

Neglected Health Systems Research: Health Information Systems

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Key Messages

- Sound health statistics are essential for health decision-making at all levels of the health system, whether for individual patient care, for the management of specific health programmes or at the policy level where strategic decisions are made;
- Although, the connections between health information systems and research are typically thought of in terms of the role of the health information system in contributing data for research studies, the health information system itself also has research needs;
- With the scale up of overseas development aid there is now increased attention on tracking performance, monitoring progress and evaluating effectiveness, efficiency and impact. But the information systems needed to deliver sound data are weak and often fragmented by disease-focused data requirements related to donor initiatives;
- Multiple needs for health information systems can be identified, but it seems that the most pressing need is for different types of implementation research that document the strategies used to strengthen health information systems, their effectiveness, costs and unanticipated effects;
- In order to move the agenda of research on health information forward, three key actions are proposed:
 - Develop consensus around a prioritized research agenda;
 - Enhance communication between researchers and health information experts;
 - Mobilize resources for research in this field especially implementation research.

Background

Sound health statistics are essential for health decision-making at all levels of the health system, whether for individual patient care, for the management of specific health programmes or at the policy level where strategic decisions are made. The World Health Organization (WHO) has defined the health information system as an "integrated effort to collect, process, report and use health information and knowledge to influence policy making, programme action and research." (WHO 2003).

Health information is much more than collecting figures. Data have no value in themselves; value and relevance come when they are analysed, transformed into meaningful information and used. *"The ultimate objective of a health information system is to produce information for taking action in the health sector. Performance of such a system should therefore be measured not only on the basis of the quality of data produced, but on evidence on the continued use of these data for improving health systems operations and health status."* (Routine Health Information Network 2003). A health information system is thus not a static entity but a process whereby health-related data are gathered, shared, analysed, and used for decision-making in health – information is transformed into knowledge for action.



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The boundaries of the health information system are not confined to health; there is strong inter-dependence of health information systems with information systems in other sectors. For example, higher female literacy is associated with higher compliance with home treatment for diarrhoea/dehydration in infants; improved sanitation is associated with increased child survival; food and nutrition policies affect the health of children and adults alike. Making links such as these and identifying broad areas of data common to health and other sectors is properly within the responsibility of a health information system. Within the health sector, different types of information are generated, ranging from data on the management and administration of health services to health system outputs such as coverage and quality of care. Although the health system has a particular interest in health outcomes, notably mortality, such data are not always generated through the health sector.

The health information system is a core building block of the health system as a whole and provides the data needed for other building blocks, such as human resources, financing, and service delivery, to perform their functions (WHO 2007). The health information system is also a component of a wider statistical system that generates data across all sectors. Many of the data sources upon which a health information system draws, are also used to generate data for other sectors. The decennial census, the civil registration system and household surveys are examples of data sources serving multiple sectoral statistical needs.

The connections between health information systems and research are typically thought of in terms of the role of the health information system in contributing data for research studies. But the health information system itself also has research needs. This paper addresses this question: how research can contribute to the strengthening of health information systems.

A conceptual framework for health information systems

The Health Metrics Network (HMN) has contributed significantly to our understanding of health information systems. A conceptual framework for the health information system maps the interrelationships between the **demand** for data at different levels of the health care system, the **supply** of statistics from

multiple sources, and the transformation of data into information for **use** in decision-making. This mapping will permit an assessment of the effectiveness of the health information system in bringing together demand and supply for efficient generation of data and their use at all levels of the health system, from patient and facility management to strategic decision-making and resource allocation (HMN 2008)

