Association of Refugee Health Coordinators Surveillance Committee

Recommendations
Executive Summary

CDC describes public health disease surveillance as “the ongoing systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health.”

Surveillance can serve a range of purposes, including:

- Assessing changes in the trend of a disease or its distribution.
- Enabling predictions about the pattern of occurrence of a disease.
- Identifying specific groups at risk.
- Assessing the magnitude of a health problem.
- Monitoring the impact of health interventions.
- Better understanding the epidemiology of disease.

Currently, state refugee health programs do not have ongoing, systematic collection systems. Each has its own process for collection and analysis of refugee medical screening data, ranging from no system for data collection to sophisticated web-based applications. There is very limited sharing of these data between states and with CDC, and there is no national system to compile data from the domestic refugee medical screening exams. With refugee populations spread across the United States and no national refugee health surveillance system, it is difficult to track major health trends and identify emerging medical issues in resettled refugee populations.

The objectives set forth for the ARHC Surveillance Committee are:

**Objective 1:** Review and report the existing data collection systems, for both refugee health data and public health data more broadly.
   a) Identify capacity of refugee health programs to collect data.
   b) Identify gaps in data collection.
   c) Identify barriers to data collection (e.g., personnel limitations).

**Objective 2:** Provide recommendations for improving refugee health tracking and surveillance.
   a) Identify core functions related to data for state refugee programs (i.e., specify the initial reasons for refugee health surveillance).
   b) Provide strategies for supporting state programs with minimal data collection capacity (e.g., the development of an Access database or similar product for state programs with minimal IT support that need a user-friendly system to track their screening results).
c) Determine feasibility of developing minimum standards for data collection processes.
d) Provide additional national mechanisms for capturing timely information about reportable diseases and emerging infections.

**Objective 3:** Develop and provide recommendations for mechanism(s) to collect, analyze, and disseminate multi-state refugee health data.

a) Assess interest and capacity to participate among states.
b) Report on varying data privacy practices across states and implications of sharing health screening data with CDC.
c) Provide feasibility of options such as sentinel surveillance sites, providing CDC with state refugee screening results on a regular basis (probably de-identified) via CDC’s Electronic Disease Notification (EDN), and/or other venues.

Recommendations were developed to provide means to address some of the current limitations in refugee health surveillance, thereby allowing state and federal partners to better collect, analyze, and disseminate data related to the health of newly-arriving refugee populations.

Recommendations include:

- Funding should be obtained to develop a national domestic refugee health surveillance system. Resources and support must be identified and directed to national, state, and local/county surveillance sites.
- Efforts must be made to better standardize data collection related to refugee health screening.
- States should prioritize health screening data variables, above and beyond the minimum standards, to collect based on proposed health screening priorities and on which variables would best inform programmatic priorities if analyzed at the national level.
- The refugee health data surveillance system should collect health and demographic data as well as screening status information, to provide indicators of screening coverage and timeliness.
- *De-identified, raw* data files should be shared in a national surveillance system.

Three potential models of surveillance mechanisms are proposed.

The ongoing Association of Refugee Health Coordinators (ARHC) Data Committee plays a significant role nationally by focusing on the following goals: (1) Provide epidemiologic information and surveillance support for emerging health conditions or during disease outbreaks or investigations; (2) advocate for regional or national surveillance including
post-arrival health assessment data collection, analysis, and reporting; (3) promote and discuss pre-arrival country of origin/refugee population health profiles; (4) monitor and address notification issues; and (5) promote special studies.

The ARHC Data Committee will carry on the task of prioritizing and implementing the recommendations. Many thanks to those who participated in creating these tools, guidelines, and recommendations.
Recommendations and Operational Guidance

Overview

The mission of the Association of Refugee Health Coordinators (ARHC) is to strengthen state and local refugee health leadership, expertise, and advocacy to achieve wellness in domestic refugee populations. ARHC membership is comprised of state refugee health coordinators and staff from state or local governmental agencies or nonprofits who provide health services to refugees. While infrastructure and capacities vary by state, state refugee health programs work to ensure that refugee populations receive domestic health assessments, immunizations, and linkages with ongoing medical services.

In fall 2010, the CDC’s Division of Global Migration and Quarantine (CDC/DGMQ) provided short-term support to ARHC through a cooperative agreement with the Association of State and Territorial Health Officials (ASTHO). This project is called “Enhancing Partnerships in Refugee Health.”

Three committees were formed: Health Education, Medical Screening, and Surveillance. Under the guidance of the Enhancing Partnerships in Refugee Health leadership team, the Surveillance Committee focused on reviewing what currently exists in data collection systems nationally and providing recommendations for improvement and the development of mechanisms to collect, analyze, and disseminate multi-state refugee health data.

Nearly 80,000 refugees are resettled into the United States annually. Each refugee must undergo an overseas exclusionary exam to determine eligibility to enter the United States. The health information gleaned from this overseas medical examination is made available to county and state refugee health coordinators via CDC’s Electronic Disease Notification (EDN) system. Once the overseas medical examinations are received, state and county health departments in the refugee’s state of destination initiate the coordination of the domestic medical screening examination.

