Health information systems in humanitarian emergencies

Michel Thieren[1]

Abstract Health information systems (HIS) in emergencies face a double dilemma: the information necessary to understand and respond to humanitarian crises must be timely and detailed, whereas the circumstances of these crises makes it challenging to collect it. Building on the technical work of the Health Metrics Network on HIS and starting with a systemic definition of HIS in emergencies, this paper reviews the various data-collection platforms in these contexts, looking at their respective contributions to providing what humanitarian actors need to know to target their intervention to where the needs really are. Although reporting or sampling errors are unavoidable, it is important to identify them and acknowledge the limitations inherent in generalizing data that were collected in highly heterogeneous environments. To perform well in emergencies, HIS require integration and participation. In spite of notable efforts to coordinate data collection and dissemination practices among humanitarian agencies, it is noted that coordination on the ground depends on the strengths and presence of a lead agency, often WHO, and on the commitment of humanitarian agencies to investing resources in data production. Poorly integrated HIS generate fragmented, incomplete and often contradictory statistics, a situation that leads to a misuse of numbers with negative consequences on humanitarian interventions. As a means to avoid confusion regarding humanitarian health statistics, this paper stresses the importance of submitting statistics to a rigorous and coordinated auditing process prior to their publication. The audit trail should describe the various steps of the data production chains both technically and operationally, and indicate the limits and assumptions under which each number can be used. Finally emphasis is placed on the ethical obligation for humanitarian agencies to ensure that the necessary safeguards on data are in place to protect the confidentiality of victims and minority groups in politically sensitive contexts.

Keywords Information systems/organization and administration/standards; Information dissemination; Emergencies; Relief work; Statistics/standards; Data collection/methods; Confidentiality; Interinstitutional relations (*source: MeSH, NLM*).

Mots clés Système information/organisation et administration; Diffusion de l'information; Urgences; Aide humanitaire; Statistique/ normes; Collecte données/méthodes; Confidentialité; Evaluation besoins; Relation interinstitutionnelle (*source: MeSH, INSERM*).

Palabras clave Sistemas de información/organización y administración/normas; Diseminación de la información; Urgencias médicas; Sistemas de socorro; Estadística/normas; Recolección de datos/métodos; Confidencialidad; Evaluación de necesidades; Relaciones interinstitucionales (*fuente: DeCS, BIREME*).

الكلمات المفتاحية: نُظُم المعلومات، تنظيم وإدارة نُظُم المعلومات، معايــــير تنظيم وإدارة نُظُم المعلومات، نشر المعلومات، الطوارئ، أعمال الإغاثة، الإحصائيات، معايــــير الإحصائيات، جمع المعطيات، طرق جمع المعطيات، السرية، العلاقات الدولية. (المصدر: رؤوس الموضوعات الطبية، المكتب الإقليمي لشرق المتوسط)

Introduction

The production of health information is an important function of a health system. It has been said that, "health information is what holds a health system together" (*1*). The peculiarity of a health system in an emergency situation is that no one seems to be in charge. Public health institutions are either disrupted or unable to cope and basic services are mostly supplied by external aid agencies following a programmatic logic: i.e. verticalization of action, self-sufficiency and independence. In the absence of national stewardship, that logic also applies to health information systems (HIS): the information produced by an agency is used mainly for a "rolling review of programmes" upon the basis of which a decision "to continue, amend, or wind [them] down" has to be taken (*2*). Because health systems are not integrated, neither is health information. Consequently, data produced by

non-integrated health systems are often incomplete, cannot be aggregated and are unsuitable for assessing a situation.

In emergency situations it is also difficult to collect the data, and the information needed to understand these situations needs to be timely and detailed especially when it comes to addressing critical questions such as: What is the health status of the people affected? Where and who are they? What are the immediate and long-term risks? What resources are locally available and what supplies are needed? What is most urgent? How much is needed? To be up to the task, HIS in emergencies must be harmonized across all humanitarian actors on the ground and include local participation whenever possible to ensure continuity after the crisis.