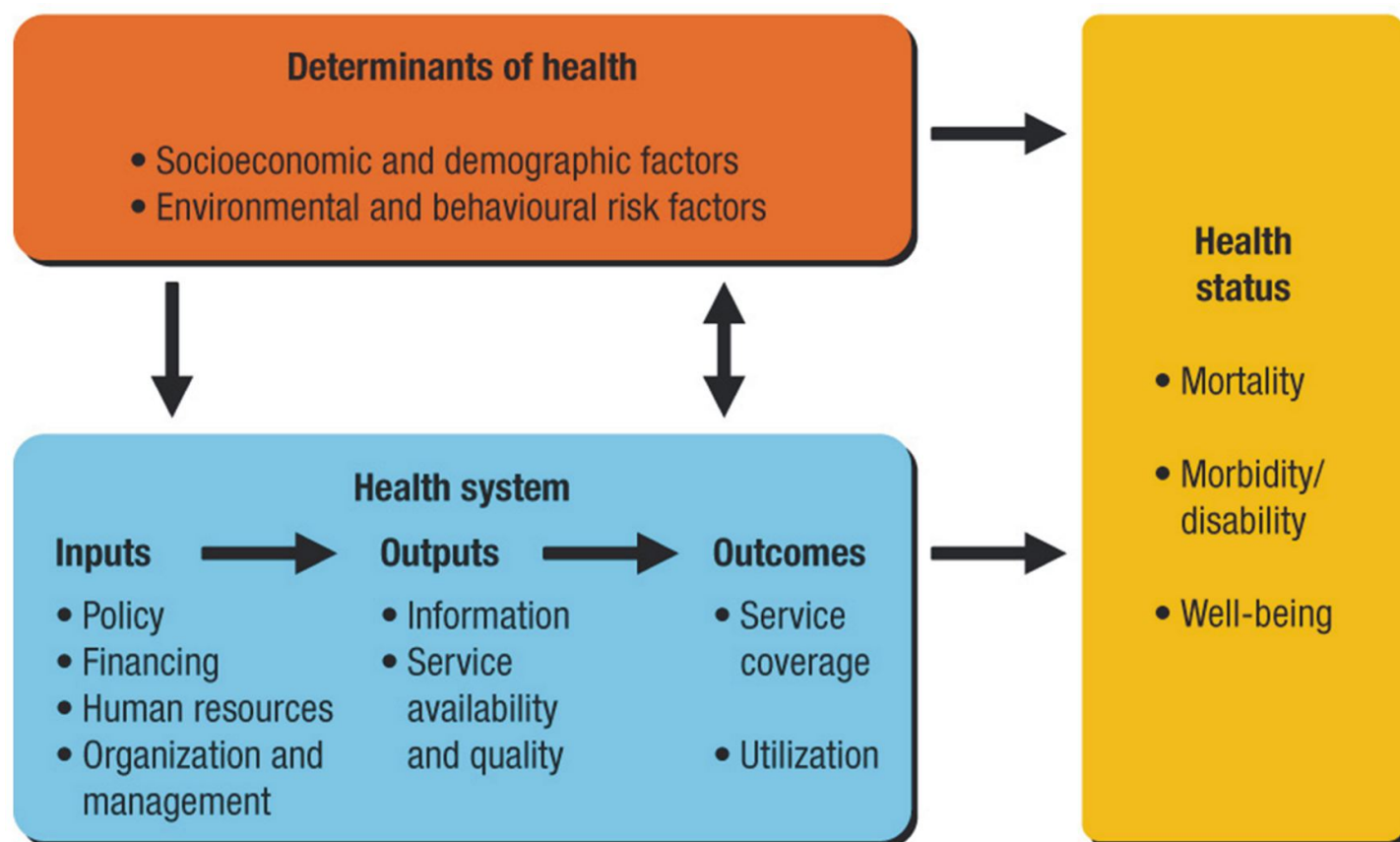
Demand

Health planners and decision-makers need different kinds of information (Figure 1) including:

- health determinants (socio-economic, environmental, behavioural, genetic factors) and the contextual environments within which the health system operates;
- inputs to the health system and related processes including policy and organization, health infrastructure, facilities and equipment, costs, human and financial resources, health information systems;
- the performance or outputs of the health system such as availability, accessibility, and quality of health information and services, responsiveness of the system to user needs, and financial risk protection;
- health outcomes in terms of the utilization or coverage of services;
- and health impact (a function of many external factors and determinants, not only health system activities) as described by levels of mortality, morbidity, disease outbreaks, health status, disability, wellbeing.

