Eritrea
Ethiopia
Fiji
Gabon
Gambia, The
Georgia
Ghana
Grenada
Guatemala
Guinea
Guinea-Bissau
Guyana
Haiti
Honduras
India
Indonesia
Iran, Islamic Rep.
Iraq
Jamaica
Jordan
Kazakhstan
Kenya
Kiribati
Korea, Dem. People's Rep.
Kosovo
Kyrgyz Republic Lao PDR
Lebanon
Lesotho
Liberia
Libya
Macedonia, FYR
Madagascar
Malawi
Malaysia
Maldives
Mali
Marshall Islands
Mauritania
Mauritius
Mexico
Micronesia, Fed. Sts.
Moldova
Mongolia
Montenegro Morocco
Mozambique
Myanmar
Namibia
Nepal
Nicaragua
Niger
Nigeria
Pakistan
Panama
Papua New Guinea
Paraguay
Peru
Philippines Romania
Russian Federation
Rwanda
Samoa
Sao Tome & Principe
Senegal
Siberia
Sierra Leone
Solomon Islands
Somalia
South Africa
South Sudan
Sri Lanka
St. Lucia
St. Vincent & the Grenadines
Sudan
Suriname
Swaziland
Syrian Arab Republic
Tajikistan
Tanzania
Thailand
Timor-Leste
Togo
Tonga
Tunisia
Turkey
Turkmenistan
Tuvalu
Uganda
Ukraine
Uzbekistan
Vanuatu
Venezuela, RB
Vietnam
West Bank & Gaza
Yemen, Rep.
Zambia
Zimbabwe

and evaluation of any community diagnosis project. However, the effectiveness of health metrics selected and used relies heavily on the data available. Thus, robust information systems that can support timely collection, analysis, and distribution of high-quality data are central to any effective community diagnosis project. Recognition of the interconnectedness of community diagnosis, health metrics, and health information systems is important for supporting the iterative improvement of all three over time, especially in LMIC where sustained development is at its most challenging, yet the need for overall improvement in health status is greatest.

Community diagnosis

In contrast to clinical diagnosis, where health is assessed at an individual level through patient–physician interaction, community diagnosis is an assessment of health at a population level through community engagement in public health practice. As such, *community diagnosis* (sometimes also called a community health profile or health needs assessment) is defined by the WHO as *'a quantitative and qualitative description of the health of citizens and the factors which influence their health. It identifies problems, proposes areas for improvement and stimulates action'* (WHO 1995).

Community diagnosis projects can have one or more overarching goals, such as:

- Description of a community's health status, health problems, and their determinants
- Assessment of a community's health resources, services, and systems
- Evaluation of community members' attitudes toward health and health services
- Identification of priority issues and development of action plans for improvement
- Definition of an epidemiologic baseline for measurement of change over time

A *community*, in the sense of community diagnosis, can be any cluster of people within the broader society who share at least one common characteristic; for example, geographic location, ethnicity, occupation, exposure to a specific environmental factor, or presence of a particular risk factor. However, it is not only the characteristics of the people (e.g. vital statistics, sociodemographics, religious and cultural beliefs, educational attainment) that define the community. Other factors—environment, safety, physical, and mental health and social services, economics, communication, transportation, and government—must also be included as the community is defined and as the current state of health in the community is described. Notably, any one individual may be a member of several different communities by this definition—citizen of Village A, but practitioner of Religion B, and worker in Factory C, etc. (Tindana et al. 2007).

The process of community diagnosis

Community diagnosis, whether performed in high-income settings or in LMIC, generally follows a fairly well-defined process that includes five main steps (see for example Box 4.2.3). However, the process is not only customizable, it is meant to be customized. Ideally, the base process of community diagnosis outlined here should be tailored to match the intent of the community diagnosis initiative, the resources and time available to execute it, and the unique attributes of the community itself. The process is meant to be pragmatic and its result is meant to be informative (i.e. improve understanding of the issue) and actionable (i.e. identify actions to be taken to improve the situation).

Box 4.2.3 Community diagnosis in a small village in Iran

Summary of methods used and results obtained in a community diagnosis effort in Qala-Sayed village, Kazeroun, Fars Province, Iran in 2013 (Basseej et al. 2015).

Step 1: Community assessment team created
Step 2: Primary and secondary data collected
Step 3 and 4: Data analysed and combined
Step 5: Community informed
Step 6. Health priorities selected
Step 7: Community assessment document created
Step 8: Action plan developed

A total of 649 households comprised of a mostly-rural population of 2,514, 25% of which were under the age of 11. For many years already, the village has had working water, electricity, gas, and telephone utilities. It had one 'health house', four schools, five mosques, one nursery school, four butchers, and 21 grocery stores.

Insufficient health knowledge was identified as the highest priority problem, followed by diabetes, oral health, addiction, and hypertension.

The plan of action focused on non-academic training designed to improve villagers' knowledge (regardless of educational attainment) of diabetes, with particular emphasis on healthy eating habits.

Step 1: Initiation. It is important that any community diagnosis effort is managed and coordinated by a dedicated team, committee, or working group. This team should be cross-functional in make-up, comprised of individuals from relevant government agencies, health bureaus, non-governmental organizations (NGOs), and representatives from the community. Once formed, this team should begin the process with refining the scope of the project. Taking into consideration the goals of the initiative, the financial budget and other resources available, and the time allotted to conduct the work, the team should have a detailed understanding of the work ahead, a plan for the methods of data collection and analysis to be used, and at least a high-level strategy for the ultimate output of the community diagnosis project (i.e. development and dissemination of the community diagnosis report). Development of a strategy for engagement of, and communication with, the community the project is intended to serve should be a critical element of the project's up-front planning. Another important component of this early planning stage is the selection of health indicators that ideally would be used, although this may be modified during the project based on data availability and analyses conducted. Furthermore, the team should anticipate obstacles and risks to the project and draft plans for overcoming barriers and mitigations for risks realized.

Step 2: Collection. Both primary (e.g. surveys, interviews, focus group discussions, mapping, observations) and secondary (e.g. records review) data collection methods are critical for gaining a thorough understanding of the community being studied. For the same reason, both quantitative and qualitative data must be collected

Box 4.2.4 Malaria community diagnosis in Lomahasha, Swaziland

The importance of qualitative data is highlighted in a mixed-methods community diagnosis project aimed at better understanding social and behavioural factors influencing the success of malaria control measures in a rural area of Swaziland (Dlamini et al. 2017).

Individual interviews
Multiple researchers were strategically stationed around the village of Lomahasha on walkways and roadsides. They randomly stopped individuals passing by and interviewed them using a semi-structured questionnaire meant to collect both quantitative and qualitative information.

Focus group discussions
Focus group discussions were spontaneously convened by researchers who approached groups of people in Lomahasha already collected for some social reason (e.g. boy soccer players loitering in the street, women socializing near a water source, people waiting at bus stops).

Researcher observations
Six, one-day visits were made each year in 2004, 2006, and 2010 during which researchers drove around different parts of the Lomahasha community or stayed inside individual homesteads from early morning to late evening noting behaviours of individuals and social interactions among groups.

Several key findings important to future malaria control efforts were gleaned from qualitative data:

- Knowledge of malaria was relatively high, yet social norms and behaviours remained contradictory to control programme intentions—people stayed outside late into the evening, maintained pools of stagnant water, and sought care for symptoms late and in the wrong places.
- Severe poverty, drought, and the persistent presence of malaria in the community have desensitized people Lomahasha such that they regard malaria as a less serious problem and a normal part of life.

since neither provide a complete picture without the other (see for example Box 4.2.4).

Care must be taken to ensure representativeness of the data collected. For example, teams should be cautions of potentially causing over-representation of subgroups from which data are easier to obtain. This and other types of bias could lead to inaccurate findings and interpretations. Even more dangerous is the possibility that, as a result of these biases, inappropriate actions are taken, time and resources are wasted, opportunities for health intervention are lost, appropriate actions are delayed, and trust and belief in this process by the community is eroded. To help prevent these issues, it is crucial that different types of data be collected from multiple sources. While each source may be important individually, each will also have strengths and weaknesses. Taken together, however, data collected from a broad variety of sources are likely to be complimentary, more comprehensive, and less susceptible to bias.

The study design most commonly employed for community diagnosis projects is cross-sectional. *Cross-sectional studies*, which consist of retrospectively evaluating a representative sample of a population at a single point in time, have the advantage of being relatively inexpensive and fast. They also facilitate the simultaneous investigation of multiple exposures and outcomes while providing the ability to control for confounding. Although these types of studies to not allow for assessment of temporality or causality (Thiese 2014), repeated cross-sectional measurement nevertheless facilitates observations of changes over time for the purpose of evaluating action plans executed or interventions implemented.