Although the public health literature shows good understanding of the issues linked to HIS (*3*), these issues have seldom been addressed explicitly. Recently, however, the newly

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established Health Metrics Network (HMN) "a group of stakeholders coming together to devise innovative solutions to the HIS conundrum" (*4*) has sought technical consensus on a variety of critical HIS domains. Building on the outcomes of this work, the present paper aims to address those HIS issues that are peculiar to humanitarian emergencies, situations that have in common the impossibility of the population affected being able to meet its basic needs without external assistance and protection. The following questions are addressed.

- How should HIS be structured in emergencies?
- What are the information needs and how can the information be collected in emergency circumstances?
- How can the data collection practices of the many humanitarian actors be integrated and coordinated?
- How can politically sensitive information be disseminated ethically?

Because of the exceptional dynamics of a humanitarian emergency, HIS in emergencies are specific entities that follow rules and procedures not necessarily applicable under normal conditions.

A framework for health information systems in emergencies

A first step towards understanding HIS in emergencies is to propose a definition that covers three basic systemic elements: what makes the system, how it works and for what purposes. The recently developed Consensus Technical Framework for HIS, a summary of the technical agreements among HMN stakeholders (*5*), provides the background against which to formulate such a definition: "HIS in emergencies is a set of data collection platforms implemented by a coordinated group of humanitarian actors generating information to support strategic decisions, monitor changes, prioritize action and allocate resources, manage programmes, scaling up or scaling down operations, advocate and formulate concerns in relation to an emergency context."

The definitional elements listed above are shown in Fig. 1. The data collected (column 1) are further processed into usable information (column 2) on a variety of health and health systems domains (column 3) for a variety of decisional purposes (column 4). This layout provides a parsimonious organizational matrix for designing a health information system as well as a framework for its implementation. The cohesion of HIS requires resources, management and coordination, and periodic evaluation of performance.

Information needs and data collection approaches

As Fig. 1 shows, the role of HIS in emergencies is to determine priority needs and assist in allocating resources accordingly. HIS in emergencies should focus on quantifying the "health sector gap", defined as the "excess needs attributed to the crisis" (*6*). In practice, this may not be easy as this attributable gap tends to normalize, not because the situation improves, but because there is an inevitable trend for the international community to accommodate to higher emergency thresholds. For example, the 20% malnutrition rate in the Sudan that, 15 years ago, triggered the Operation Lifeline Sudan would not lead today to a humanitarian inter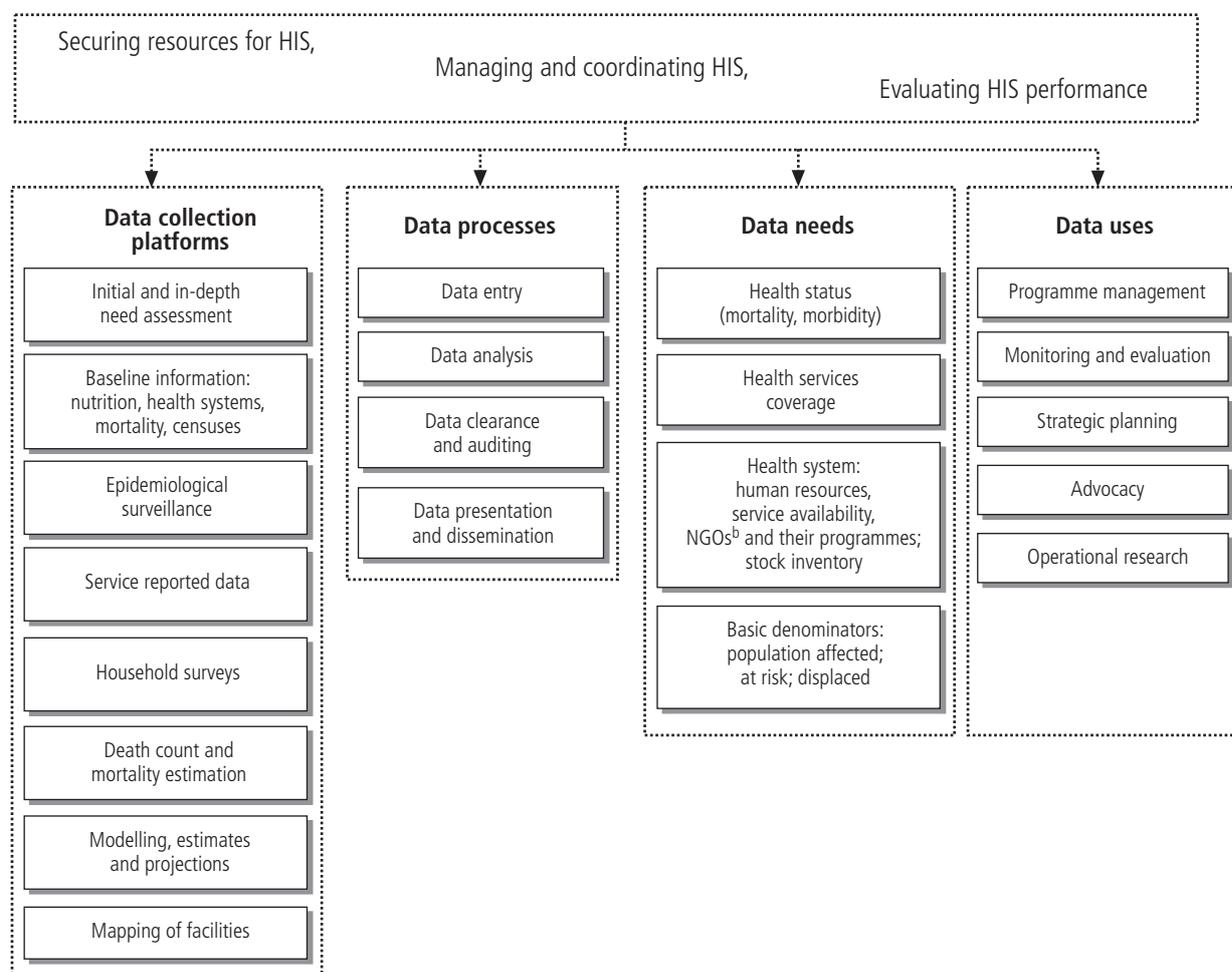vention because that rate is now accepted as "normal" in that country (*7*). To avoid this normalization trap, HIS should generate health statistics with various levels of aggregation and analyse them in the prevailing context. The health information system should focus on tracking changes and on promptly identifying the pockets of deterioration in a country.