Cutting across all these domains of health information is the need to be able to generate data on health inequities, in terms of determinants, coverage of use of services, and health outcomes, and including key stratifiers such as sex, socio-economic status, ethnic group, geographic location etc.

DOMAINS OF MEASUREMENT FOR HEALTH INFORMATION SYSTEMS



Source: Health Metrics Network (2008)

Fig.1

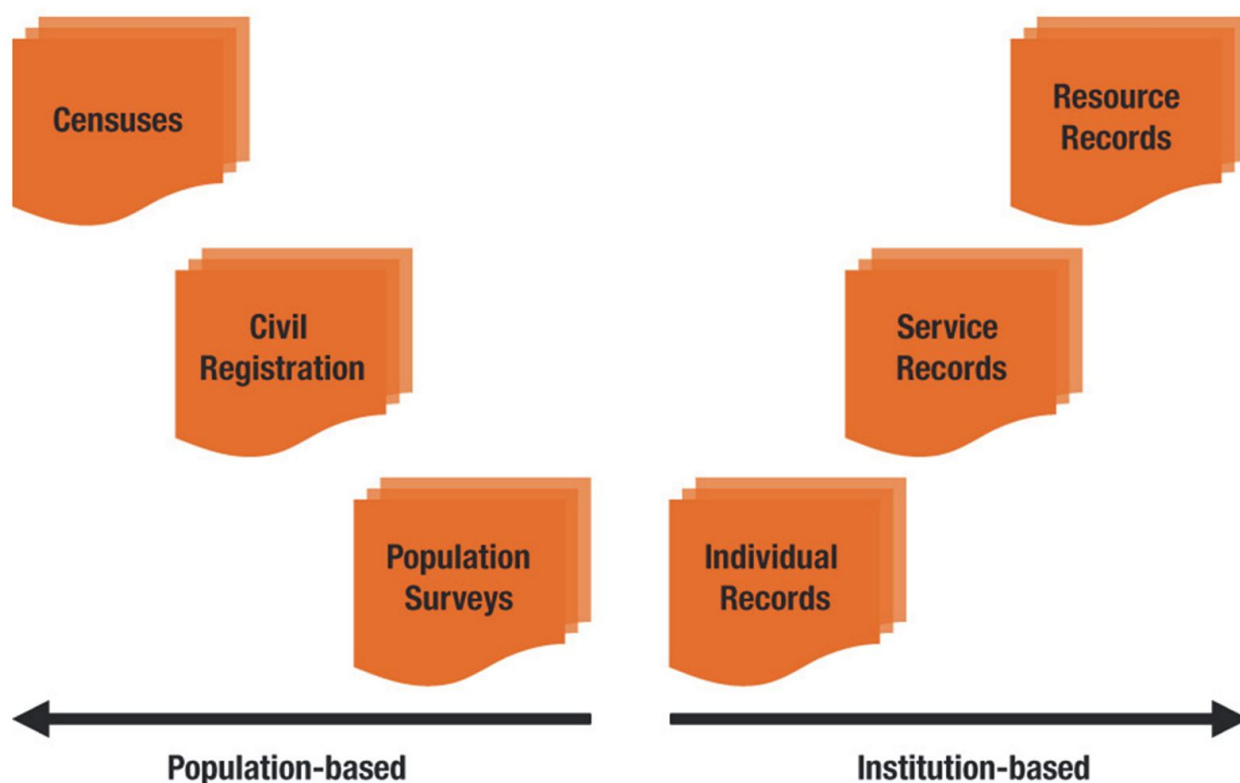
Supply

Health information system data are usually generated either directly from **populations** or from the operations of health and other **institutions** (Figure 2).