Step 3: Analysis. Raw data should be compiled, tabulated, and summarized using descriptive statistics. Statistical tests may be run and inferences made. Rates and ratios may be further analysed to assess correlates or determinants of health, injury, disease, etc. Historical trends in certain indicators may be accessible for comparison to current data, and projections may be made to help predict future changes in health indicators for planning purposes. Re-analysis (by the same methods) of selected health indicators after action plans are carried out or interventions are implemented is important for evaluating their effectiveness. Additionally, community data may be compared to that of other similar communities (i.e. Village A compared to Village B) and to larger geographical or administrative areas (i.e. village to county/district to province/state). Ultimately, the analyses selected by the team must relate to the objectives of the project, but again, caution must be exercised to ensure that bias is not introduced at this stage as well. Additionally, in selecting the analyses to be conducted, the team should be mindful of the need to communicate results of the project. The output of the analyses should be reasonably accessible and understandable to a broad range of audiences—government officials, public health and healthcare workers, and the general public.

Step 4: Diagnosis. Interpretations and conclusions drawn from the results of the analyses form the diagnosis of the community. This includes for example, the current state of health, determinants of health, and health problems prioritized for intervention. This diagnosis must relate back to the initial intent of the community diagnosis project, and the diagnosis itself must be informative and actionable—suggestions for actions to be taken to improve health in the community should follow easily from the diagnosis. Furthermore, it must be specific and relevant to the community it is meant to serve.

Step 5: Dissemination. At its most basic, this step is the generation of a community diagnosis report, describing in detail the scope of the project, the methods used to collect and analyse data for the project, the results observed (i.e. the diagnosis), and the team's recommendations for further action. Emphasis should be placed on transparency. The report should be detailed, yet also include easily understood summaries of key points.

However, generation of the report itself is not enough. The report must be written in such a way that the information it contains is accessible not only to policymakers, public health authorities, or officials, other government agencies, and health workers, but also to the community members themselves. Ideally, a communication plan should be generated in parallel with the report. The results of the community diagnosis project should be shared with the general public in a variety of ways; for example, through presentations at meetings of local government committees, NGOs, and community-based organizations, through press-releases and news stories, and through community events such as health fairs or kick-off celebrations for new health interventions. Taking an active role in helping the community understand the project and how it will help improve health is important for building trust and belief in the process. Since the community diagnosis process is meant to be iterative, these kinds of activities may deliver the added benefit of improving participation in future community diagnosis projects.

Community engagement

Successfully conducting community diagnosis not only requires meticulous planning and execution, but also engagement and mobilization of the community to participate in the process.

Community diagnosis cannot be successfully performed or applied without involvement of community it serves. *Community engagement* (CE), the collaborative process of working with community members and groups to address issues that impact their well-being, can take many forms. For instance, rates of participation by members of the community must be high in order for large-scale community-based studies or household surveys to be successful. Thus, involving community leaders, influencers, and champions in the planning process, communication plan, and launch, and ensuring that they are seen and heard by the community through all stages of the project can be important for encouraging participation from those who may be reluctant.

There are several important points during a community diagnosis initiative where focus should be placed on CE. A selection of these CE activities is listed here, but this list is meant to be neither exclusive nor comprehensive:

- Creation of a project subteam whose mission is to lead CE
- Identification of community leaders, influencers, and champions to be involved at each stage of the project
- Review of plans to ensure the project is relevant to the community, culturally sensitive and pragmatic, not disruptive, designed to ensure fairness in community members' receipt of benefits from the project, and protective of vulnerable members
- Identification of local community health workers who will participate in data collection
- Development of a clear and consistent messaging strategy to ensure the community understands the project goals, processes, timelines, and expected outcomes and benefits
- Sensitization of the community and the local media about the launch of the project
- Execution of a high-profile launch, perhaps with a special community event where community leaders, influencers, and champions show their support for the effort
- Provision of regular updates and feedback to the community during the project
- Execution of a similarly high-profile project closure, with gratitude for community participation, transparent reporting on project outcomes, and details of action plans as well as funding and execution timelines for those plans

The benefit of collaboratively working with the community itself through truly authentic partnerships before, during, and after a community diagnosis project cannot be overstated (see for example Box 4.2.5). It is not only palpable in the near-term on the current project, but also carries over in the longer term on future projects if community members feel their voices are heard, their contributions are valued, and their lives or the lives of those in their families or in their communities are bettered through this iterative and focused effort on improving health and well-being.

Finally, CE is increasingly considered an ethical requirement of research involving human subjects, and thus, is no longer really considered optional (Tindana et al. 2007).

Box 4.2.5 Community engagement in rural Vietnam

A descriptive study of rural communes in Quang Tri Province in north central Vietnam underscores the value of community engagement (CE) in the community diagnosis process (Cho et al. 2018).

CE embedded in study methods

- **Study teams:** Study teams were comprised of nurse researchers, physicians, programme officers, programme evaluators, and local Vietnamese medical school faculty members.
- **Instruments review:** Local experts reviewed all questions included in all instruments used in the study for appropriateness relative to the local context.
- **RPA approach:** The study employed a rapid participatory appraisal (RPA) approach, which is a method for quickly collecting information about a set of problems and their causes that places strong emphasis on involvement of community members (Annett and Rifkin 1995).

Value of CE reflected in study findings

- **Multiple data sources:** Inclusion of multiple sources and types of data, made possible by CE, facilitated a better and more comprehensive understanding of community health needs.
- **Qualitative data:** Use of qualitative data, obtained through CE, helped compensate for relatively weak quantitative data (small data set from a small convenience sample).
- **Collaboration with local experts:** Many of the study communes were approached for the first time in this study and collaboration with local experts was essential for understanding the sociocultural context.
- **Community involvement:** Involvement of community members in the collection of information was critical to creating *'an acceptable and sustainable environment for successfully undertaking a new study'*.

Community diagnosis in low- and middle-income countries

In LMIC, community diagnosis is particularly challenging for a wide variety of reasons. Primary data collection is fraught with difficulty in creating representative, non-biased samples and retaining participants in studies, as well as barriers to field work including low educational attainment and poor infrastructure. Secondary data collection efforts can be frustrating as the data required are often unavailable, incomplete, inaccurate, out-of-date, and difficult to obtain. These complications make for complex and labour-intensive data entry and analysis, which may reduce confidence in results obtained and interpretations made.

Challenges with primary data collection

It is nearly impossible to remove all bias when sampling a population. One significant source of bias is caused simply by community member participation in primary data collection efforts. Those who elect to participate are very likely to be more informed or more concerned about the issue being examined and addressed through the project and those who decline may, in fact, be the more vulnerable to the issue at hand. Obtaining high participation rates in LMIC is already challenging but obtaining any level of participation from those most in need of intervention is extremely difficult.

Dropout is an issue for projects that require repeated measurement or even just a seemingly-small time interval between study enrolment and primary data collection. Dropout can be caused by a wide range of issues, but in LMIC, predominant among these is the

movement of people over time. Large proportions of populations in LMIC communities are either transient (i.e. characterized by frequent movement due to lack of stable housing and/or employment) or migrant (i.e. characterized by regular movement over large distances between family residence and employment).

Low education levels and literacy rates, more common in LMIC settings, mean the target population for a community diagnosis project is often ill-informed or unable to understand the importance of the health research project. This can render less expensive primary data collection techniques, such as self-administered questionnaires, impossible. Rather, home visits by study workers with high-level language skills and cultural knowledge may be required. This drives up the cost of the study, thereby driving down the feasible sample size, and increasing the risk of non-representative, biased sampling.

There are innumerable challenges with this kind of house-to-house field work in LMIC. Remote rural communities as well as poorer urban communities lacking or having poor-quality basic infrastructure that is susceptible to seasonal or severe weather effects mean transportation into and out of communities by field workers can be difficult, time-consuming, and sometimes dangerous. Lack of geospatial mapping, or simply street names and house numbers, creates obstacles for ensuring the homes of enrolled participants are correctly located. Field work that requires electricity (e.g. for visual observations or inspections), water (e.g. for hand washing before and after physical examinations), internet access (e.g. for record keeping), or other utilities can be problematic.

Finally, some of the world's LMIC most in need of improvements to community health are in the midst of ongoing violent conflict. Accessing these regions is unsafe for field workers seeking to gather primary data, and moreover, engaging with foreigners may be unsafe for community members as well. Additionally, interest among community members in participating in a community health needs assessment in regions of conflict is likely to be low, since primary among their concerns is not falling victim to the violence around them.

Challenges with secondary data collection

Challenges with secondary data collection in LMIC are numerous and persistent and can be frustrating for researchers attempting to conduct a community diagnosis or evaluate the effects of health policy changes or health interventions. Secondary data collection centres around review of records from a wide variety of sources—vital statistics from registries and censuses, surveillance systems, routine information systems, electronic medical records, disease registries, and other forms of information repositories. These records can be a rich source of quantitative information for community diagnosis initiatives and are frequently the focus of study in the public health field.