The relative importance of the various data collection platforms listed in Fig.1 depends on the context and the phase of the emergency. In the acute phase of an emergency, HIS need to emphasize a minimum set of indicators and population figures such as crude mortality among children under-five years of age, incidence of epidemic diseases, nutritional status, food security, access to water and sanitation, and number of affected and displaced people (*8*). The HIS should also provide information on the vital needs, the coping mechanisms and the residual capacity of the population affected. These parameters are important sensors of the magnitude and the course of an emergency. At the earlier stages, pre-existing background information, rapid assessment techniques, mortality and nutrition surveys, disease surveillance and an inventory of drug and medical supplies in warehouses are all that humanitarian workers can rely on to gain a sense of how to deliver appropriate assistance. These HIS components are reviewed briefly below.

Rapid needs assessments usually consist of standardized protocols listing the information items to be collected or verified on the ground (*9*). They can trigger a decision to intervene and on what scale, provide first guidance on the allocation of resources, and assist in programme design and planning (*2*). Disease surveillance information is provided by health facilities or a sentinel surveillance facility where cases of communicable diseases are reported on a daily and weekly basis using standard reporting forms. Laboratory services report biologically confirmed cases, for instance of cholera or typhoid fever. The extent to which service reports may be aggregated depends on the level of consensus established among all the humanitarian agencies with regard to the reporting forms and the timing of reporting (*8*).

Surveys are often used to estimate mortality and nutritional status, but also to obtain baseline population data. Various methods exist, all with the objective of reducing the burden of sampling without compromising statistical robustness. The cluster-sampling method (*10–12*) is the method most commonly used in emergencies because it is simple to implement. Recently it was applied to estimate the crude mortality rate in Darfur (*13*) and in Iraq (*14*). In both cases the method showed the limitations of extrapolating results in a highly heterogeneous context characterized by repeated population displacements and limited access to these populations. Innovative approaches have been proposed to measure access to services in emergencies (*15*), or to estimate numbers of population affected (*16*). Lot quality assurance sampling (LQAS), which has been used with success in estimating immunization coverage (*17, 18*) could be tested in emergency settings as a way to highlight areas that fail to meet preset humanitarian health standards when compared to other areas where these standards are met. All sampling methods are "context-specific" and they should be selected accordingly, the important consideration being "to recognize their potential biases and how these might limit their applicability" (*19*). However, sampling errors do often occur as demonstrated in a recent review of 125 nutrition surveys in Ethiopia (*20*). When a survey cannot be conducted for security reasons, assessment

