# Surveillance beyond Camp Settings in Humanitarian Emergencies: Findings from the Humanitarian Health Information Management Working Group

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Abbreviations:
HIS = health information system
HHIM = Humanitarian Health Information
    Management Working Group
IDP = internally displaced persons
MSF = Médecins sans Frontières
NGO = non-governmental organization
UN = United Nations
UNHCR = United Nations High
    Commissioner for Refugees

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## Abstract

**Introduction:** Surveillance is an essential component of health and nutrition information management during humanitarian situations. Changes in the nature and scope of humanitarian assistance activities have created new challenges in health surveillance, particularly outside of camp-based settings.

**Objectives:** The primary aim of the Humanitarian Health Information Management Working Group was to identify challenges and areas that need further elucidation in a range of non-camp settings, including urban and rural as well as low- and middle-income countries.

**Results:** Three major themes emerged: (1) standardization of measures and methodologies; (2) context in data collection and management; and (3) hidden populations and the purpose of surveillance in urban settings. Innovative examples of data collection and management in community-based surveillance were discussed, including task-shifting, health worker to community member ratio, and literacy needs.

**Conclusions:** Surveillance in non-camp settings can be informed by surveillance activities in camp-based settings, but requires additional consideration of new methods and population needs to achieve its objectives.

## Background

Surveillance is an essential component of health and nutritional information management in humanitarian situations. Data gathering is not uniform across humanitarian settings; the indicators, sources of data, and uses of information may differ between emergency and post-emergency, camp and non-camp, urban and rural, and middle- and low-income settings. Data collection and information analysis are critical in the development, prioritization, monitoring, and evaluation of health programs by humanitarian organizations delivering services to those most in need. Communication of data between non-governmental organizations (NGOs), United Nations (UN) agencies, and governments is essential to coordinate effective and efficient operations. Timely and accurate reporting of surveillance data by organizations to donors influences future funding opportunities, allowing donors to allocate resources based on evidence from the field. Of equal importance, the participation of and feedback to populations affected by humanitarian emergencies at all stages are essential components of a good health information system (HIS).

### Health Information Management Working Group from 2007 to 2009

Founded during the 2006 Humanitarian Health Conference, which was co-sponsored by Dartmouth Medical School and the Harvard Humanitarian Initiative and convened in Hanover, New Hampshire, the Humanitarian Health Information Management Working Group (HHIM) created a forum for discussing information and data management issues related to surveillance

and surveys in humanitarian work. Three major sub-working groups were created as a result of the 2007 Summit that focused on facility- and population-based: (1) quantitative data accrual; (2) data quality and reliability; and (3) surveillance during the acute phase of emergencies. Key consensus points and action steps from the 2006 and 2007 Summits are articulated in the Summit Summary[1] and subsequent peer-reviewed publication.[2]

Updates from organizations represented at the 2007 Summit showcased a newly developed, early warning system (EWARN), the use of Internet technology for managing and analyzing surveillance activities, and continued challenges in gathering quality data and using adequately skilled personnel.

Since 2007, three EWARN systems have been implemented to facilitate early detection of epidemics, to aid in preparation for potential outbreaks, and to build capacity to improve routine surveillance. The systems have effectively facilitated the timely arrival of expert technical staff to disaster sites, and have resulted in a high uptake of the system by non-state providers of assistance. The use of new technology, close collaboration with local authorities and NGOs, and sustainability are strong markers of the effectiveness of EWARN for surveillance activities. Potential improvements in the early implementation of EWARN in the future include early collaboration with state and local partners, including Ministries of Health, in addition to increased coordination with existing surveillance systems and national reference laboratories.

