# Strengthening health information systems to address health equity challenges

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**Abstract** Special studies and isolated initiatives over the past several decades in low-, middle- and high-income countries have consistently shown inequalities in health among socioeconomic groups and by gender, race or ethnicity, geographical area and other measures associated with social advantage. Significant health inequalities linked to social (dis)advantage rather than to inherent biological differences are generally considered unfair or inequitable. Such health inequities are the main object of health development efforts, including global targets such as the Millennium Development Goals, which require monitoring to evaluate progress. However, most national health information systems (HIS) lack key information needed to assess and address health inequities, namely, reliable, longitudinal and representative data linking measures of health with measures of social status or advantage at the individual or small-area level. Without empirical documentation and monitoring of such inequities, as well as country-level capacity to use this information for effective planning and monitoring of progress in response to interventions, movement towards equity is unlikely to occur.

This paper reviews core information requirements and potential databases and proposes short-term and longer term strategies for strengthening the capabilities of HIS for the analysis of health equity and discusses HIS-related entry points for supporting a culture of equity-oriented decision-making and policy development.

**Keywords** Information systems/organization and administration/standards; Delivery of health care; Social justice; Health status indicators; Socioeconomic factors; Demography; Data collection; Databases, Factual; Policy making; Developing countries (*source: MeSH*, *NLM*).

**Mots clés** Système information/organisation et administration/normes; Délivrance soins; Justice sociale; Indicateur état sanitaire; Facteur socioéconomique; Démographie; Collecte données; Choix d'une politique; Pays en développement (*source: MeSH, INSERM*).

**Palabras clave** Sistemas de información/organización y administración/normas; Prestación de atención de salud; Justicia social; Indicadores de salud; Factores socioeconómicos; Demografía; Recolección de datos; Bases de datos factuales; Formulación de políticas; Países en desarrollo (*fuente: DeCS, BIREME*).

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#### Introduction: why measure health equity?

Health equity is the absence of health differences between more and less socially advantaged groups (1). Sen (2) and others have argued that health equity is a central dimension of overall social equity or justice, as it conditions the capabilities of individuals and groups to participate in and benefit from social and economic development. Without specific attention to equity issues, societies tend towards inequity, as social advantage and disadvantage come to be seen as natural and inevitable, while socially disadvantaged groups and individuals generally lack the political voice to challenge the status quo. Societies that wish to increase equity in health must therefore be able to:

- identify health inequalities; and
- differentiate health inequalities reflecting random variation or immutable biological differences from those that could be decreased through medical, public health or social policy interventions feasible for a given context.

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#### Special Theme – Health Information Systems

Health information systems and equity challenges

This paper proposes strategies to support a more systematic identification and understanding of health inequities through health information systems (HIS), particularly in low- and middle-income countries (LMIC), to support a culture of equity-oriented decision-making and policy development.

#### Current knowledge

For several decades, studies have consistently shown inequalities in health among socioeconomic groups and by gender, race or ethnicity, geographical area and other social categories (3–6); these inequalities are widely recognized to be important challenges both to health development and to the creation of a just society. Strong HIS incorporating both population and facilitybased data are essential in helping governments to demonstrate and address such inequalities, but HIS currently provide few of the data needed. Because health inequities generally reflect imbalances in power and wealth in society, addressing them requires strategic action. Better information alone is not sufficient to resolve the problems; continuous monitoring of inequities, as well as country-level capacity to use this information for effective planning are also required for progress towards health equity and movement towards social justice in health to take place.

Studies have revealed health inequities such as higher mortality rates in poor children than in children from wealthier families (7), as well as significant barriers to accessing quality health care faced by aboriginal populations or ethnic minorities (8). Such studies have proven invaluable in promoting proequity policy, but only when the political will and technical capacity to translate information into policy and action was present. In countries with HIS that routinely incorporate equity information, pro-equity decisions can be more readily translated into health policy. For instance, Chile's ongoing, nationwide CASEN (Encuesta de Caracterización Socioeconómica Nacional) household survey, which monitors living conditions was recently revised to include health data, led to broad, explicitly pro-equity reforms of health and other social sector policies (8) (see Fig. 1). Until equity-oriented information collection and analysis have been institutionalized throughout the health information system rather than through isolated initiatives, it is unlikely that governments and health development agencies will be able to secure comprehensive, long-term, and effective reductions in health inequities.