Fig. 1. **Implementation framework for health information systems (HIS) in emergencies adapted from HMN[a] Consensus Technical Framework**

Securing resources for HIS,

Managing and coordinating HIS,

Evaluating HIS performance

Data collection platforms
- Initial and in-depth need assessment
- Baseline information: nutrition, health systems, mortality, censuses
- Epidemiological surveillance
- Service reported data
- Household surveys
- Death count and mortality estimation
- Modelling, estimates and projections
- Mapping of facilities

Data processes
- Data entry
- Data analysis
- Data clearance and auditing
- Data presentation and dissemination

Data needs
- Health status (mortality, morbidity)
- Health services coverage
- Health system: human resources, service availability, NGOs[b] and their programmes; stock inventory
- Basic denominators: population affected; at risk; displaced

Data uses
- Programme management
- Monitoring and evaluation
- Strategic planning
- Advocacy
- Operational research

[a] HMN = Health Metrics Network.   [b] NGOs = Nongovernmental organizations.

WHO 05.69

must rely on incomplete measures obtained using qualitative methods such as interviews of population members arriving from insecure areas.

The introduction of information technology (IT) in HIS in emergencies can considerably reduce data-collection and processing errors. The use of a personal digital assistant, for example, can facilitate the collection of data during survey interviews by recording a respondent's answers electronically, thus saving time and reducing data-entry errors (21). The use of geographical information systems, global positioning systems and remote sensing can, in the earliest stage of an emergency, help to estimate population sizes especially in inaccessible areas (21). They can also help in mapping the availability of health facilities and services and indicate how functional they are.

As the emergency situation consolidates, new types of information are needed to ensure appropriate assistance. The documentation of reproductive health outcomes (22), and health systems metrics (23) such as service availability and utilization, drug stock-out (used to quantify the shortage in drugs), human resources and the brain drain associated with emergency conditions becomes critical. Questions about the quality of services, the follow-up of chronic diseases and the referral of patients,

all require answers. The supply of more detailed information certainly implies a need for more detailed data collection platforms. Service-reported information may use more comprehensive reporting forms and household surveys can use longer questionnaires; stock inventory, health system performance assessment and measurement of access to services can gradually be added to the health information system. However, despite growing information needs, HIS should not be over-expanded and unnecessarily burden a humanitarian operation.

Fig. 1 also stresses other data collection platforms such as vital registration and statistical modelling. However, the counting of fatal events is almost impossible in emergencies. Bodies are often buried or cremated without being identified. Counting the deaths overlaps with counting the missing. Service-based mortality data are incomplete and exclude most of the deaths that occur outside health facilities. The application of statistical modelling is hazardous in emergencies because primary measures are performed in highly volatile and heterogeneous environments and cannot be easily generalized to an entire affected population. Also, background information based on a census may reflect pre-emergency situations that no longer prevail.

A critical evaluation of the data collection platforms available must be conducted periodically. This requires dialogue and coordination among humanitarian actors.

Coordination and integration of health information systems in emergencies

The cohesive aspect of HIS is often missing in the course of an emergency for two reasons. First, because no one feels compelled to collaborate in a situation where no one is in charge. Second, agencies tend to safeguard their own information to ensure donor support in a competitive funding environment. However, as information begins to flow and the need to aggregate data from different sources becomes evident, a lead health agency takes responsibility for coordinating the various data collection practices. The success of HIS coordination is a question of political and technical leadership. Whereas the former is rather a matter of statute recognition, negotiation power and competencies on the ground, the latter operates under consensus from all participating agencies on the methodological and implementation aspects of data production. Where the government is weak or contested, WHO, ideally, should fulfil the role of lead agency. However, the capacity of the organization varies from crisis to crisis and in some resource-constrained chronic emergencies, health sector leadership may be assigned to a humanitarian actor with more representation that is better established in the area concerned.