- **Population-based** sources generate data on all individuals within defined populations and can include total population counts (such as the census and civil registration) and data on representative populations or subpopulations (such as household and other population surveys). What these data sources have in common is that they relate to the whole population, not only to groups using institutional services. Such data sources can either be continuous and generated from administrative records (such as civil registers) or periodic (such as cross-sectional household surveys);
- **Institution-based** sources generate data as a result of administrative and operational activities. These activities

are not confined to the health sector and include police records (such as reports of accidents or violent deaths), occupational reports (such as work-related injuries), and food and agricultural records (such as levels of food production and distribution). Within the health sector, the wide variety of health service data includes morbidity and mortality data among people using services; services delivered; drugs and commodities provided; information on the availability and quality of services; case reporting; and resource, human, financial and logistics information.

HEALTH INFORMATION DATA SOURCES



Source: Health Metrics Network (2008)

Fig.2

Most data on the provision of clinical services or health status at the time of clinical encounters are generated "routinely" during the recording and reporting of services delivered. Health facility surveys, involving data collection from a representative sample of health facilities, provide another important methodology for collecting data on health services and for validating routine health service data by observing service delivery, inspecting facilities, interviewing staff and clients, and reviewing archives.

It is clear that no single data-collection or research method can provide the broad range of information required by countries. Disease surveillance, for example, draws on data from a wide range of different data sources. The most appropriate data sources will depend upon the information required and the cost-effectiveness and feasibility of individual methods (Table 1). The optimal choice will depend upon a range of factors, including epidemiology, specific characteristics of the measurement instrument, programme needs, cost and the human and

technical capacities required to collect, manage and disseminate data.

Information about the functioning of the health information system can be obtained from the different sectors and agencies that have responsibilities for the generation, synthesis, analysis and use of data. At country level, ministries of health record the timeliness and quality of data reported through health services and disease surveillance systems. National Statistics Offices maintain information about the availability and quality of data generated through the decennial census, large scale household surveys, and the civil registration system. As custodians of national official statistics, they often have explicit requirements for the way data are collected, compiled and shared, and adhere to the Fundamental Principles of Official Statistics (United Nations 1994). International agencies working in health also maintain information about the availability and quality of data on international health goals, including but not limited to the Millennium Development Goals.

TABLE 1 - SOURCES OF DATA FOR HEALTH INDICATORS BY DOMAIN

| | Determinants of Health | Health Systems | | Health status |
|---------------------------|---------------------------|-----------------------|--------------------------------|------------------|
| | | Inputs and outputs | Outcomes (coverage and use) | |
| Censuses | • | • | | • |
| Civil Registration | • | | | • |
| Population Surveys | • | • | • | • |
| Individual Records | • | • | • | • |
| Service Records | | • | • | • |
| Resource Records | | • | | |

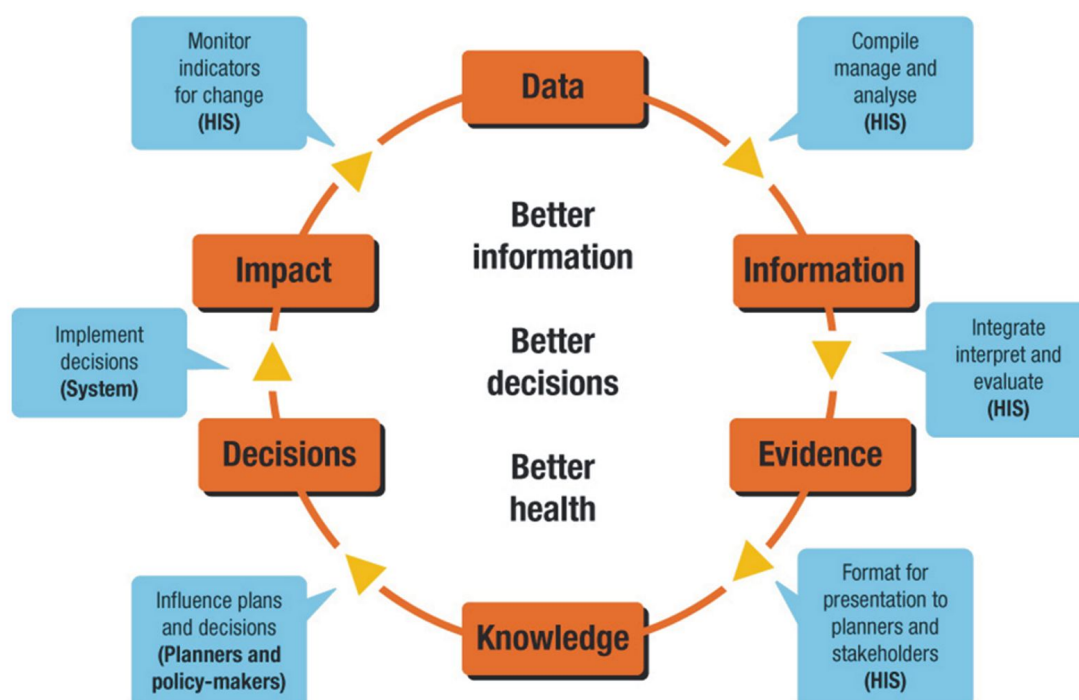
Source: Health Metrics Network (2008)