However, one of the most frequently cited challenges during the MDG era was the poor availability and reliability of data in LMIC—both for baseline assessment and for evaluation of progress toward MDG targets. What information systems did exist at that time suffered from, for instance, large gaps in record keeping, incomplete records, and poor-quality data entry (see for example Box 4.2.6 and Box 4.2.7). Many LMIC lacked birth and death registries, health records repositories, or health statistics at any administrative level. Methods for gathering information in the absence of these secondary data sources were often unreliable and sometimes based on assumptions. Furthermore, these methods were variable within and between countries and over time, making individual country progress difficult to interpret and nearly impossible to compare. These issues, caused by widespread lack of robust, thoughtfully-designed, and secure information systems in LMIC, persists today, presenting

Box 4.2.6 Timeliness of spotted fever surveillance reporting in Brazil

Study of spotted fever (SF) surveillance records in Brazil highlighting challenges with timely data availability (de Oliveira and Angerami 2018).

Background: In 2001, SF, an infectious tick-borne disease endemic to southeastern Brazil, became a compulsorily notifiable disease and in 2014 became an immediately-notifiable disease (within 24 hours of suspicion). Two systems have tracked SF reports in Brazil: the digital disease detection (DDD) system launched in 1997 and the national surveillance (SINAN) system launched in 2007.

Aim: To examine the timeliness of SF notification in the DDD and SINAN systems in southeastern Brazil.

Method: Records from Brazil's DDD and SINAN systems were matched and dates compared.

Findings: Only 62 records contained sufficient information to be matched and included in the study. More than 90% of these cases were reported to SINAN a median of 20.5 days earlier than DDD. Both systems' records contained different information and the data that could be extracted from each system were valuable and complementary.

Interpretation: The authors noted several critical limitations of these surveillance systems. For instance, although reporting to SINAN was faster due to immediate mandatory reporting of suspicion, reports were not available until diagnoses were confirmed generally 30 days later. Furthermore, SINAN did not contain location information, forcing reliance on the DDD system for identification of new transmission areas, clusters, and outbreaks. Delayed access to fragmented information prevents rapid and informed responses to health needs.

Box 4.2.7 Continuity of cancer registry reporting in Kosovo

Study of cancer registry records in Kosovo highlighting challenges with data quality and quantity (Berisha et al. 2018).

Background: Although malignant disease is a leading cause of death worldwide and an important contributor to morbidity and disability, public health efforts continue to be hindered in LMIC like Kosovo by lack of non-communicable disease registry data, which prevents informed allocation of limited resources.

Aim: To investigate the incidence, prevalence, and types of malignancies reported in Kosovo.

Method: Records from the Kosova Cancer Registry (KCR), which was reinstated in 2011 after an extended gap in reporting, were reviewed. Data were collected and tabulated and incidence and prevalence calculated.

Findings: Incidence was 93.4 (per 100,000) in 2012, 83.3 in 2013, and 167.9 in 2014, while prevalence was 135.8 (per 100,000) in 2012, 101.6 in 2013, and 186.5 in 2014. Most common among men were malignancies of the skin and respiratory and intrathoracic organs, and among women were malignancies of the breast and reproductive tract.

Interpretation: Although the authors concluded that cancer incidence and prevalence are increasing in Kosovo, and that investments must be made in prevention, screening, diagnostics, and therapeutics, they also emphasized several critical limitations of their study. They stated that they were *'not satisfied with the quantity and quality of the reporting'* and highlighted the importance of better quality data for better public health planning and the critical need for political commitment to support and expand coverage of existing reporting efforts, such as the KCR.

major challenges to the mission of global public health and global sustainable development (Fehling et al. 2013).

Challenges with data management and analysis

Aforementioned issues with the data and data collection methods all have ramifications for the management of datasets as well as statistical analyses, which can be difficult to overcome. For example, collection of handwritten data on paper forms—common in LMIC where use of laptops or tablets is often precluded by financial constraints and suboptimal internet access—creates the momentous task of keeping track of all the paper generated by the study, accurately deciphering and entering all the data, and then quality-checking the data entry. In terms of analysis, for instance, standard practice to address issues of representativeness or bias in sampling is to attempt to control for confounding. However, in LMIC, confounding may be caused by a multitude of factors, many of which researchers, due to their own unconscious biases and lack of knowledge, may be unaware. This can easily result in confounding by unmeasured factors having a substantial effect on results and interpretation. As another example, in the case of high dropout-rate, teams will often add 'replacements'. However, these replacement participants, often added late in the study, may have different characteristics and perhaps different exposures, which can be difficult to handle in the analysis phase.

The future of community diagnosis in low- and middle-income countries

Without question, properly executing community diagnosis in LMIC is difficult work. However, despite all of the barriers and challenges, performing a community diagnosis initiative is still a worthwhile endeavour, and having a little data or lesser-quality data is nevertheless better than having zero data. After all, the work of global public health is both a science and an art, meant to achieve a noble purpose—to prevent disease, prolong life, and promote health. In LMIC, where health needs are greatest and resources are most constrained, effectively executing the methodical process of community diagnosis can be especially impactful.

The Sustainable Development Goals

The Sustainable Development Goals (SDGs), the successor to the MDGs, were launched by the UN GA in 2016 and were comprised of 17 goals and 169 associated targets (see **Box 4.2.8**) (UN GA 2015). In contrast to the MDGs, where three of the eight goals were focused on improving community health, the SDGs contained only one goal directly related to health—Goal 3: Ensure healthy lives and promote well-being for all at all ages—which contained 13 targets.

A great many of the aforementioned criticisms of the MDGs have been attributed to the way in which they were developed—largely by the United States, Europe, and Japan together with the World Bank, the International Monetary Fund, and the Organization for Economic Cooperation and Development without consultation from, and some would say, even without consideration of, LMIC. Regardless of whether one subscribes to this view or not, the complaints by many of LMIC not being represented in the MDG development process and then being the recipient of its dictated priorities, targets, measures, and deadlines (Cohen et al. 2014; Easterly 2009; Fehling et al. 2013; Vandemoortle 2009), combined with the emerging notion of 'global public health' as well as other factors, drove a very different approach to the development of the SDGs leading up to the 2015 MDG deadline (Coonrod 2014; Marten 2019).

In many ways, the process used to develop the SDGs strongly resembled community diagnosis effort on a global scale. Cross-functional working groups were formed, the scope of the project was refined, and a plan for community engagement was developed (i.e. initiation step). Massive amounts of information were collected (i.e., collection step), compiled, and tabulated (i.e. analysis step). Interpretations were made, priorities were set, and metrics were selected (i.e. diagnosis step), and finally, the SDGs were communicated (i.e. dissemination step).

Engagement of the global community in preparation for the development of the SDGs began in 2012. It was an extraordinarily large effort—widely considered the most inclusive and consultive participatory processes the world has ever seen. Led by a 30-member Open Working Group of the UN GA, government officials from more than 100 countries were engaged in face-to-face discussions, recommendations of more than 5,000 civil society organizations were reviewed, executives from more than 250 companies were consulted, and feedback from more than a million individual citizens was collected via the UN's online Survey for a Better World, which asked people to select six issues that matter most to them (UN 2013).

The SDGs were the output of this massive, global-scale community diagnosis initiative. Without question, the new goals address a much broader range of issues, and the targets beneath the health and well-being goal are much more comprehensive (see **Box 4.2.8**) (UN GA 2015). However, it remains to be seen how successful the health and well-being SDG will be at driving forward a unified global public health agenda and improving health and well-being for all peoples of the world (UN 2017; Marten 2019).

The 'data revolution'

The crucial importance of information sources and data to global sustainable development was recognized in the MDG era, and the UN High-Level Panel, tasked with developing recommendations on the post-2015 development agenda, called for a 'data revolution'. The panel identified the need for substantial investment to build capacity worldwide in data collection and statistical analysis methods and tools to ensure that monitoring and evaluation at all stages is strengthened to support decision-making, guide prioritization, and ensure accountability (UN 2013). This theme extended into the 2015 UN GA resolution detailing the SDGs and its critical nature is underscored by its inclusion as targets under SDG 17 (UN GA 2015) (see **Box 4.2.9**).

The need to 'harness the power of data for sustainable development' features prominently in the UN SDGs Report 2017 (UN 2017):

> To fully implement and monitor progress on the SDGs, decision makers need data and statistics that are accurate, timely, sufficiently disaggregated, relevant, accessible and easy to use. Data availability and quality have steadily improved over the years. However, statistical capacity still needs strengthening and data literacy must be enhanced at all levels of decision-making. This will require coordinated efforts on the part of data producers and users from multiple data systems. It will also demand innovative ways to produce and apply data and statistics in addressing the multifaceted challenges of sustainable development.