Standardization in data and information management and analysis as well as limited comparability reporting over time and across countries are important issues hindering HIS progress in humanitarian emergencies. Several international humanitarian organizations, including the United Nations High Commissioner for Refugees (UNHCR) and Médecins sans Frontières (MSF), are examining the viability of using field-based databases that eventually will be Web-enabled for collecting, analyzing, and reporting surveillance and survey information. Examples using drag and drop services for graph creation that are able to import and export to other formats including Excel were presented. Field tests have uncovered some challenges that must be addressed, including the creation of standard codes for outcomes and the need to work with individual rather than aggregate data. Using personal digital assistants for surveys also was noted as a potential opportunity for increasing the reliability, efficiency, and accuracy of data collection. Other continuing data and information management challenges included the employment of staff with appropriate data skills, reliance on inaccurate or unreliable data, and the creation of institutional pressure to incentivize managers to use data well. These issues persist despite (or concomitant with) the transition to digital data collection and standardization of tools.

*Emerging Issues*
Changes in the nature and scope of humanitarian assistance activities have created new challenges in health surveillance, particularly outside of camp-based settings. Non-camp settings primarily refer to populations located in urban or scattered rural areas. These settings were chosen because more and more humanitarian organizations are working in non-traditional disaster situations; in other words, with internally displaced persons (IDPs) and refugees who may not be located in camps. While UNHCR has developed an effective and widely used, camp-based HIS, there is less known about current practices and challenges related to surveillance in these non-camp settings.

Some issues related to surveillance are common to all settings; however, unique challenges exist in undertaking health surveillance in non-camp settings. There is a great deal that remains unknown about what currently is being done and how we need to progress in this challenging area of health and nutrition surveillance in humanitarian emergencies in non-camp settings.

## Objectives
The primary aim of the HHIM Working Group was to identify the challenges and areas that need further elucidation in a range of non-camp settings, including urban and rural as well as low- and middle-income countries. The objectives were to outline the current practices and relevant methodologies for surveillance in these various settings, and to discuss the possible future directions of humanitarian health surveillance systems.

## Discussion
Panel presentations provided an introduction to the issues and challenges of conducting surveillance in non-camp settings. Ms. Melanie Morrow, Director of Maternal and Child Health Programs at World Vision, provided a case study of community-based health information collection in Mozambique. The project relies on illiterate female volunteers from the community; each is responsible for training persons in 10 other households. These women perform focused data gathering, including births, deaths, pregnancies, immunizations, and latrine use. They verbally pass this information to staff members during an intensive 1–2 hour meeting every two weeks. The information then flows upwards in the organization and to the local health clinics and the ministry of health. No pay is provided; only a small yearly incentive, such as a t-shirt, is provided, but the women gain training and prestige from the program.

Dr. Paul Spiegel discussed challenges of surveillance with regard to Iraqi refugees in the urban-settings of Jordan and Syria. One major issue was how to identify the target population. Related to this problem is the difficulty of enumerating the underlying population size when refugees may not desire to be found due to protection concerns. Healthcare delivery is more fragmented and requires integration of information from many different sources, including hospitals and clinics, both public and private. Services required also are more expensive, as populations in mid-income countries tend to be older with complex and chronic diseases as well as being more medically sophisticated. Overall, this tends to be a more resource-intensive population.

These two presentations highlighted the differences in population need and current methodologies for surveillance in low-income, rural populations compared with middle-income, urban populations. The panel discussion also pro-

vided insight into some of the similarities in the challenges in camp and non-camp settings, such as the challenges of enumerating the population, the need for quality data using standard case definitions, difficulty of supervision and training, and the need for collaboration with local and national governments, especially at the referral level in urban settings.

A break-out session provided an opportunity for the core Working Group members to meet and discuss the issues raised by Morrow and Spiegel and to delve deeper into the issues related to surveillance in non-camp settings.

Three major themes emerged during the discussion: (1) standardization of measures and methodologies; (2) context in data collection and management; and (3) hidden populations and the purpose of surveillance in urban settings.