Use

Demand and supply deal with data, the raw materials of a health information system. In reality, raw data alone are rarely useful; they need to be converted into credible and compelling evidence that informs local health system decision-making. Only after data have been compiled, managed and analysed do

they produce information (Figure 3). At present, health information systems in many low- and middle-income countries tend to be “data-rich” but “information-poor”. Information is of far greater value when it is integrated with other information and evaluated in terms of the issues confronting the health system.

TRANSFORMING DATA INTO INFORMATION AND EVIDENCE



Source: Health Metrics Network (2008)

Fig.3

Why is research on health information systems needed?

Resources for health interventions have surged over the past few years, both because national governments are spending more on health but also from external sources such as a number of networks, alliances, and partnerships for health. There are currently over 100 global health partnerships (GHPs), some of which are funding entities whereas others focus on advocacy, research or coordination. Although highly diverse in terms of legal status, size, composition, structures and goals, the GHPs commit to accelerating the achievement of specific health goals, demonstrating performance and measuring results. In general throughout the development community, there is now increased attention to tracking performance, monitoring progress and evaluating effectiveness, efficiency and impact. With some US\$ 120 billion of overseas development aid currently allocated to health, questions of value for money cannot be left unanswered.

At the same time there is increasing awareness on the part of national policy makers as to how data and other evidence can strengthen policy and decision making. As civil society organizations and other stakeholders become more active in policy development these groups are also beginning to ask for up-to-date and reliable information to inform their policy positions (Alliance HPSR 2008).

The problem is that tracking performance and measuring results are difficult; the statistical information systems needed to deliver sound data are weak, especially so in the countries to which global health investments are ostensibly directed. Whereas demand for better health statistics is growing, supply is fragmented by disease-focused data requirements related to donor initiatives. Intense pressure for the rapid availability of data, driven by performance-based funding, contributes to the establishment of disease-specific, stand alone information systems that are poorly integrated into national health information systems and thus unlikely to be sustainable once external funding ceases. Countries are overwhelmed by multiple, and often parallel, information demands. Health workers are overburdened by excessive reporting requirements. Responsibilities are divided among different ministries or institutions, and coordination may be difficult due to financial and administrative constraints. Of the vast amount of data collected, only a small proportion is synthesized, analysed and used.

Emerging awareness of the imbalances between demand and supply in health statistics has spurred the development of initiatives to address the situation (AbouZahr and Boerma 2005). These initiatives explicitly note the need for increased research and development of new tools and methods that will permit a better match between supply and demand for health information and enhance country capacities for data generation, analysis and use.

Why is the research agenda in health information neglected?

Despite the recognition of the importance of strong health information systems, there has been little attention given to research needs in this area. It is widely acknowledged that a core responsibility of an effective health information system is to deliver useable statistics that will enable informed policy making and health system management and provide a platform for research. However, the health information system itself also has research needs. Currently, the relationship between health statistics and research is unidirectional, with a focus on activities that will generate better data for research purposes, rather than on research questions that need to be answered in order to improve health data in general. While research is often undertaken to develop methodologies for disease-specific data generation, for example for malaria, HIV, maternal and child health etc, research on ways of strengthening the health information system overall, independent of disease specific concerns, is lacking.