The report goes on to emphasize the importance of building capacity via innovative approaches, creating synergies across different data environments, ensuring data improve clarity and do not mask disparities,

Box 4.2.8 The United Nations Sustainable Development Goals (SDGs)

Launched in 2016, the 17 SDGs to be achieved by 2030 contained one goal directly related to health (Goal 3), which itself had 13 targets (UN GA 2016) (see Fig. 4.2.1.)

Fig. 4.2.1 Targets.
Reprinted from United Nations (2017) 'The United Nations Sustainable Development Goals', https://unstats.un.org/sdgs/report/2017/overview/

Goal 3: Ensure healthy lives and promote well-being for all at all ages

3.1 By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births
3.2 By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births
3.3 By 2030, end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases and combat hepatitis, water-borne diseases, and other communicable diseases
3.4 By 2030, reduce by one-third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being
3.5 Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol
3.6 By 2020, halve the number of global deaths and injuries from road traffic accidents
3.7 By 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes
3.8 Achieve universal health coverage, including financial risk protection, access to quality essential healthcare services and access to safe, effective, high-quality, and affordable essential medicines and vaccines for all
3.9 By 2030, substantially reduce the number of deaths and illnesses from hazardous chemicals and air, water and soil pollution and contamination
3.a Strengthen the implementation of the World Health Organization Framework Convention on Tobacco Control in all countries, as appropriate
3.b Support the research and development of vaccines and medicines for the communicable and non-communicable diseases that primarily affect developing countries, provide access to affordable essential medicines and vaccines
3.c Substantially increase health financing and the recruitment, development, training, and retention of the health workforce in developing countries, especially in least developed countries and small island developing states
3.d Strengthen the capacity of all countries, in particular developing countries, for early warning, risk reduction, and management of national and global health risks

improving data presentation and literacy, and implementing best practices and standards related to data management.

Sources of information

There are many sources of information and data that are employed to conduct community diagnoses and to evaluate changes in community health over time. Each individual source has its own advantages and disadvantages, yet in combination with other sources (that have different advantages and disadvantages), the complementary larger data set becomes more powerful. Several of the most common sources of health information used in LMIC are detailed here.

Census

Generally conducted every 10 years and typically at the national level, a *census* systematically collects data on the population number

Box 4.2.9 SDG targets for data, monitoring, and accountability

SDG Goal 17: Strengthen the means of implementation and revitalize the Global Partnership for Sustainable Development contains two targets important to the improvement of data, monitoring, and accountability (UN GA 2015).

17.18: By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing states, to increase significantly the availability of high-quality, timely, and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location, and other characteristics relevant in national contexts.

17.19: By 2030, build on existing initiatives to develop measurements of progress on sustainable development that complement gross domestic product, and support statistical capacity-building in developing countries

and sociodemographic profile of citizens. A major advantage of census data is its provision of a population count and age profile that may be disaggregated by a range of geographical, social, economic, and demographic variables, which can contribute significantly to health planning (see for example **Box 4.2.10**).

However, while this form of data collection is somewhat successful in avoiding the pitfalls of sampling bias due to its focus on full participation by all citizens, bias still exists as many of those who fail to comply are perhaps the most vulnerable in society to health disparities. This is particularly true in LMIC. Furthermore, a census normally does not collect data that are directly related to the health of citizens and thus, cannot usually stand on its own for community health evaluation and monitoring.

Vital registry

Vital registration is the systematic recording of vital events including births, deaths, adoptions, marriages, and divorces. A country's vital registry (VR) can therefore provide important information on population dynamics (i.e. life expectancies, fertility rates, population growth rates) and health, via death records that can be used to evaluate morbidity and mortality, that a census cannot. Although VR is also intended to capture data from a nation's entire population, vital events are commonly under-reported in LMIC. According to a 2014 World Bank and WHO report, an estimated 85 million children under the age of five in Africa and 135 million in Asia and the Pacific were not registered. Likewise, an estimated 67% of deaths worldwide are not accounted for in VRs (WB and WHO 2014). Inadequacy of death reporting severely limits the use of VR alone to infer mortality rates from death records. Even deaths that are recorded sometimes have somewhat limited value since medical certification of deaths is often limited and thus, causes of death are not classified or miss-classified.

Verbal autopsy

VR death records can be augmented by *verbal autopsy* (VA), a process whereby a trained health worker interviews a person familiar with the deceased using a structured questionnaire for the purpose of gathering enough health information to determine a probable cause of death. However, VA has significant limitations beyond the obvious fact that it requires substantial time and resources. Although the WHO has developed VA standards as well as an instrument designed for routine use in cases were undocumented or poorly documented deaths require investigation (WHO 2016), considerable variability in VA procedures persist in many settings. Furthermore,

Box 4.2.10 Census data identifies an ageing population in Jamaica

Jamaica's census data has provided concrete evidence of significant and meaningful population ageing, 2001 compared to 2011 (Eldemire-Shearer et al. 2014), and projected to 2021 (PopulationPyramid.net).

Since ageing is associated with increased disease burden, urgent action must be taken to ensure that health and social services are expanded to meet the demands not only of the current, but also the future, elderly population. To promote the health and well-being of Jamaica's ageing population, investments need to be made in combatting chronic disease and age discrimination, creating programmes that support healthy, active ageing, and expand services for diagnosing and treating acute and chronic mental and physical illness in the elderly population. See Figure 4.2.2.

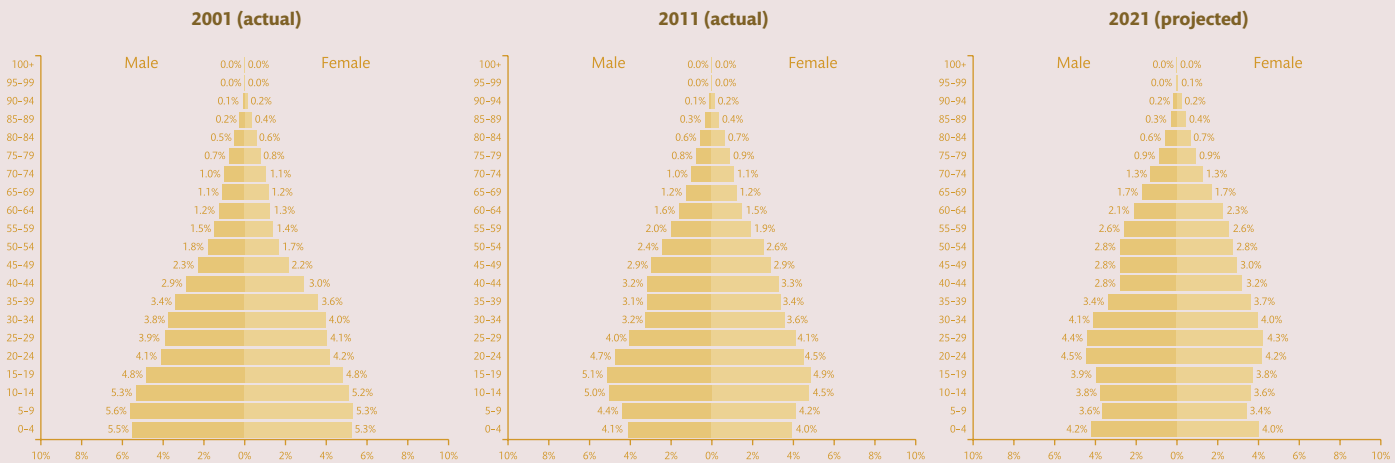


Fig. 4.2.2 Population pyramids.

Source: data from Eldemire-Shearer D, et al. (2014) 'Ageing of Jamaica's population—what are the implications for healthcare?' *West Indian Med J* 63(1): 3–8 and Statistical Institute of Jamaica (STATIN). Population and Housing Census 2011: General report. Volume 1. Kingston: STATIN; 2011.

non-standard VA conducted by untrained or inexperienced individuals tends to be highly subjective, risking bias, or miss-classifications of causes of death.

Household surveys

Household surveys may be used to collect a broad range of data both as a means of regular surveillance and as a method for evaluating health interventions (see for example **Box 4.2.11**). *Household surveys* are a relatively common way of collecting demographic, social, wealth, and health data in LMIC as the size and complexity of the survey questionnaire and the size and complexity of the survey sample can be easily scaled up or down according to research needs and resource constraints.

Ideally, household surveys involve multistage or two-stage stratified sampling designs to facilitate generation of a sample that is representative on a provincial or national level and to facilitate acquisition of data that may be aggregated and disaggregated by sampling stage/geographic area. However, single-stage cluster sampling plans may also be used if two-stage designs are not feasible, this may reduce costs and increase efficiencies in some cases.

To support the conduct of the household surveys, a standardized, structured questionnaire is developed and preferably pilot tested prior to use to ensure the data collected indeed answer the questions being asked in the study, to ensure the language used is easily understood, and to ensure the questions are culturally sensitive. However, although biomarker testing for clinical factors (e.g. anaemia, blood pressure, lead, vitamin A) and communicable diseases (e.g., diabetes malaria, measles, syphilis) has increasingly been included in household surveys in LMIC, information collected by household survey still relies heavily on self-reporting and is therefore subject to recall and social desirability biases.