The objective is to optimize HIS practices by avoiding duplication in data collection, filling information gaps, merging skills and capacities, and pooling resources. In the past few years, at least at the institutional level, this consensus has been sought through a series of normative initiatives and projects such as the Sphere Project for minimum humanitarian standards (http://www.sphereproject.org/), the Standardized Monitoring and Assessment of Relief and Transition Protocols (SMART) for mortality and nutritional surveys (http://www.smartindicators. org/), and the humanitarian information centres (HIC) for the collection and dissemination of background information (http://ochaonline.un.org/webpage.asp?Page=695). Additionally, the Inter-Agency Standing Committee (IASC), an official high-level coordination mechanism for humanitarian action, has set up a task force to look at ways to better harmonize the production of humanitarian information (http://www.humanitarianinfo.org/iasc/).

In spite of these notable efforts to unify information systems in emergencies, individualism still prevails as illustrated by the conflicting reporting by two United Nations Agencies of crude mortality rates associated with Darfur in the same period. Whereas WHO concluded that "deaths in Darfur exceed the emergency threshold" (24), the World Food Programme maintained at the same time that "crude mortality rates fall below the emergency benchmarks" (25). Although the latter report noted, referring to the former, that for sampling divergences "it is not possible to compare the results with other surveys" the public audience interpreted them as contradictory. Months later, the mortality figures associated with Darfur remain a matter of political debate: some wish to support their pessimistic views by extrapolating a mortality measure performed in the displaced population to the entire population of the province of Darfur, others wish to support a less extreme position by affirming that such an extrapolation is statistically incorrect and

by emphasizing what the death toll does not incorporate. On the ground, HIS integration requires all participating agencies to provide resources and operational capacity. To what extent this constitutes a good return on investment remains to be proved (26) and it may be hard to convince donors to divert even a small fraction of their funding from assisting victims directly to developing information systems. Paradoxically, it is unlikely that the same donors would take further funding decisions based on weak evidence. The HMN offers resource pooling opportunities for implementing HIS in emergencies as it does in normal situations. Well-funded HIS will ensure the coordination mechanisms required to enhance the quality and credibility of disseminated statistics.

Dissemination procedures

It is common for health statistics associated with a disaster to be taken for granted, without further enquiries being made about their origin and validity. Indeed, scientific verification does not systematically precede the publication of a statistical number and once published, statistics are not necessarily peer-reviewed. Figures are published by the press, adopted by the public and reported in historical records. This is particularly the case for aggregated figures such as death tolls, numbers of injured people, and numbers of people displaced or without access food and health services. Such figures are rarely published with an explicit and understandable data audit trail — a set of descriptive information on how a number has been generated. Recent enquiries by the author on the way mortality and population numbers associated with the Asian tsunami of December 2004 were published confirmed the absence of any verification procedure at the country level and even beyond that level (Thieren, unpublished report, 2005). Enquiries also revealed inconsistent use of data collection and estimation methodologies within and across countries. Nonetheless, these numbers continue to be aggregated as if they had followed a common data-production chain and relayed as such by international humanitarian organizations. The data audit trail provides information on the processes undertaken at the various steps of the data-production chain from the collection of data to its publication: What definition is applied? What measurement instrument is used? What is the margin of error attributable to the figure? Under which assumptions can the number be used? With what population and what period is the number truly associated? Who is accountable for the number?

Auditing a number constitutes an ethical obligation because it shows accountability and transparency. It is also ethically mandatory to ensure that the necessary confidentiality safeguards are in place for any published number especially in emergencies where numbers are politically sensitive. For example, data on places of origin or ethnicity may put certain population groups at risk of persecution; a high prevalence of infection such as human immunodeficiency virus (HIV) in minority groups may further stigmatize them; the magnitude of a natural disaster may be underestimated to protect a tourist-based economy; exaggerated prediction of an epidemic risk may unnecessarily ruin the economy; mortality rates may be manipulated to serve a particular political interest, for example, to attest to or deny war crimes or an increase in human rights abuses.

