Perspectives

A standardized health information system for refugee settings: rationale, challenges and the way forward

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Introduction

The past 10 years have seen a significant increase in the amount of resources allocated to public health programmes for refugees.[1] Increased funding and complex challenges in providing effective public health interventions in refugee settings have brought associated demands for better data and improved accountability.

In the past five years, the Office of the United Nations High Commissioner for Refugees (UNHCR) and its partners have developed and implemented a standardized health information system (HIS) in numerous countries to monitor camp-based refugee health programmes.[2] The aim has been to improve the health status of refugees and other displaced persons through evidence-based policy formulation and better management of health programmes. At the end of 2009, a total of 17 operations in Africa, Asia and the Middle East were reporting into a standardized HIS using common tools and guidelines. The total population under surveillance was approximately 1.5 million refugees in 85 refugee camps across 24 different partners.

The introduction of standardized data collection and reporting tools into refugee camps, and the increased availability and accessibility of data to decision-makers, has brought with it several advantages. However, it has also raised important questions, the most fundamental of which is: how should a refugee HIS work alongside its much larger national equivalent within the ministry of health?

This paper discusses the rationale for establishing a refugee HIS in countries that host camp-based refugee populations. It attempts to dispel a common misconception that refugee and national HIS are two competing and incompatible alternatives. Instead it describes how a refugee HIS can be used to support data management within host government systems.

Need for data

A strong evidence-base exists to document the public health challenges faced by refugees and the need to establish strong information systems in displacement settings.[3,4] However, there has been little documentation of the reasons that refugee health data are of public health importance to national governments, or how refugee information systems should relate to their national equivalents. Some of the most significant reasons that explain the need for refugee data are described here.

Disease surveillance and outbreaks

The geographic location of refugee camps, often close to international borders, places them at greater risk of cross-border transmission and outbreaks of epidemic-prone disease. Therefore, disease surveillance within refugee camps is of high importance and has a crucial role to play in district-level early warning and response in refugee hosting areas.

Resource allocation and monitoring

Ministries of health increasingly recognize the importance of including refugees within strategic plans and resource allocations for national disease prevention and control efforts. Active engagement by ministries of health and inclusion of refugees in national planning exercises brings with it associated demands for information from camps for purposes of monitoring and evaluation.

Implementation of services

In the majority of refugee operations, responsibility for implementing health services within refugee camps falls on nongovernmental organizations. However, in protracted crises, district health authorities often assume a greater role in delivering health services to refugees. This increasing involvement carries concomitant demands for accountability and reporting to host governments.

Equity

Refugee health services should be established according to the important principle of equity, where host communities have similar access to services as refugees in camps. In some countries, this can lead to health services within refugee camps becoming an important source of health care for local populations. If national information systems are to remain accurate and representative, it is therefore important for statistics from refugee services to be included within national HIS.

Rationale for an HIS

Given the value of refugee data to host governments, the question remains as to how they should be collected and shared with national information systems. Leaving aside the capacity and willingness of governments to extend support to HIS within refugee camps, we describe here five unique requirements of refugee health programmes that distinguish their monitoring requirements from national equivalents and prevent refugee health data from being collected directly within a host Government's HIS.

Disaggregation

Refugees and other displaced populations are unique groups that often have special needs. It is of fundamental importance that a camp-based refugee HIS has the ability to clearly disaggregate health data by refugee status (i.e. national versus refugee). This not only requires appropriate design of data collection and reporting

tools, but also the clear definition, analysis and presentation of results. National systems are not designed to support this level of disaggregation by beneficiary type.

Monitor services

As far as possible, refugee public health and HIV policies and programmes are integrated with those available to the host community. However, in settings where host country policies do not meet international standards (or have been shown to be ineffective), internationally accepted policies must be followed while advocating for a change in national equivalents. Moreover, services are sometimes provided to refugees that are not routinely available through the ministry of health due to differences in resource endowment, logistics and staffing. National information systems often do not have the flexibility to accommodate these changes or to monitor the different types of services offered within refugee settings.