Routine health information systems

The day-to-day collection of health information at public and private healthcare facilities and institutions is supported by *routine health information systems* (RHIS). A primary goal of RHIS is to provide reliable information that can be used to support health system improvement. As such, RHIS can be used to examine all manner of health indicators related to, for example, healthcare delivery, utilization, and policy implementation. Today, nearly all countries maintain these data repositories albeit in varying levels of completeness, complexity, and compliance. LMIC, especially, tend to have RHIS that operate on a suboptimal level, unable to provide complete and accurate information that is relevant and easily accessible in a timely fashion. Many types of interventions designed to strengthen RHIS have been evaluated, but evidence of effectiveness of these interventions in a range of settings has been mixed (Leon et al. 2015). Furthermore, even the most highly evolved RHIS still has limitations. For example, the creation of RHIS records and the augmentation of those records over time selects for those with more serious symptoms and those more likely to seek care. Many different types of RHIS exist (two examples described as follows), sometimes even within the same LMIC, often created for different purposes, and typically disconnected from each other, which causes fragmentation and reduced access to timely data.

Electronic medical records (EMR) are a system of digital patient records that replaces traditional, paper-based patient charts in clinical settings. This important source of information can shed light on all kinds of health indicators including facility-centric metrics (e.g. healthcare delivery, utilization, cost, and quality metrics) and patient-centric metrics (e.g. mortality, morbidity, and disability metrics). Having a facility-based or health system-based EMR system facilitates horizontal integration and greatly improves the speed with which health indicators can be evaluated. However, implementation of EMR systems in LMIC settings can be challenging and adopting practices for regular use of the data contained within the EMR system to evaluate and improve upon healthcare delivery is often slow and difficult due to constraints on human resource capacity.

Disease-specific information systems are generally developed, implemented, and maintained in response to a major emerging health issue. The structure and degree of complexity of these systems is highly variable as they are often constructed quickly with bare minimum functionality to meet the urgent needs of an acute situation, and then expanded over time.

One example of such a system is China's HIV/AIDS Comprehensive Response Information Management System (CRIMS). Early in China's HIV response, data collection was a highly-fragmented, paper-based, and labour-intensive exercise that was at once incomplete and duplicative—the many international aid organizations and donors who were funding much of China's initial efforts all required different reporting. Health workers, particularly at the local levels, were inundated with paperwork that did not directly serve their main mission, providing and expanding testing, treatment, and care services. This was exacerbated by fragmentation of information at the China Center for Disease Control (China CDC), the public health arm of the central government's Ministry of Health (now called the National Health and Family Planning Commission). The China CDC was maintaining eight different databases for sentinel surveillance, case reporting, treatment, prevention, methadone maintenance treatment (MMT), and other services and indicators. By 2005, the situation had become untenable. It was impossible to understand the epidemic and the effects of epidemic response efforts in a clear and holistic way.

Thus, in 2006, the National Center for AIDS/STD Control and Prevention (NCAIDS, a division of the China CDC) began developing an integrated, national HIV-specific information system, and in 2008, CRIMS was finally launched. CRIMS is a fully-secure, real-time, web-based system that contains records for all individuals ever

Box 4.2.11 Household survey of essential obstetric and newborn care (ENOC) in Ecuador

A study of the impact of a 3-year intervention intended to improve ENOC availability, accessibility, demand, uptake, and quality in rural Cotopaxi province, Ecuador highlights the utility of household surveys, and the value of combining these data with data collected through other means (Broughton et al. 2016).

Method: Household survey

Women with a child under the age of 24 months were surveyed using a structured questionnaire meant to assess access to and uptake of postpartum and post-neonatal care, knowledge and practices, and patient-reported quality of care at study baseline (2010) and completion (2013). Women in geographic areas known (via census data) to have many households with children were selected by multistage sampling.

Method: Routine health information system

Clinical records at participating facilities were randomly sampled and extracted data were used to assess facility quality of care.

Method: Vital registry

Vital registry data were provided by the provincial government to support evaluation of neonatal mortality for the study.

Researchers found that receipt of postnatal visits and postpartum counselling on newborn care rose, health knowledge increased, quality of care improved, and newborn mortality declined.

diagnosed with HIV in China and all individuals ever enrolled in MMT in China. It was built not only to optimize efficiency for health workers putting information into the system, but also to maximize performance for public health personnel and researchers extracting information out of the system.

The power of the new system in delivering value to health and public health workers and officials, researchers, and policymakers was felt nearly immediately. CRIMS has helped to generate an enormous body of evidence for the development and implementation of numerous important iterative improvements in HIV testing, treatment, care, and prevention programmes and has most certainly had an immeasurable positive impact on the trajectory of China's HIV epidemic (Mao et al. 2010) (see **Box 4.2.12**).

Box 4.2.12 The human immunodeficiency virus (HIV) care continuum in China

In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) set ambitious targets for the global HIV response to be achieved by the year 2020. These so-called 90-90-90 targets are 90% of those with HIV infection know their status, 90% of those with a confirmed diagnosis on antiretroviral therapy (ART), and 90% of those on ART virologically suppressed (UNAIDS 2014; UNAIDS 2017).

China was a partner in the development of these targets and is supportive of transparent and objective measurement of performance against the targets. In China, this would not be possible without the national HIV/AIDS Comprehensive Response Information Management System (CRIMS) (Ma et al. 2018).

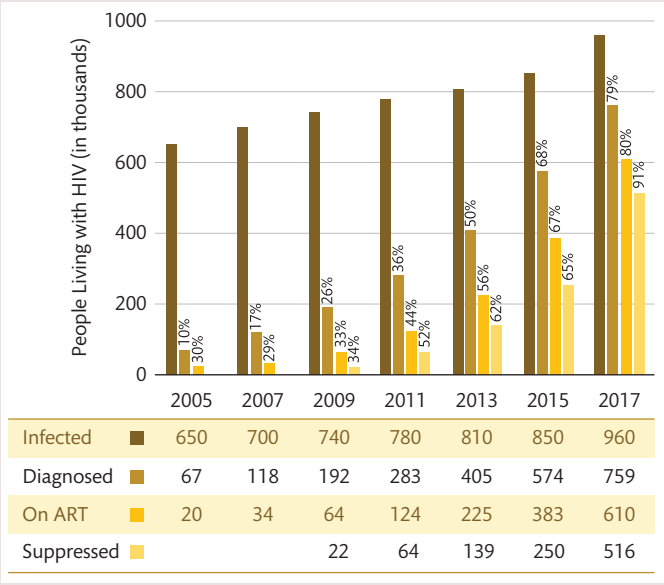
Methods:

A nationwide, biennial cross-sectional study was conducted using CRIMS records from 2005 to 2015 (Ma et al. 2018), and 2017 (NCAIDS 2018). Individuals were categorized based on the definitions in the table. These definitions and the method by which proportions were calculated were consistent with the UNAIDS guidance on the evaluating progress toward the 90–90–90 targets (UNAIDS 2017).

Category	Number and proportion
Infected	Total number of individuals with HIV infection in China as estimated via a joint effort between UNAIDS, WHO, and China's Health and Family Planning Commission.
Diagnosed	Total number of individuals in CRIMS with diagnosed HIV infection who were still alive at the end of the year. Proportion diagnosed = number diagnosed/ estimated number infected.
On ART	Total number of individuals in CRIMS who were receiving ART during the year and were still alive at the end of the year. Proportion on ART = number on ART/number diagnosed.
Suppressed	Total number of individuals in CRIMS who achieved viral suppression during the year and were still alive at the end of the year. Proportion suppressed = number suppressed/ number on ART.

Results:

Consistent improvement in the performance of China's HIV care continuum is shown in Figure 4.2.3. Bars represent the total number of people living with HIV and proportions are presented above the bars. As of the end of 2015, 68% of those estimated to be infected had been diagnosed, 67% of those diagnosed were on ART, and 65% of those on ART were virally suppressed (68–67–65) (Ma et al. 2018), and as of the end of 2017, performance against the targets had again improved to 79–80–91 (NCAIDS 2018).



	2005	2007	2009	2011	2013	2015	2017
Infected	650	700	740	780	810	850	960
Diagnosed	67	118	192	283	405	574	759
On ART	20	34	64	124	225	383	610
Suppressed			22	64	139	250	516

Fig. 4.2.3 Improvement in the performance of China's HIV care continuum.

Source: data from National Center for AIDS/STD Control and Prevention, China CDC. (2018) Annual progress of national HIV/HCV programs in 2017 and priorities and challenges in 2018. Presentation at the National Annual Provincial AIDS Directors Meeting. Ningbo, Zhejiang, China, 19 April 2018.