#### Data required for equity analyses

Health equity is the absence of systematic health differences between more and less socially advantaged groups; it is based on principles of justice, reflecting equal opportunity for all people (individuals and groups) to be as healthy as possible (1). To document the existence or magnitude of health inequities, data are required on:

- a measure of health; and
- a measure of social position or advantage (an "equity stratifier") that defines strata in a social hierarchy.

The magnitude of health inequities across different social strata can then be summarized using simple calculations such as rate ratios and rate differences, or more complex calculations such as the slope index of inequality (10–13).

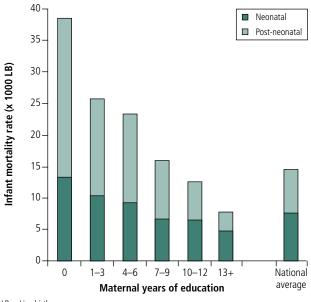
Combining health measures and equity stratifiers in particular ways can yield policy-relevant information that also reveals a basic injustice in society. For instance, in Nairobi,

Kenya, documentation of (the existence as well as) the educational and health needs of the 60% of the population living in slums led to the provision of city services for them (8). In 1982, when the mortality rate in young girls in Bangladesh was found to be between 6.7 and 21.1 times higher than that in young boys, depending on parental educational level, local organizations campaigned for women's rights, enrolled girls in schools, and increased access to health care. By 1996, these and other actions had reduced the gap significantly, with female mortality rates between 1.8 and 2.3 times higher than male rates (8) (see Fig. 2). The choice of which health measure and equity stratifier to focus on in a particular context will depend on priority health and human rights challenges, policy information needs and opportunities for effective action. Having a range of health measures and equity stratifiers within the HIS facilitates timely recognition of emerging or hidden inequities, and improves accountability for protecting vulnerable populations. Specific health measures and equity stratifiers that inform pro-equity policy are described below.

#### **Health measures**

Ideally, core health indicators should cover a range of categories, including health status, health care and other determinants, and the social and economic consequences of ill health. Useful health status indicators for equity analyses include mortality, morbidity, nutritional status, functional status/disability, and suffering/quality of life. Health care indicators include access to and utilization of public health care facilities and preventive and curative services, as well as quality of services, allocation of financial and human resources, and household financing and insurance. Access to safe water and sanitation traditionally falls within the public health realm in developed countries and is increasingly recognized as a core public health service in LMIC. Key health determinants that are currently measured and addressed unevenly across countries include food security,

Fig. 1. Data such as these spurred health reform in Chile explicitly focused on equity issues. Infant mortality rate according to maternal years of education in Chile, 1990–95

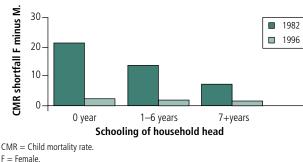


LB = Live births.

Source: ref. (9). Reproduced with permission of the author.

WHO 05.96

Fig. 2. The gap in mortality rates between boys and girls for families of low, medium, and high educational levels in Bangladesh fell significantly following monitoring and equity-oriented interventions. Gender gap in child mortality by head of household educational level in Bangladesh in 1982 and 1996



M = Male.

Source: Bhuiya et al., 2001 (14). Reproduced with permission of the author. WHO 05.97

environmental conditions, war and other types of violence, social networks, and individual risk factors such as tobacco use, excessive alcohol use and sedentary lifestyle. Finally, acute and chronic ill health have different social and economic consequences for different social strata, e.g. catastrophic illness can cause or exacerbate household poverty among disadvantaged groups where there is no social protection.