Even within organizations whose mandate is to strengthen health systems, research is rarely directed at improving the health information system component. One current publication, while recognizing weaknesses in the quality of information on which policy-makers base decisions, offers no guidance on the kinds of research questions that need to be answered in order to improve the availability and quality of data (Varkevisser, Pathmanathan and Brownlee 2003).

The Global Forum for Health Research does not include research on health information system strengthening among its current priorities (Global Forum on Health Research 2008). The three priority research areas identified by the Alliance for Health Policy and Systems Research are the health workforce, health financing and the role of the non state sector (Alliance HPSR 2008). An exception to the general rule is the Disease Control

Priorities Project (Stansfield *et al.* 2006) which includes a section on research and development needs within an overall chapter on health information. Why has this area of research been neglected? In part the neglect is a reflection of the general under-investment in health information systems. Health information is a particularly difficult area in which to invest energies and research resources. Systematic data collection at national level is a fairly recent phenomenon even in developed countries. In many countries, data collection is decentralized and thus prone to lack of standardization in terms of terminology, coverage, data collection methodologies and presentation. Collecting sound data at national level requires human and financial resources, as well as organizational, analytical and statistical skills and capacities that are constrained in many developing countries.

Further, improved information may be perceived as not having direct impacts on health outcomes but, rather, as a precondition or by-product of activities designed to improve health. There are few incentives for researchers to focus on the underlying statistics, which are seen as merely instrumental to the higher goal of demonstrating impact.

How research on the topic would make a difference ?

The range of research issues in health information systems can be classified into four broad types: overall health information systems strengthening at national and sub-national levels; strengthening specific data sources; enhancing demand for sound data; strengthening data analysis, dissemination and use. Within each of these broad areas, different types of research efforts are required, addressing conceptual issues; development and testing of methodological tools; and field-based, implementation or operations research. Table 2 summarizes the views of the authors on where the priorities lie. The text below elaborates on the type of research that may be useful with respect to each of these research needs. The ideas presented in this section do not reflect the outcome of a structured priority setting process, rather, the breadth and scope of possible important research is described.

TABLE 2 - RELATIVE PRIORITY BY TYPE OF RESEARCH NEED

| Range of research needs | Type of research needed | | |
|---|-------------------------|--|-------------------------------------|
| | Conceptual development | Methodological tools development and testing | Field work; implementation research |
| Systems building for health information | ++ | + | +++ |
| Enhancing demand for data | + | + | ++ |
| Strengthening specific data sources | + | +++ | +++ |
| Strengthening data analysis, and use | + | ++ | +++ |

Key: +++ Highest priority
 ++ High priority
 + Priority

Systems building for health information

Conceptual development

Research is needed to map and identify strengths and weaknesses of different policy frameworks and organizational structures for health information systems in various settings and levels of development. Documentation of the information value chain, with special attention to improving the identification of information needs, overcoming disincentives to information sharing, and enabling better use of information, would help to strengthen the case for investment in health information in a systemic way as opposed to fragmented, project-based monitoring and evaluation (Stansfield *et al.* 2006). Research would be of particular value in identifying low-cost health information systems appropriate to the needs of poor countries with high burdens of disease.

Methodological development

There is an urgent need for tools for use at district level to generate data on health status as well as health system performance and readiness, such as human resources, health infrastructure, and finance. The challenge is to develop methods and tools that would improve effectiveness in data collection while reducing costs in resource constrained settings. For example, innovative approaches to sampling are needed to enable population-based data generation at district level with minimal bias and reduced sample sizes. This is especially relevant in the context of performance-based funding strategies which require timely and affordable data to solve management problems (Kleinau 2009).

Implementation research

A major constraint to mobilizing resources for health information systems is the absence of reliable data on what resources are required. Currently, estimates of the annual cost of a comprehensive health information system range from US\$ 0.53 to US\$ 2.99 per capita (Rommelman *et al.* 2004, Stansfield *et al.* 2006). Implementation research could help document resource requirements in countries at different levels of development and capacity. Costing should take account of both human resource needs and investments in information technology. Implementation research is also needed to determine cost-effectiveness of different tools for field-based data capture, instantaneous data transmission, GIS-based mapping of indicators (O'Carroll 2003).