Key findings made possible by CRIMS

- The performance of China's HIV care continuum has consistently improved since 2005, and by the end of 2017, China had met 'The Third 90' target—90% of those on ART virally suppressed.
- However, China must urgently redouble its efforts in case finding and treatment initiation and retention, especially among those at greatest risk for attrition—adolescents, minorities, and injecting drug users.

HIV care policy implications

- Suboptimal care continuum performance observed from 2005 to 2013 spurred an interventional study and a cluster-randomized clinical trial (Wu et al. 2015, 2017), which provided ample, quality evidence for the individual (i.e. improved mortality rates) and community (i.e. improved viral suppression rates) benefit of streamlining and accelerating the care continuum.
- As a result, China began implementation of a new testing and treatment algorithm intended to drive faster diagnosis and treatment initiation, the effects of which are, at least in part, reflected in the performance of the care continuum in 2017.

Sentinel surveillance systems

When high-quality data on a disease or condition of interest are unavailable through passive channels (e.g. RHISs), other means of identifying health trends and disease outbreaks must be used. *Sentinel surveillance systems* can be a fairly economical method whereby a limited number of reporting units (e.g. hospitals) are carefully selected for their high likelihood of accurately identifying cases and their commitment to promptly report those cases. Sentinel surveillance data can provide estimates of symptom frequency, disease prevalence, incidence, and geographical distribution, and other key indicators, either among a broader population as a whole, or among subpopulations at particular risk.

Geographic information systems

Although spatial mapping of health problems is not new to public health, the development of new technologies and methods for rapidly manipulating enormous datasets has substantially increased our capacity for examining larger problems over larger geographic areas. *Geographic information systems* (GIS) are systems of computer hardware and software that are capable of combining high precision location information with health databases and analysis tools to visualize geographic distributions of health indicators such as morbidity, mortality, prevalence, and incidence related to a particular disease or condition of interest.

Other sources

There are many other sources of important information that can contribute to community diagnosis. These include lot quality assurance sampling, community key informants, risk factor surveillance mechanisms, morbidity and mortality data, and health system data related to facilities and human resources, as well as service delivery, utilization, and cost.

Health metrics

Communities are diagnosed and changes in health status are measured over time using a wide range of objective health indicators or metrics. However, selecting the appropriate group of metrics is as important as properly measuring performance against them using quality data. Ideally, metrics for the assessment of community health should be (Bilheimer 2010):

- **Feasible**—Performance against the indicator must be measurable. Good-quality, current data required to accurately assess performance against the metric must be available.
- **Valid**—The indicator must be valid, meaning it must actually measure what it was designed to measure. Validation of the method of measurement should be prioritized.
- **Reliable**—Measurement of performance against the metric must be robust enough to be unaffected by the individual doing the measuring. This reduces bias and facilitates comparison of repeated measurements.
- **Relevant**—The indicator must be relevant. It should substantively contribute to improving understanding of the health issue being investigated.
- **Sensitive**—The metric must be sensitive enough to allow detection of meaningful changes in performance against the metric.
- **Specific**—The indicator must be specific enough to reflect changes only in the health issue being investigated.
- **Actionable**—The metric should be actionable at some level—if not at the community level, then at the state/province or national level.
- **Accessible**—The indicator should be accessible, meaning it should be quickly and easily understood by policymakers, health and public health workers, and community members.

Additionally, using metrics that have been used before and have recognized operational definitions can be advantageous. Finally, itis also important to consider the ability to aggregate or disaggregate selected metrics by geography, age group, sex, ethnicity, and perhaps other sociodemographic parameters.

Arguably, individual metrics that do not meet these criteria may be of questionable value. Thus, when considering selection of an indicator that lacks one or more of these characteristics, the benefit of using it should be weighed against the cost of measuring performance against it. However, it would be a rare situation where a single metric would provide sufficient information to adequately assess changes in the health of a community over time. Hence, groups of metrics should generally be selected—each individual metric providing meaningful information on its own and complementary information to other selected metrics, and together as a group of metrics providing a comprehensive assessment that is capable of meeting the needs of the project.

Community diagnosis projects have used a broad range of health metrics to investigate issues of interest (see **Box 4.2.13**). Since each individual community diagnosis project will have different research questions, each will spend considerable time carefully selecting the group of health metrics that best meet the aforementioned criteria alone, are complementary and comprehensive together, and meaningfully address the issues of interest (Bilheimer 2010).

Since the effective use of health metrics to drive active, intentional efforts to improve community health is heavily dependent on the availability of good-quality, timely data, which is a serious challenge in most LMIC, many of the most helpful health metrics may be very difficult, if not impossible, to use in some settings. Thus, there must be some flexibility in the assessment of the value of particular health metrics. Above all, it is critical that a pragmatic and iterative approach to the selection of health metrics in LMIC settings is taken. This may first mean assessing what data are available that meet reasonable standards of completeness, quality, reliability, and timeliness, and using that data to measure what is possible to measure in the short term. Then, assessing what health indicators should be measured, and developing the information system infrastructure to make it possible to measure what should be measured in the longer term. A few of the health metrics more commonly used LMIC are described in more detail here.

Mortality metrics

A broad range of mortality measures may be used to assess health in communities, all of which rely heavily on VRs, and where vital registration data are incomplete, on census data, household surveys, and health services records. However, since deaths commonly go unreported in LMIC, measures of mortality in these settings can generally be considered underestimates. *Mortality rates* may be calculated overall, or for a specific subgroup within

Box 4.2.13 Health metrics

The following list of health metrics is intended to be neither exclusive nor comprehensive. Rather, it is meant to be a categorized selection of health indicators commonly used in community health projects.

Mortality metrics
- Case fatality rates
- Crude death rates
- Infant/child mortality rates
- Life expectancies
- Maternal mortality rates
- Mortality rates
- Proportionate mortality ratios
- Specific death rates

Morbidity metrics
- Admission/discharge rates
- Attendance rates
- Causes of death
- Disease incidence
- Disease prevalence
- Hospital stay duration rates
- Morbidity rates
- Notification rates

Disability metrics
- Disability-free life expectancy
- Disability rates
- Functional health status
- Lost work/school rates
- Restricted activity rates

Social/mental health metrics
- Accident/injury rates
- Alcohol dependence prevalence
- Mental illness incidence
- Mental illness prevalence
- Substance use prevalence
- Suicide/homicide rates
- Traffic accident rates

Nutritional metrics
- Anthropometrics measurements
- Clinical indicators of nutritional status (e.g. anaemia)
- Low birth weight rates
- Obesity rates

Healthcare delivery metrics
- Cost-effectiveness measures
- Hospital bed/population ratios
- Hospital facility/population ratios
- Physician/nurse ratios
- Physician/population ratios

Healthcare utilization metrics
- Antenatal care attendance rates
- Family planning uptake rates
- Hospital bed occupancy/ turnover rates
- Infant immunization rates
- Oral health attendance rates

Environmental metrics
- Clean water coverage rates
- Food safety indicators
- Pollution measures
- Safe sanitation coverage rates
- Tobacco use rates
- Vector density rates

Socioeconomic metrics
- Family sizes
- Homelessness rates
- Household income
- Housing condition measures
- Literacy rates
- Per capita GDP
- Population change rate
- Poverty rates
- Unemployment rates

Health policy metrics
- Healthcare expenditure per capita
- Proportion of GDP spent on healthcare
- Proportion of total health resources dedicated to primary care

Other metrics
- Basic needs indicators
- Quality of life indicators
- Risk factors for disease/injury

the community (e.g. age group, ethnic group), as the numbers of deaths in a year per unit of population, usually per 1,000 or 10,000. This fairly simple metric is a valuable means of easily understanding health in the community as health must be improving if mortality is declining. Disaggregation of mortality measures by geography, demographic, and socioeconomic factors may offer clues as to how to help improve community health. However, there are many more specific methods of measuring mortality that are also commonly used and standardization of measurement aids comparison across communities and countries.

Maternal mortality ratio (MMR) is the number of maternal deaths per 100,000 live births in one year where a maternal death is defined as the death of a women due to pregnancy or childbirth, during pregnancy, or within 42 days after delivery. Since complications during pregnancy and childbirth are a leading cause of death and disability among women in LMIC, the MMR is an important indicator of women's health. MMR is the subject of the first of the 17 SDG health goal targets—reduce MMR to less than 70 per 100,000 live births by 2030.

Child mortality may be measured in a number of ways and is a good indicator of health among a community's most vulnerable members. Child mortality is usually measured based on specific age-based categories—probability of death within the first month of life (i.e. neonatal mortality), before the first birthday (i.e. infant mortality), before the fifth birthday (i.e. under-5 mortality), and between 5 and 14 years of age (i.e. mortality among children aged 5–14). Neonatal, infant, and under-5 mortality is generally expressed per 1,000 live births, while mortality among children 5–14 is usually per 1,000 children surviving to 12 months of age. Child mortality is also emphasized in the health SDG as the second of 17 health targets—reduce neonatal mortality to less than 12 per 1,000 live births and under-5 mortality to less than 25 per 1,000 live births by 2030. Although many LMIC are still far from meeting these targets, measurement of child mortality is improving, which should help draw attention to the issue and facilitate development of meaningful interventions (see for example **Box 4.2.14**).