#### **Equity stratifiers**

Virtually everywhere in the world, social advantage varies by four general equity stratifiers — socioeconomic status, gender, ethnicity and geographical area (6, 7, 15–20). These stratifiers interact in complex ways, and subgroups defined by several characteristics of these equity stratifiers are at a particular disadvantage, e.g. poor women in a marginalized ethnic group.

Socioeconomic position can be reflected by economic resources, education, and/or occupation. Household wealth or assets is a particularly meaningful measure of economic resources because accumulated assets can be used (e.g. when income is temporarily low) to cover health care expenses and maintain a standard of living that promotes health. Schooling (educational attainment) and occupation are important indicators of social status in their own right, but should not be viewed as proxies for wealth or income.

Sex or gender are meaningful equity stratifiers for many, but not all, health measures. For example, low birth weight according to sex of the infant is not meaningful for equity analysis because it is not amenable to social policy, but analysing differences in prevalence rates of malnutrition between boys and girls is meaningful because it indicates discriminatory treatment (4).

Discrimination against ethnic or racial groups can have serious health and social effects (4, 6). Indicators for characterizing ethnicity include self-identification, social perception of race or ethnicity, religion, language spoken at home, tribal affiliation, or status as an immigrant or native-born citizen.

Finally, groups can be advantaged according to the geographical area (e.g. urban versus rural, or better- and worse-off provinces or districts) where they live or work. Resources are often allocated on a geographical basis, reflecting both logistic issues such as distance, topography and transport as well as the tendency for political power to be concentrated in urban areas or particular regions. Comparing allocations of health measures across different provinces and districts is useful, and such comparisons are easily understood by non-specialists.

#### Linking data

Monitoring health inequities is easiest if the data on health and stratifiers are derived from the same data source. If this is not possible, a mechanism is needed for linking health data from one database to stratifiers in another. Furthermore, the data must be assessed at the same unit of analysis, be it at the individual, household, or small-area level. The feasibility of linking data between sources varies between and within countries, for reasons that include technical coordination, resource constraints and legal restrictions. The easiest scenario for linking records is simply to match a unique identifier in both databases. This may be an individual's unique identifier for a small area (e.g. a census tract, postal code or village name).

Although unique identifiers for individuals are the most useful, to avoid complex legal and ethical issues related to the confidentiality of data on individuals, and to move forward quickly, a feasible short-term recommendation is to incorporate small-area identifiers into all sources. For the longer term, national and international institutions should develop legal frameworks for incorporating unique identifiers and sharing disaggregated data while preserving anonymity and privacy. Finally, individual and institutional technical capacity for data source linkage must be developed as part of the tool kit of equity work (21-34).

# Potential of common databases to provide data on equity

The databases that show the most promise for sustainability and maximum impact on equity include censuses, vital registration systems, household surveys, small-area data and administrative data. Factors to consider for each database include which health measures and equity stratifiers are currently available, how the information can be used, and what changes could improve the potential for equity analysis.

#### Censuses

In many countries censuses are often the only available source of socioeconomic information, and censuses and vital registration systems that cover the entire population provide essential denominator data. Although some censuses focus only on population size by age and sex, many provide information on socioeconomic status, ethnicity and geographical area. Information on health status is, however, limited. Disaggregating census data is difficult, and linking data at the individual level is often impossible because records generally do not include unique identifiers. Recommendations for improving the contribution of censuses to equity analyses include conducting censuses regularly and transparently, and including small-area identifiers. Standardizing identifiers for all sources in a country according to census measures would facilitate the linking of databases.

#### Vital registration systems

Vital registration systems can reveal, for instance, inequities between genders related to child mortality or differences in life expectancy according to socioeconomic status. Information on

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several stratifiers is generally available, including geographical areas, gender and, in some cases, educational level or occupation. If geographical areas are closely related to socioeconomic status or ethnicity, those stratifiers might be inferred. Health measures usually include age at death and sometimes include cause of death and age of mothers at times of delivery.