There is a need to document lessons learnt on how to improve coordination in data collection activities supported by different partners and how to introduce greater integration of monitoring and evaluation without loss of quality. It is also important to document experiences in fostering closer integration between the ministries of health and national statistics offices (Economic Commission for Africa 2003).

Implementation research could help answer questions such as the costs, benefits and potential unintended effects of allocating responsibility for health monitoring and evaluation to independent or quasi autonomous bodies such as academic institutions.

Enhancing demand for data

Conceptual development

Little is known currently about what motivates decision-makers to use data appropriately when determining health policy or allocating resources. There is a need for research to identify what kinds of approaches are most successful in making health statistics more relevant and meaningful to potential users, including policy-makers, donors, individuals and communities (Bailey and Pang 2004).

Methodological development

Tools are needed for accelerating equitable access to information and improving the management and use of knowledge for improved health (Pappaioanou *et al.* 2003).

Implementation research

A critical area for research is the ability to demonstrate the extent to which improved health outcomes and lower costs can be attributed to investments in better health data (Zayan *et al.* 1992).

Implementation research is needed on the effectiveness or otherwise of participatory approaches to empowering health managers and planners to use information for decision-making. This could enable the compilation of best practices in improving demand for, access to and understanding of information and knowledge (Loevinsohn 1994).

Strengthening specific data sources

Conceptual development

Research is needed on how to identify and implement strategies to overcome barriers to registration of vital events at community level, for example, community awareness building, use of financial and other incentives.

Methodological development

Research and development is needed on innovative statistical techniques that would enable the use for public health decision-making of incomplete and biased data such as hospital records and incomplete civil registration records. There is an urgent need for field-testing and validation of sentinel methods of vital events monitoring and cause-of-death attribution and for validation of verbal-autopsy tools for attributing cause of death in setting where deaths are not medically certified.

Implementation research

Demand is increasing for documentation of experiences and best practices in enhancing the monitoring of vital events, including training in certification and coding causes of death. There is a need to bring together examples and best practices in ensuring the integration of data from the private health care sector into the health information system and the role that incentives and regulation might play in this process (Duran-Arenas *et al.* 1998). Documentation is needed on lessons learnt in the use of field-appropriate and cost-effective diagnostic technologies to obtain biomarkers in household surveys (Boerma *et al.* 2001).

Strengthening data analysis and use

Conceptual development

Whereas there is a widespread appreciation among scientists of the need for statistical and demographic techniques for correcting data for missing values and bias, such corrections are not well understood by policy-makers. Research is needed on how to present complex statistical issues such as uncertainty in ways that are understood and accepted by users.

Methodological development

Research is needed to formulate strategies for overcoming the technical, behavioural and environmental constraints that impede effective data use at different levels of the health care system.

Implementation research

In the broad area of data presentation, dissemination and use, there is a need for research to document the effectiveness of different kinds of interventions, including:

- skills building for health workers to generate, interpret, disseminate, use and value health information;
- effectiveness of training, supervision, feedback and incentive schemes in improving data quality;
- effectiveness of information-dissemination methods to enhance information use by different audiences (such as health facility managers, policy makers, community groups);
- sociocultural factors and constraints affecting information use;
- community involvement in the analysis of data/indicators, and in using the results to improve health care seeking behaviour;
- software database applications for data management, presentation and dissemination, including public health mapping. These should be open-source, end-user-friendly and flexible, while remaining stable.