Box 4.2.14 Perinatal mortality in Kirakira, Solomon Islands

In a study conducted in the remote, provincial Kirakira Hospital, Solomon Islands, stillbirths, and early neonatal deaths in years 2014 to 2016 were examined to evaluate perinatal mortality rate (Jones et al. 2018).

Method: Birth registry and hospital records

A retrospective audit of birth registry and hospital records was conducted for 2014 to 2016. Perinatal deaths were classified as either stillbirths (i.e. infants that failed to breathe independently after birth) or early neonatal deaths (i.e. infants that breathed independently after birth and subsequently died).

Measure: Perinatal mortality rate

Perinatal mortality rate was calculated as the sum of stillbirths and early neonatal deaths divided by the total number of live births expressed per 1,000.

Result: Persistently very high

A mortality rate of 31 per 1,000 live births was observed, double the 12 per 1,000 SDG target rate, and unchanged over the past 6 years.

Although likely an underestimate since only an estimated 28% of deliveries in the province occurred in Kirakira Hospital, this study found that perinatal mortality was twice the figure officially reported previously for the Solomon Islands.

Morbidity metrics

Morbidity encompasses all conditions that are a departure from being healthy, or in a state of physiological and psychological well-being. There are many ways to measure morbidity in a community, many of which focus on data from RHISs. However, VR, VA, household surveys, and sentinel surveillance systems can also be important sources of data for evaluating morbidity metrics. Similar to mortality indicators, morbidity metrics are generally also easy to grasp as community health improves as morbidity declines and disaggregation by a number of factors may yield clues as to how to help improve health in the community.

Prevalence, or the total number of people living with a particular disease, disability, or injury among a population at a given time (i.e. point prevalence) or within a given time interval (i.e. period prevalence), is a very common measure of morbidity in LMIC since it is fairly easy to measure or estimate. It is also accessible to a broad audience since it is simply expressed as a percentage of the entire population or per some unit of population. For example, in the Russian Federation, the prevalence of chronic hepatitis C Virus (HCV) infection was estimated to be 336 cases per 100,000 people in 2013 (Mukomolov et al. 2016), making it one of the top countries in the world for chronic HCV cases in the world. Prevalence measurement is one of the most straightforward means of evaluating the effect of interventions on burden of disease in a community (see for example **Box 4.2.15**).

Incidence is the occurrence of new cases of disease, injury, or disability in a population. Generally, it may be measured as either a proportion (i.e. the number of newly identified cases among a population) or a rate (i.e. the number of newly identified cases in a population during a measured quantity of observed time). While prevalence measures the cumulative total number of cases regardless of the cases being new or old, incidence measures focus solely on new cases. Measurement of incidence tends to be considerably more difficult as it requires long-term observation of a cohort of people, which may be time and resource intensive.

Causes of death, commonly evaluated for a population as a whole, and for adults (age 15 and older) separately from children (age 14 and younger), may also be used as a good indicator of morbidity. VR is the standard source of information for evaluating causes of death. However, as these data are often incomplete in LMIC, they are supplemented with information obtained via VA and health services records. There are a number of ways to look at causes of death. For example, top causes may be ranked by crude death rates either overall or categorized into communicable diseases, non-communicable diseases, injury, and other causes (e.g. maternal, perinatal, nutritional).

Other metrics

There are a great many other indicators that can make important contributions to community health understanding (see **Box 4.2.13**), which cannot be covered in any depth here. However, careful consideration of metric selection, measurement, and communication is a critical task that must be prioritized early in any community diagnosis effort. Although the limitations in information sources and metrics measurement in LMIC must be recognized, it should not be merely accepted. It is imperative not only that health indicators are pragmatically selected (i.e. select from among metrics that are currently measurable), but also that health information sources are pragmatically developed to achieve the ability to measure health indicators that are important to the future improvement of health in the community they are meant to serve.

Box 4.2.15 Mali trachoma prevalence

A study conducted the Kayes region of Mali underscores the value of using prevalence measures to evaluate the effects of interventions (Traoré et al. 2018).

Background: Trachoma, an eye disease caused by infection, is the leading cause of preventable blindness globally. Endemic in 41 countries, trachoma has been highly prevalent in Mali's southwestern Kayes region. In 2002, Mali implemented the WHO's comprehensive strategy to combat trachoma that focuses on surgery, antibiotics, cleanliness, and water/sanitation. Three rounds of mass drug administrations occurred prior to 2006, and since 2009, surgical, behavioural, and environmental interventions have been scaled up.

Aim: To evaluate the effectiveness of these interventions by measuring trachoma prevalence in Kayes, Mali in 2015.

Method: The 2015 population of the Kayes region was estimated, using census data, to be 2.5 million. A cross-sectional study using two-stage, cluster random sampling was performed in the four Kayes districts with the aid of village authorities to facilitate data collection via household survey with both questionnaire and medical examination components.

Result: A total of 11,620 people were examined. Prevalence of active trachoma among children aged 1–9 years declined below the 5% elimination threshold in all four districts and prevalence of trichiasis among adults >15 years decreased below the 0.1% elimination threshold in three districts.

Conclusion: Trachoma interventions implemented in Mali have successfully improved community health and Mali is nearing trachoma elimination.

Looking forward

There are many good paths forward for community diagnosis and information systems in LMIC. However, to accelerate improvement in community health at any level beyond its current rate, new methods of solving problems and working together toward common goals must be both creative and realistic.

Private–public partnerships for health

Over the past roughly 20 years, some LMIC have engaged in what is now known as international private–public partnerships for health (PPPHs) (Kostyak et al. 2017). This is where a private, for-profit companies (e.g. pharmaceutical companies), typically based in other countries, enter into collaborative relationships with a public, non-profit entities (e.g. national governments) for the purpose of investigating and addressing larger, more expensive public health problems and providing humanitarian aid. These PPPHs can range from the simple, short-term, one-way arrangements (e.g. the pharmaceutical industry has spent billions of US dollars on cash and product donations to LMIC) to the complex, long-term, true partnerships where experience, expertise, and resources are pooled to achieve common health goals that would be out of reach by either party working independently, maximizing benefit to communities while minimizing risk to stakeholders.

The biggest benefits of PPPHs are the acceleration of innovation and research and development and the expansion of access to affordable health interventions. However, many challenges remain.

Geopolitical instability and insecurity make private enterprises reluctant to invest in some countries, gains achieved through PPPHs may be unsustainable beyond the funded period, accountability and oversight is often lacking, and ethical questions abound. Profit-driven private companies may not be motivated purely by altruism, may not measure performance or success by unbiased means, and may not ensure conflicts of interest are properly investigated and adjudicated. Creation of guidelines or regulations governing PPPHs and mechanisms to audit compliance, may mean that LMIC entering into these partnerships can better ensure their people reap the full benefit of these relationships (Kostyak et al. 2017).

Multisectoral collaboration

The interconnectedness and indivisibility of the 17 SDGs was recognized by the UN and heavy emphasis has been placed on cross-sector collaboration and partnerships (UN GA 2015). Like many of the SDGs, ensuring healthy lives and promoting well-being for all at all ages (Goal 3) is unachievable by the healthcare sector alone. However, the healthcare sector has traditionally operated in a very siloed fashion, separated from, for example, the financial sector, the public security sector, the education sector, and others.

All sectors have important, complimentary contributions to make toward achievement of health SDG targets, as well as health goals at regional, national, subnational, and community levels. The untapped potential of multisector collaboration could be a huge difference-maker, particularly for LMIC where this kind of cooperation has perhaps been less common. However, in order to attain full benefit of this kind of coordinated effort, strong leadership is required. Leadership capacity in LMIC must therefore be expanded and not only distributed across sectors, but connected across sectors, to ensure collaboration naturally yields solutions that are inclusive and implementation plans that are practical. Furthermore, it is critical that champions for health 'causes', or targets, are cultivated within the different sectors and they a have clear vision of how each of their pieces of the tactical and strategic work contribute to the larger common goal (Rasanathan et al. 2017).

New technologies

Promising new technologies have the potential to help the field of public health to make more than just incremental steps forward in LMIC. We are only just starting to embark on development of mHealth technologies, and the power of 'big data' is only beginning to be understood and applied. Together with new portable and point-of-care health technologies for clinical diagnosis and evaluation, the possibilities for rapidly collecting enormous data sets from the field and then applying newly emerging data analytics techniques mean global public health is on the precipice of making huge leaps forward.