The primary barrier to equity analysis is coverage, because the poorest countries, and the poorest population groups within countries, tend to have lowest registration coverage (35, 36). Improvements would aim at expanding registries to all countries (they currently function well in only 57 countries); ensuring full (or at least unbiased) population coverage; and including causes of death, birth weight and gestational age, individual or small-area identifiers, and at least one additional socioeconomic stratifier.

#### Household surveys

Household surveys are especially useful in revealing health inequities, and are the primary source of health information for most of sub-Saharan Africa. Surveys usually include a number of equity stratifiers and more health measures than censuses. Household surveys generally collect data on child morbidity and mortality, satisfaction with health services, access and distance to health care facilities, financial access and cost of care, and other data. Surveys can provide information on the quality of housing and access to water, and whether water, sanitation and electricity as well as access to education, have been fairly distributed within a society. Finally, they can be a rare source of information on issues such as poverty resulting from family illness.

Possible improvements include regular repetition of surveys to track changes over time, harmonization of questions across countries to support comparisons between them, inclusion of additional health outcomes, increased sample sizes to allow more extensive analyses of inequities, and proactive strategies to increase use of Demographic and Health Survey (DHS) data within LMIC (*37–39*).

#### Small-area databases

Small-area data can be useful in the absence of micro-data, which provide information on individual persons and households. Small-area data usually include population, death rate, and socioeconomic or demographic covariates for a county, municipality or postcode. Ideally, small areas correspond to a governmental level at which health care decisions are made. Small-area data are often derived from census data, but another source is demographic surveillance sites (DSS). Each DSS is a geographically-defined population under continuous demographic monitoring, and includes data on all births, deaths, and migrations as well as socioeconomic information on individuals and households. Although not nationally representative, the longitudinal data are extensive, complement survey data, allow streamlining of facility-based HIS, and can reveal erroneous denominator data in HIS. DSS have also provided information for the first life tables for Africa based on African data. Twenty-nine DSS currently operate in Africa and Asia; a feasible improvement would be to expand the size and number of DSS to include additional low-income countries.

#### Administrative data

Administrative data from various governmental sectors, such as primary school enrolment or immunization coverage, is rarely used in equity analyses. However, if equity stratifiers and denominator data are available, information such as health service delivery data at the sub-district level is useful for programme planning. Administrative data could be improved by reducing bias resulting from non-random sampling, expanding population coverage to ensure coverage of marginalized groups and including a small-area identifier.

# Building a culture for equity-oriented decision-making

Improved data collection alone is unlikely to result in the development of equity-oriented policy, as barriers to change are related to underlying conditions ranging from lack of awareness of and capacity to address inequities, to entrenched interests that are served in an unjust system. Health stakeholders could strengthen capacity and political will to effect policy changes, interventions, and measurable reductions in health inequalities through increased research, training, accountability and demand for equity data, and public participation.

Important areas of research include: pathways of health inequities; the impact of interventions; and systemic, political and social factors that affect the development of pro-equity policy, implementation of changes, and social action. Such research would help translate data into policy, increase demand for equity data and provide direction for the development of interventions.

Currently there are few opportunities for training in equity analysis and interpretation. Priority areas for training include quantitative analysis and how to strengthen policy relevance of HIS, as well as equity-oriented policy analysis, use of qualitative information and development of interventions. Training should target high-level decision-makers, statisticians, researchers and civil society, and would create a critical mass of people and institutions familiar with the issues and the possible solutions.

Increased accountability and demand for equity data would create pressure to collect information and spur policy development. Accountability and demand could be increased by sensitizing the public, civil society, donors and other institutions to health inequities; organizational requests for routine reporting of data disaggregated by equity stratifiers; and integrating and monitoring explicit equity goals in global initiatives, such as the Millennium Development Goals.

Civil society plays an important role in supporting public participation, providing feedback on which to base improvements and intervention efforts. An informed and active civic engagement can be supported by strategies aimed at ensuring broad public access to data, together with transparent and fair processes for ensuring dialogue about policy among all stakeholders.