The uses and misuses of health statistics associated with emergencies have consequences on the health of the affected population. As a recent example, the global "humanitarian

impulse" for South Asia triggered by unprecedented mortality numbers "helped" the children of Banda Aceh to receive up to four measles vaccinations (*27*) whereas the children of Darfur who were not covered by the immunization campaign of July 2004 may not have had a second chance to be protected against the disease. ∎

Résumé

Rôle des systèmes d'information sanitaire dans les situations d'urgence

Dans les situations d'urgence, les systèmes d'information sanitaire (SIS) doivent faire face à un dilemme : les informations nécessaires pour comprendre les crises humanitaires et y répondre doivent être disponibles en temps utile et détaillées, alors que les conditions régnant pendant ces crises rendent extrêmement difficiles leur collecte. En s'appuyant sur le travail technique effectué par le Réseau de métrologie sanitaire sur les SIS et en partant d'une définition systémique de ces systèmes dans les situations d'urgence, le présent article passe en revue les diverses plateformes de collecte des données dans ce type de contexte. Il examine notamment ce que ces plateformes peuvent apporter en matière d'information sanitaire et permet ainsi aux acteurs humanitaires de mieux cibler leur intervention en fonction des besoins réels. Si les erreurs de notification de cas ou d'échantillonnage de population sont inévitables, il importe toutefois de les identifier et, par là même, de reconnaître les limites à la généralisation des données recueillies dans des environnements fortement hétérogènes. Pour être efficaces en situation d'urgence, les SIS exigent intégration et participation. Malgré des efforts notables pour coordonner la collecte des données

et les méthodes de diffusion entre les organisations humanitaires, il est noté que la coordination sur le terrain dépend du poids et de la présence d'une organisation chef de file, souvent l'OMS, et de l'engagement financier des organisations humanitaires dans la production de données. Les SIS mal intégrés génèrent des statistiques fragmentaires, incomplètes et souvent contradictoires, d'où un mauvais usage des chiffres, ayant des conséquences négatives sur les interventions humanitaires. L'article souligne l'importance de soumettre les statistiques sanitaires dans le domaine humanitaire à un processus de vérification rigoureux et coordonné avant de les publier, en tant que moyen d'éviter la confusion à leur propos. Le protocole de vérification doit décrire les différentes étapes de la chaîne de production de telle ou telle donnée, tant sur le plan technique que fonctionnel, et indiquer les limites et les hypothèses dans le cadre desquels les chiffres sont utilisables. Enfin, l'accent doit être mis sur l'obligation éthique, pour les organisations humanitaires, de s'assurer de l'application de mesures de sécurité permettant de préserver la confidentialité des informations relatives aux victimes et aux minorités dans les contextes politiquement sensibles.

Resumen

Sistemas de información sanitaria en las emergencias humanitarias

En las situaciones de emergencia los sistemas de información sanitaria (SIS) se encuentran ante un espinoso dilema: la información necesaria para comprender las crisis humanitarias y responder a ellas debe ser detallada y se debe obtener con rapidez, pero las circunstancias que rodean a esas crisis dificultan el acopio de información. Aprovechando los trabajos técnicos de la Red de Sanimetría sobre los SIS, y partiendo de una definición general de los SIS en las situaciones de emergencia, se examinan en este artículo las diversas plataformas de recopilación de datos empleadas en esos contextos, analizando sus respectivas contribuciones a los conocimientos que los agentes de asistencia humanitaria han de manejar para focalizar sus intervenciones en las necesidades reales. Aunque los errores de información o muestreo son inevitables, es importante identificarlos y reconocer las limitaciones inherentes a cualquier generalización de datos reunidos en entornos altamente heterogéneos. Para funcionar satisfactoriamente en las situaciones de emergencia, los SIS exigen integración y participación. A pesar de los notables esfuerzos desplegados para coordinar las prácticas de recopilación y difusión de datos entre los organismos