Conclusion

As an international community, we must renew and redouble our focus on a human-rights based approach to improvement of global public health. One way to do this is through enhancement of community diagnosis in LMIC by helping in the further development of information systems that support the measurement of performance against important and actionable health metrics. Greater sharing across borders of experience and expertise, tools and protocols, and lessons learned from both failures and successes can accelerate development of robust information systems in these settings. The resulting larger quantities of higher-quality data, properly analysed by reliable and validated methods, can yield invaluable information upon which health and public health authorities, funding agencies, international aid organizations, and policymakers can better base critical decisions related to allocation of limited resources, programme development, and implementation, and application of emergency services. This evidence-based, targeted approach will maximize improvements in health in individual LMIC, which will naturally drive the betterment global public health.

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4.3

New communication technologies, social media, and public health

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Introduction

Communication technologies have evolved at a breathtaking pace, and the resulting opportunities to disseminate information and to engage in interpersonal communication have critical implications for public health. These conduits for dissemination of public health content—whether prevention messages, public health advisories or alerts, or clinical or public health guidelines—offer opportunities to reach the right people with the right information more quickly than ever. Considering the public health framework for capitalizing on new communication technologies requires us to consider the technologies themselves, the kinds of content that can be shared, the audiences for such information, and theories of behavioural and systems change. This discussion must also acknowledge that the technology platforms, data speeds, and predominant communications software are heterogenous around the world. In this chapter, we articulate the major dimensions and considerations of the use of new communication technologies for public health, and reflect on important differences in different global public health settings.

Global versus developed country trends in the United States

Two-thirds of the global population are now mobile subscribers with smartphones, accounting for over half of the total connections globally (GSMA Intelligence 2017). According to the International Telecommunication Union, in 2015 there were more than 7 billion mobile telephone subscriptions across the world, over 70% of which were in low-or middle-income countries (International Telecommunications Union 2015; International Telecommunications Union 2017). However, even though smartphone adoption is near saturated in many developed countries, approximately half the world is not yet online. India and sub-Saharan Africa account for 42% of the world's unconnected, with more than 60% of their respective populations not yet on the internet.

Trends in the United States follow a similar pattern, with the digital divide still seen related to income and geographic locations. Roughly three in ten adults with household incomes below $30,000 a year (29%) don't own a smartphone. More than four in ten with low incomes don't have home broadband services (44%) or a traditional computer (46%) (Pew Research Center 2019). By comparison, each of these technologies is nearly ubiquitous among adults in households earning $100,000 or more a year. Rural Americans also remain less likely than non-rural adults to have home broadband, smartphones, and other devices (Pew Research Center 2019).

eHealth has been a priority for the World Health Organization (WHO) since 2005, when the World Health Assembly resolution WHA58.28 was adopted: 'eHealth is the cost-effective and secure use of information communication technologies (ICT) in support of health and health-related fields, including healthcare services, health surveillance, health literature, and health education, knowledge and research'. The WHO Global Observatory for eHealth (GOe) 2015 survey of Member States documented the surge in adoption of eHealth in countries. All 194 WHO Member States were surveyed, of which 125 responded. Slightly more than half of the countries (n = 73; 58%) reported having an eHealth strategy in place (WHO 2016). Of those countries with an eHealth strategy, 69 (94%) reported that they had special funding allocated for the implementation of their strategy

Phone technology, data speed, data replacing cellular, cost structures

Although fixed-telephone subscriptions continue to decline with a penetration rate of 12.4% in 2018, the number of mobile cellular telephone subscriptions is greater than the global population. In 2018, there were more fixed-broadband connections (1.1 billion) than fixed-telephone connections (942 million). The number of active mobile broadband subscriptions have increased from 268 million in 2007 to 5.3 billion in 2018. Mobile broadband is more affordable than fixed-broadband services in most developing countries. However, mobile broadband prices represent more than 5% of gross national income (GNI) per capita in most least developed countries (LDCs) and are therefore unaffordable for most of the population. Nearly the

entire world population (96%) now lives within reach of a mobile cellular network, and most of the global population (90%) can access the internet through a 3G or higher speed network. Declining cost of smartphones and data plans globally is likely to continue and allow for increased access.

Since the inception of mobile phone service, there has been an ongoing trend towards increasing data speed. Data speeds have increased three orders of magnitude since the introduction of 2G service in 1991; the maximum speed of 5G networks (10 Gbps) are nearly 200,000 times faster than the 2G speeds of three decades earlier. These trends are important, because some public health applications of technology (e.g. streaming videos, transmitting high resolution images, video-based counselling, or situational assessments) require faster data speeds. As is the case for coverage of smartphone technologies, access to higher data speeds has substantial variability along dimensions of urbanicity versus rurality, and between low-/middle-income countries and high-income countries.

Multiple social networking channels, time on social network, generational changes

Social media platforms are ubiquitous globally, with substantial differences in use based on geography and demographics (race, age, gender). Within the United States, those ages 18 to 24 are substantially more likely than those ages 25 to 29 to say they use Snapchat (73% vs. 47%) and Instagram (75% vs. 57%). Roughly three-quarters of Facebook users (74%) visit the site daily, including about half who do so several times a day. Roughly eight in ten Snapchat users ages 18 to 29 (77%) say they use the app every day, including 68% who say they do so multiple times day. Similarly, 76% of Instagram users in this age group visit the site daily, with 60% reporting that they do so several times per day.

Popular social media and messaging platforms like Facebook and WhatsApp have drawn attention for their potential role in spreading misinformation, facilitating political manipulation, and increasing violence and hate crimes. However, social media may also have a positive impact on the lives of youth. Most teens aged 13–17 (81%) say social media makes them feel more connected to what's going on in their friends' lives, while around two-thirds say these platforms make them feel as if they have people who will support them through tough times.

Need to anticipate technologies that work for youth

According to a 2017 report by ICT, in developed countries, 94% of young people aged 15–24 use the internet, compared with 67% of young people in developing countries and only 30% in LDCs. The proportion of young people aged 15–24 using the internet (71%) is significantly higher than the proportion of the total population using the internet (48%).

Types of social media

Social media channels constitute a dynamic set of applications that are designed to facilitate the circulation and promotion of information through social connections. Because the specific apps delivering these channels evolve over time, we here describe types of channels and their features, and cite current-day examples of these communication types. They vary largely based on the format of information sharing and length of messages, and on the means of sharing through social networks. Subsequently, we will discuss public health applications of these types of communication channels and provide examples of such applications.

Interaction of technology and public health

Technology-based public health services may interact with members of communities, healthcare providers, and policymakers in multiple ways.

Providing information: Websites, including mobile optimized websites, and apps provide static information on a wide range of topics. For example, public health agencies may provide information and guidelines on topics ranging from vaccine recommendations,[1] local and regional HIV prevention and care plans,[2] and Malaria control.[3] Twitter is used by many public agencies to distribute public health alerts (see **Fig. 4.3.1a**). Formats include text about health programmes or conditions, infographics (which illustrate data through simple illustrations; see **Fig. 4.3.1b**).

Providing counselling or navigation: Chat functions and service locators are used by public health providers to distribute information, make referrals for appropriate services, and provide recommendations for service providers nearest to users. For example, PleasePrEPME: Connect is an online programme to promote appropriate use of pre-exposure prophylaxis (PrEP) that offers chat-based navigation for PrEP to US residents.[4] Services include health systems navigation, identifying appropriate providers, and HIV information.

Behavioural change interventions: The concept of providing behaviour change interventions through eHealth or mHealth channels is appealing for many reasons, including the opportunity to reach people in need of behaviour change services who do not live near public health centres, and the opportunity to provide such services at minimal marginal cost through computer-delivered interventions (Sullivan et al. 2013). In general, excitement about the promise of such interventions has been more consistent than rigorous evidence of the interventions themselves (Evers 2006). In fields as diverse as smoking cessation (Augustson et al. 2016; Ponciano-Rodríguez et al. 2018), diabetes prevention (Joiner et al. 2017), medication adherence (Linn et al. 2011), and engagement in health research (Khosropour et al. 2013), results on the efficacy of eHealth interventions have been mixed. However, newer generations of eHealth interventions feature increasingly interactive technologies (Muessig et al. 2015), and recent reports suggest efficacy of theory-based interventions that include multiple sessions, rich media, and interactive components (Mustanski et al. 2018). Meta-analyses suggest that certain types of interventions may be especially well suited to certain health behaviours (e.g. text messaging for smoking cessation and physical activity (Head et al. 2013)).

Identifying service locations: Other service leverage the geolocation features of computers and smartphones to provide tailored

[1] https://www.canada.ca/en/public-health/services/provincial-territorial-immunization-information/provincial-territorial-routine-vaccination-programs-infants-children.html

[2] https://sanac.org.za/

[3] https://health.go.ug/programs/national-malaria-control-program

[4] https://www.pleaseprepme.org/sites/default/files/file-attachments/PleasePrEPMe%20Connect%20AIDS%202018_0.pdf