Although different organizations, such as donors, government, civil society and inter-governmental organizations may be best situated to address these issues, a coordinated effort led by international or global institutions could galvanize improvements in technical capacity, political will and public participation.

#### Conclusions and standards for an equityoriented health information system

This paper has proposed immediate possibilities as well as longer term strategies for strengthening the potential of HIS to

#### Box 1. Recommendations for integrating equity into health information systems

#### Technical recommendations related to specific databases

- Regularly repeat transparent censuses; incorporate socioeconomic information
- Establish functioning vital registration systems with unbiased, even if incomplete, coverage; include individual or small-area identifiers and at least one socioeconomic stratifier; record cause of death
- Regularly repeat household surveys to increase availability of trend data; increase sample size to improve robustness of equity analyses; include
  adult morbidity/mortality and quality-of-life data as well as stratifiers
- Expand the size and number of demographic surveillance sites to additional low-income countries
- Improve administrative data by reducing bias, expanding population coverage, and including a small-area identifier

#### Systems-wide recommendations that would improve potential for equity analysis and pro-equity policy

- Support information audits to help countries determine the most appropriate stratifiers to integrate into their databases and consider how best to support policy-making and monitoring
- Promote, through appropriate existing channels, the development of international legal standards that protect privacy for record identification, including a geographical code indicator (according to census tract) and the sharing of disaggregated data
- Work with existing databases (vital registration, censuses, major household surveys and disease surveillance) to include a unique identifier and a geographical code indicator that would enable linking of databases
- Support intersectoral coordination and sharing of data from databases maintained by different institutions or sectors; improve the collaborative processes and strengthen the voice of ministries of health in discourses with all those who collect the data needed for health equity, e.g. ministries of planning, finance and statistics
- Support research in key areas of health equity, including pathways of health inequities, effective interventions, and the systemic, political and social factors that hinder or foster development of pro-equity policy, policy implementation and social action
- Support training in quantitative analysis and strengthening policy relevance of HIS, as well as equity-oriented policy analysis, use of qualitative information, and development and implementation of interventions; support training at various levels (e.g. policy-makers, statisticians and civil society groups) to support both political will and capacity throughout society
- Support increased accountability and demand for equity data through sensitization to health inequities, organizational requests for routine reporting of data disaggregated by equity stratifiers (especially gender), and integrating and monitoring equity goals in global initiatives
- Support the participation of civil society, donors and others in public discussion; support open-membership networks for interventions and knowledge sharing

support equity analysis. Ideally, all countries would have a wide range of health measures and equity stratifiers in each population-based database, or the ability to link records, as well as the technical and political ability to use information to implement pro-equity interventions. The short-term goals are more modest, because the ideal is distant even in countries with strong HIS and there remain daunting challenges in regard to the technical and political prerequisites for change. However, every country could achieve important improvements within the next few years while developing longer term plans for tracking and addressing health inequities within and between countries.

At present, only 39 of the 192 WHO Member States, mostly industrialized countries, have a vital registration system coupled with a major household survey (or record linkage capacity), which are prerequisite for a basic health equity analysis. Ninety countries have data from only one census or an old household survey (10 years old), or no data at all. The priority for HIS development should be to ensure that every country has a basic capability for health equity analysis. This means that both countries and donors must recognize the importance of, and increase financial and technical support for, routine and widespread collection, analysis and application of equitysensitive health data. The countries with the fewest data and least human resource capability for equity analysis should receive the greatest and earliest support, as they face the longest road. A secondary strategy would be to identify and work with a few low-income countries with a high disease burden that have sufficient data and capacity for analysis, thus allowing a more modest investment to "tip the balance" and demonstrate success.

It is also vital to plan a long-term strategy for improving the support that HIS can provide to societies in addressing health equity challenges. Several of the specific recommendations listed in Box 1 involve technical and political processes, and countries will be able to undertake some sooner than others. It is to be hoped that these recommendations would be initiated by countries themselves, with support from other institutions. Champions of improved HIS and health equity would need to play a strong role in initiating these improvements, particularly because equity has not been a traditional focus for HIS in most countries.