humanitarios, se observa que la coordinación sobre el terreno depende de la presencia de un organismo principal, a menudo la OMS, de sus puntos fuertes, y de la determinación de los organismos humanitarios para invertir recursos en la producción de datos. Unos SIS mal integrados generan datos estadísticos fragmentados, incompletos y a menudo contradictorios, lo que lleva a usar indebidamente las cifras, con consecuencias negativas para las intervenciones humanitarias. Como medida para evitar la confusión en torno a los datos estadísticos sobre salud en los contextos de ayuda humanitaria, en este artículo se subraya la necesidad de someter las estadísticas a un proceso de verificación riguroso y coordinado antes de su publicación. En esa verificación retrospectiva se deben describir los diversos pasos de las cadenas de producción de datos, tanto técnica como operativamente, y se deben indicar las limitaciones de cada cifra y los supuestos con que tendrán que emplearse. Por último, se hace hincapié en que los organismos humanitarios tienen la obligación ética de garantizar la necesaria protección de los datos para asegurar la confidencialidad de las víctimas y los grupos minoritarios en los contextos políticamente delicados.

ملخص
نُظُم الطوارئ الطبية في البلدان المنخفضة والمتوسطة الدخل: توصيات عملية

تواجه نُظُم المعلومات الصحية في الطوارئ الإنسانية دوامة مزدوجة من المصاعب: ففي الوقت الذي ينبغي أن تكون فيه المعلومات ضرورية لفهم الأزمات الإنسانية والاستجابة بها مفصلة ومتوافرة في الوقت المناسب، تجعل هذه الأزمات وظروفها جمع هذه المعلومات تحدِّياً صعباً. وتستعرض هذه الورقة المنطلقات الأساسية لجمع المعطيات في هذا السياق، بالاستناد إلى العمل التقني في شبكة القياسات الصحية وفي نظم المعلومات الصحية، ابتداء بتعريف منهجي لنظم المعلومات الصحية أثناء الطوارئ، مع البحث في المساهمات التي يقدمها العاملون في الحقول الإنسانية لمعرفة ما ترمي إليه مداخلتهم التي تمس الحاجة إليها، ورغم تعذُّر تجنُّب الوقوع في الأخطاء الناجمة عن أخذ العينات وعن الإبلاغ، فإن من الأهمية بمكان كشف هذه الأخطاء والإشارة إلى ما يشوب تعميم المعطيات من قصور وخلل عند تجميعها في بيئات تتَّسم بدرجة كبيرة من التنوُّع وعدم التجانس. ويتطلَّب الحصول على أداء جيد أثناء الطوارئ أن تكون نُظُم المعلومات الصحية متكاملة ومساهمة مساهمةً فعَّالة. وعلى الرغم من الجهود الكبيرة التي بُذلت لتنسيق ممارسات جمع ونشر المعطيات بين الوكالات العاملة في المجال الإنساني، فقد لوحظ أن

التنسيق الميداني يعتمد على مدى قوة وحضور وكالة قائدة، يغلب أن تكون منظمة الصحة العالمية، كما يعتمد على مدى التزام الوكالات العاملة في المجال الإنساني في استثمار الموارد في إنتاج المعطيات. فنُظُم المعلومات الصحية التي تفتقد التكامل ستنتج معلومات مبعثرة وناقصة وإحصائيات متناقضة في أغلب الحالات، وهو ما يؤدِّي إلى إساءة استعمال الأرقام وما يجر إليه ذلك من عواقب وخيمة على التدخلات الإنسانية. وتتمثَّل إحدى الوسائل المتبعة لتجنُّب الوقوع في اللبس والاختلاط في الإحصائيات الصحية المتعلقة بالأعمال الإنسانية، بالتركيز على أهمية إخضاع الإحصائيات لعملية تدقيق صارمة ومنسقة قبل إرسالها للطباعة والنشر، وهذا ما تركز عليه هذه الورقة. إن منهج التدقيق الذي ينبغي أن يتَّبع يجب أن يتضمَّن وصفاً للمراحل المختلفة لسلاسل إنتاج المعطيات على الصعيد التقني وعلى الصعيد الميداني، مع الإشارة إلى ما قد يختفي وراء كل رقم من أوجه القصور أو الافتراضات، كما ركزت الورقة في النهاية على الالتزام الأخلاقي لدى المنظمات العاملة في المجال الإنساني لضمان الحماية اللازمة للمعطيات المتوافرة ولضمان سريتها التي تتعلق بالضحايا وبالمجموعات من الأقليات في المجتمعات التي تعاني من حساسية خاصة لهم.

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