Humanitarian standards

In addition to host government requirements, refugee health services adhere to normative international principles that govern humanitarian action and define universally applicable minimum standards of care in all humanitarian settings.[5,6] The monitoring requirements of national systems designed for development settings remain largely different to those defined by the humanitarian community.

Challenging environments

Refugee crises are rapidly evolving environments where emergency health programmes need to be established rapidly in response to sudden cross-border influxes. These operating environments demand lightweight information systems that can be deployed at short notice and establish a flow of data from the onset of an emergency. Such systems should also be scalable to allow transition to more comprehensive reporting when the situation permits. National systems generally do not have flexibility to reduce and/or modify reporting requirements at short notice.

Language differences

In many operations, refugees play an integral role in the delivery of health services. They are often themselves the frontline staff responsible for primary data collection and reporting. As refugee staff may not speak the same language(s) as host nationals, ministry of health data

collection tools, guidelines and training materials are not always suitable for use inside refugee camps.

Benefits and costs

Despite their need for refugee data, the unique requirements of refugee health programmes generally prevent host governments from using national HIS to directly collect health data within these settings. To solve this problem, the refugee HIS was developed as a tool to support data management both among the nongovernmental organizations that implement services in refugee camps and the national governments that host them. The refugee HIS database software is able to uphold national reporting requirements by publishing refugee data directly into the ministry of health's HIS reporting formats. This ensures that the two systems are integrated. We do not advocate for the establishment of parallel refugee HIS that do not report into the national HIS.

The HIS project provides increased resources, logistics and staffing to information systems at camp-level, and thus can help to strengthen data management in districts that host refugees. In many countries, the establishment of the refugee HIS has meant that, for the first time, host governments are now able to receive and utilize data from nationals in refugee-hosting areas. At the level of the most basic record keeping, the refugee HIS provides a set of paper-based tools to support primary data collection and reporting at the health facility.[2] In resource-poor settings, where stockouts and shortages of paper-based tools are commonplace, these tools have a vital role in standardizing reporting and maintaining a continuous flow of information within health programmes.

The refugee HIS has helped to simplify reporting procedures in refugee camps, decrease the burden of data collection and reduce the amount of time taken to prepare reports. This has helped to improve data quality and also increase the time frontline health-care providers have to dedicate to clinical care. Simple database software provided to partners helps to ensure that HIS data are computerized and analysed at the earliest possible interval by UNHCR and its partners. This has led to improved accountability, resource allocation and programme decision-making at all levels of health management.

Finally, continuous monitoring and evaluation of refugee HIS is made available through regular missions by UNHCR and partners at country, regional and headquarters level. These offer a unique opportunity to obtain qualitative feedback from users, assess data quality and provide on-the-job education and training to frontline users of the system.

Evaluation of the HIS exposed several weaknesses. The system requires dedicated financial and human resource support. Data quality can vary widely, with some countries scoring comparatively lower than others. The evaluations also revealed wide disparities in the ability of end-users to interpret and use the data. Further work is needed to address these learning gaps, involve national authorities and donors in evaluation exercises, and to ensure that the results confer benefits to both national and refugee systems.

Conclusion

Refugee data are of public health importance to ministries of health. However, the unique characteristics of refugee settings prevent host governments using their existing HIS to directly monitor refugee health programmes. Refugee settings require an HIS that is adapted to meet their specific monitoring needs but that can continue to uphold national reporting requirements and share data with host governments long after they have been established.

UNHCR has developed a standardized refugee HIS for its camp-based field operations that is freely available to partners. While this system has several benefits for national information systems, closer collaboration is required between stakeholders to better integrate national and refugee systems. This includes the development of guidance materials, standardization of evaluation methodologies, organization of joint training and evaluation missions, and in dissemination and use of refugee data.

At the global level, more concerted efforts are needed to harmonize indicator selection and define common standards for coding data. This will help promote interoperability and integration between national and refugee HIS, and ensure the results can support decision-making at all levels of management and by all partners including refugees, host governments, United Nations agencies and the wider international community. ■

Competing interests: None declared.

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