Although countries could address these recommendations themselves in isolation, an international effort that coordinates activities to maximize progress in data collection, training, sharing of experiences, policy development and implementation could be invaluable in supporting the rapid development of strong equity-oriented HIS, especially in LMIC. Although there are challenges ahead, there are also strategic opportunities to improve the contributions of HIS to equity data, and to narrow the gaps in equity-relevant information among countries.

**Competing interests:** none declared.

#### Renforcement des systèmes d'information sanitaire pour combattre les injustices en matière de santé

Des études spécifiques et des initiatives isolées, menées au cours des dernières décennies dans des pays ayant des niveaux de revenus très divers, ont régulièrement mis en évidence des inégalités face à la santé entre les groupes socioéconomiques d'une part et en fonction du sexe, de la race et de l'origine ethnique ou géographique, ou autre paramètre associé à des avantages sociaux encore, d'autre part. Les inégalités importantes en matière de santé liées à des avantages ou des désavantages sur le plan social plutôt qu'à des différences biologiques propres aux individus sont généralement considérées comme injustes ou inéquitables. Ces injustices touchant à la santé sont la principale cible des efforts de développement sanitaire, parmi lesquels les Objectifs de développement pour le Millénaire, qui exigent un suivi pour évaluer les progrès accomplis. Cependant, il manque à la plupart des systèmes d'information sanitaire (SIS) les informations clés permettant d'évaluer et de combattre les injustices en

matière de santé, à savoir des données fiables, longitudinales et représentatives, reliant les mesures de l'état de santé aux mesures du statut ou des avantages sociaux au niveau individuel ou à petite échelle. En l'absence de documentation factuelle et de surveillance de ces injustices, ainsi que de moyens à l'échelon national pour exploiter ces informations en vue d'une planification efficace et d'un suivi des progrès résultant des interventions, il est peu probable qu'une évolution plus favorable à l'équité s'opère.

Le présent article examine les besoins essentiels en matière d'information et les bases de données susceptibles d'être utilisées. Il propose des stratégies à court et long termes pour renforcer la capacité des SIS à analyser les questions d'équité face à la santé et évoque les points d'entrée liés aux SIS qui permettraient d'appuyer l'intégration d'une culture de recherche de l'équité dans la prise de décisions et le développement de politiques.

#### Resumen

### Refuerzo de los sistemas de información sanitaria para afrontar los retos que plantea la equidad en materia de salud

Estudios especiales e iniciativas aisladas llevadas a cabo durante los últimos decenios en países de ingresos bajos, medios y altos han mostrado sistemáticamente desigualdades en salud entre grupos socioeconómicos, así como por género, raza o grupo étnico, zona geográfica y otros indicadores de ventajas sociales. Las desigualdades en salud significativas ligadas a (des)ventajas sociales en lugar de a diferencias biológicas se consideran en general injustas o inequitativas. Esas desigualdades son el principal objeto de las iniciativas de desarrollo sanitario, incluidas metas mundiales tales como los Objetivos de Desarrollo del Milenio, que requieren actividades de vigilancia para evaluar los progresos. Sin embargo, la mayor parte de los sistemas de información sanitaria (SIS) nacionales carecen de la información básica requerida para evaluar y corregir las inequidades en salud, esto es, de datos longitudinales fiables y representativos que relacionen indicadores de salud con indicadores del estatus o las ventajas sociales a nivel individual o en zonas reducidas. Sin documentación empírica y sin actividades de monitoreo de esas inequidades, y si los países carecen de capacidad para usar esa información para planificar y vigilar eficazmente los progresos en respuesta a las intervenciones, es improbable que se logre avanzar hacia la equidad.

En este artículo se consideran los requisitos de información básica y las posibles bases de datos, se proponen estrategias a corto y largo plazo que pueden fortalecer la capacidad de los SIS para analizar la equidad sanitaria y se examinan los puntos de acceso relacionados con los SIS en apoyo de una cultura de adopción de decisiones y desarrollo de políticas orientada a la equidad.

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