From this large research agenda, the HMN Technical Advisory Group (TAG) and Board have identified a few key priorities that HMN will promote (HMN 2007). The priorities cover each of the four areas described above but all focus on implementation research. While implementation of this research agenda remains in abeyance pending further resource mobilization, the initial priorities include:

- **Systems building for health information - Assessing the cost and economic value of better information:**
Documenting the impact of reductions in uncertainty in health statistics on morbidity and mortality indicators, causes of death and health system performance. The research would examine resource allocation and policy decision-making before and after an intervention to improve the quality of health information;
- **Enhancing demand for data - Using district health accounts (DHA) to track donor funding flows:**
Documenting spending on health services and public health programmes in order to enable effective use of limited resources in developing countries;

- **Strengthening specific data sources - *Development and testing of simple methods for assessing local coverage with key interventions:*** Initial statistical methodological work is needed to devise simple and credible methods for assessing local coverage;
- **Strengthening data analysis and use - *Measuring the health impact of sharing information with citizens:*** Implementation research to study how information can be used at local levels to produce an improvement in the way communities and individuals make use of the health system and derive improved health outcomes. Anecdotal evidence suggests that when citizens are informed about their access to and use of health services, their utilization and coverage of those services can improve.

Moving forward

There are multiple barriers to increased research in health information systems that need to be overcome. Increased funding is part of the solution but equally important is the need to stimulate the interest of researchers in this neglected field and to increase demand for more evidence-based approaches to health information system strengthening on the part of country policy-makers, development agencies and donors. Advocacy is needed to alert the research community to the need for research on health information systems (Sauerborn and Lippeveld 2000). Such research should be embedded as an integral part of health systems research overall, and not assumed to be confined to the monitoring and evaluation component.

This paper has sought to make the case for increased attention to health information systems on the part of health researchers. Both the research community and those working in health information can benefit from enhanced communication and collaboration. The health information community needs to become involved in research in order to overcome critical constraints that prevent sound data from being collected, compiled, analysed, disseminated and used to improve health. On the other hand, the health research community should be able to draw upon the outputs of the health information system in conducting research and should not have to implement special data collection exercises except in special circumstances.

The interface between these two constituencies is particularly relevant when it comes to the evaluation of health interventions and programmes. Whereas monitoring often draws upon health data available through routine systems, evaluation, requires measurement of impact, that is, improvement in outcomes such as health status. The ongoing and comprehensive measurement of health status cannot be implemented in cost-effectively by stand-alone programmes or ad hoc research efforts but is dependent on the foundation of a statistical and health information system. Evaluation may also involve the synthesis of available information, coupled with statistical modelling strategies to correct for data deficiencies and bias and thus needs to draw upon the skills and experiences of both researchers and health information system specialists.

In order to move this agenda forward, three key actions are proposed:

- **Develop consensus around a prioritized research agenda -** This paper has made an initial attempt to describe broad areas of research need in relation to health information systems. A more systematic development of a research agenda is now required, drawing in a variety of stakeholders from the research, statistical and health information constituencies and including both producers and users of health data;
- **Enhance communication between researchers and health information experts -** Mechanisms are needed both at global level, but also, more importantly in countries to promote exchange between these two communities. Currently, the involvement of the research and academic communities in health information system strengthening is the exception rather than the rule. However, researchers have potentially a critical role to play especially in relation to developing and applying new methods for data generation and analysis and in ensuring the objectivity, transparency and quality of data dissemination;
- **Mobilize resources for research in this field especially implementation research -** Current interest in the evaluation of large scale health initiatives such as health partnerships and funds offer opportunities to strengthen evaluative research in relation to health information systems. Strategies to leverage such resources should be developed.

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The Alliance for Health Policy and Systems Research is an international collaboration based within the World Health Organization (WHO), Geneva, aiming to promote the generation and use of health policy and systems research as a means to improve the health systems of developing countries. Specifically, the Alliance aims to:

- Stimulate the generation and synthesis of policy-relevant health systems knowledge, encompassing evidence, tools and methods;
- Promote the dissemination and use of health policy and systems knowledge to improve the performance of health systems;
- Facilitate the development of capacity for the generation, dissemination and use of health policy and systems research knowledge among researchers, policy-makers and other stakeholders.

This brief was written by Carla AbouZahr and Alison Commar of the Department of Health Statistics and Informatics, World Health Organization, Geneva with inputs from Sara Bennett, Alliance for Health Policy and Systems Research. The brief was technically reviewed by Don De Savigny, Swiss Tropical Institute.

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