Building on the discussion and progress from the last year, the importance of increased standardization between humanitarian organizations was discussed. Surveillance in camp and non-camp settings may benefit from organizations using similar measures and methodologies when appropriate. Examples of incongruent indicators included death in a hospital within the past 24 versus 48 hours of arrival, and assessing the delivery of prenatal care according to the number and timing of visits. Members also highlighted several sources for standardization of diseases and various categories, two of which currently are under revision—ICD-11 codes and the National Library of Medicine's MeSH headings, which might streamline this standardization process.

The members also discussed the importance of context. Context plays an important role in all humanitarian settings, and therefore, any HIS must be able to adapt to different settings and circumstances. Examples of community-based and urban surveillance highlighted the different needs and resources required for surveillance including rural versus urban settings and surveillance in low- versus middle-income countries. In addition, whether this HIS is being in stable versus unstable settings should be considered.

Innovative examples of data collection and management in community-based surveillance were discussed. Current community-based practices share several important characteristics:

1. Benefits of task-shifting data collection to community-members, volunteers, or community health workers;
2. The number and type of tasks being performed by the data collectors;
3. Compensation for data collectors' tasks (relative to quantity of work);
4. Ratio of data collectors to population;
5. Low literacy or illiteracy of data collectors in some circumstances; and
6. Challenges regarding supervision and scalability of employing low ratio, illiterate, lay data collectors in community settings.

Members of organizations provided examples of using lay community health workers or volunteers for two different, main activities: disease surveillance and service delivery. How to integrate these two activities was of great interest to HHIM participants. For example, the integration of health workers into the HIS in Southern Sudan may have the potential for use in surveillance activities given their employment as home health providers. Consensus was reached that both the number and type of tasks (e.g., collecting information for surveillance activities and treatment for common illnesses) may depend upon the number of cases that health workers are encountering and their literacy levels. Also, the need for community support (not excluding material resources), particularly for unpaid health workers, also was discussed.

Data collection and management tactics for use in non-camp, urban settings was very different than were those suggested for community-based, rural settings. Surveillance in urban settings appeared much more likely to utilize facilities that already exist within the health system. For example, the presence of Iraqi refugees in Jordan and Syria suggests that the population has significant chronic and expensive healthcare needs that often are not present in low income, camp-based settings. This may provide an opportunity to use referral services as an entry point to identify and track these persons.

An important question arose as to the purpose of surveillance in non-camp settings where the majority or a significantly minority of IDPs or refugees may not want to be found, primarily for protection reasons. These "hidden populations" (which also may occur in rural, scattered populations) create a unique challenge for non-camp-based surveillance. One proposed reason for finding and enumerating "hidden populations" is to be able to provide assistance to them if living conditions become perilous and warrant humanitarian action. Nevertheless, in cases in which enumerating or finding "hidden populations" may endanger the population, surveillance activities may have to be reduced or undertaken in a more indirect manner.

## Conclusions
Surveillance in non-camp settings can be informed by surveillance activities in camp-based settings, but requires additional consideration of new methods and population needs to achieve its objectives.

## Recommendations
Four major areas of consensus were achieved by the Working Group participants.

1. Standardize measures and methodologies used in surveillance activities;
2. Recognize the importance of context and circumstances in non-camp surveillance, particularly whether the setting is stable or unstable, rural or urban, and in a low-income versus a middle-income country;
3. Document and improve the understanding of current community-based surveillance activities; and
4. Examine the underlying needs of non-camp IDP and refugee populations including rural, scattered populations, urban populations, and the unique challenges of surveillance in this context.

## Suggested Strategies
Based on the WG discussion and recommendations, the following strategies were suggested for future work in this area:

1. Examine, compare, and agree (when possible) on key indicators among three major international organizations: MSF, UNHCR, and the World Health Organization;

2. Increase active participation among surveillance experts in discussions about indicator development and data and information classification, such as the ICD-11 and MeSH headings;

3. Systematically document and disseminate current practices in community-based surveillance according to different contexts;

4. Create a white paper on techniques and methodologies for estimating population sizes and composition in non-camp settings; and

5. Document and disseminate the range of existing health information systems for displaced populations in urban settings.

### References

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