Though the overseas medical exam is fairly routinized with a central data repository, the components of the domestic medical exam vary between and sometimes within states. Currently, domestic screening results are collected in surveillance systems housed in state or county health departments, and none of these medical screening results are captured in a national surveillance system. A centralized data system could enhance CDC’s ability to track and monitor disease trends and patterns among newly arrived refugee populations across the United States.

If the results of health screening for newly arrived refugees were collected and analyzed, the field of refugee health would greatly benefit. Unlike the overseas medical exam, domestic health screening is designed not only to contain infectious disease but
also to enhance the well-being of the refugee, providing a much richer data source. Analysis of domestic health screening data has led to awareness of chronic disease and its risk factors among refugees and asylees, health profiles of Iraqi and Karen refugees, dental caries among refugee children, and the impact of overseas pre-departure treatment on prevalence of intestinal parasites. Based on these findings, a range of interventions were put in place to the benefit of domestic refugee populations.

In spite of these successes, it remains challenging to coordinate data analysis efforts across states and assess disease trends by population. As noted above, refugee health programs and the services provided differ, sometimes dramatically, from state to state. Similarly, the methods for providing services and collecting data on the outcomes of those services also vary from state to state. Some states do not have enough refugee arrivals to warrant analysis, and others do not have the capacity to perform analysis.

Based on the knowledge of these inconsistencies, the ARHC Data Committee developed a survey in 2010 (see ARHC Data Survey, Appendix I) to assess the current landscape in data collection, management, and reporting of domestic health screenings for new refugee arrivals. The main objectives of the survey were to assess each state’s capacity to collect refugee demographic and/or domestic refugee health screening data, as well as to manage and analyze data and generate associated reports. Though the survey generated many meaningful results, a range of questions remained. This project builds on the findings of the ARHC Data Survey.

Methods

As noted above, ARHC members and nonmembers who held expertise in the subject matter were recruited to participate in the committee to develop the surveillance recommendations in January 2011. The members included academic, clinical, and programmatic experts.

The Surveillance Committee developed a work plan and utilized the ARHC Data Survey results and developed new surveys to meet the needs of the task before them. The project leadership team and the ARHC Executive Board reviewed the draft recommendations. The recommendations received further critical review and editing after they were presented to the ARHC membership and federal and national partners at the Enhancing Partnerships in Refugee Health Conference in May 2011.

The ARHC Data Survey revealed that five out of 34 states (15%) did not receive or retain any domestic medical screening results. Based on these findings, one surveillance subcommittee developed a Capacity Survey (see Appendix A) to determine the gaps and barriers to collecting refugee medical screening results (Objective 1). The supplemental Capacity Survey was sent to states with “low arrival numbers” that did not respond to the ARHC Data Survey and states identified as having “low/medium (low) data collection capacity” in the ARHC Data Survey. Twenty-one of thirty-one states responded (68%).
Another surveillance subcommittee was charged with developing minimum standards for data collection that could be recommended for use in all states (Objective 2). This group drafted the core data collection functions of a state system and created a list of demographic and health variables, which were then separated into tiers marking them as essential, preferred, and expansive for data collection. They collected screening forms from states to analyze how easy standardization of data collection across states would be and explored other data sharing systems to see if one could be adapted to ARHC’s needs.

The third priority area of the Surveillance Committee was to explore a centralized repository for national refugee health screening results (Objective 3). Based on the ARHC Data Survey results, 15 states (California, Colorado, Florida, Maryland, Massachusetts, Minnesota, New Jersey, North Carolina, Ohio, Pennsylvania, Rhode Island, Texas, Indiana, Missouri, and Washington) representing more than 50 percent of refugee arrivals in fiscal year 2010 (a total of 41,671 individuals, based on preliminary EDN data) were deemed “high capacity” in regard to their ability to perform the activities listed above.

Fourteen of the high capacity states (93%) agreed to participate in a Supplemental Survey (Appendix E), which assessed the following:

1. The agencies’ interest in being a CDC surveillance site.
2. Their capacity (e.g., information technology, infrastructure, personnel, etc.) to participate in a national refugee health surveillance system, including perceived short- and long-term challenges.
3. Their data sharing policies and the implications of sharing refugee health screening data with CDC.

In addition, various surveillance systems were assessed to evaluate feasibility options and to recommend essential technical characteristics and potential reporting (surveillance) mechanisms to CDC.

**General Recommendations**

**Recommendation 1:** Continue and expand use of EDN by all state programs for notification of arrivals and initial data collection. ARHC and CDC can encourage use in states not currently enrolled.

CDC sends notifications of refugee arrivals via EDN to all states and the District of Columbia, except Alaska, West Virginia, and Wyoming (Appendix H). EDN is actively utilized in the majority of states that responded to the “Enhancing Partnerships Capacity Survey” (57% of respondents), making it the most widely used system for notification about new arrivals.
• Of the respondents that do not use EDN, 67 percent were familiar with it.
• The majority of respondents that did not use EDN and did know about it said they preferred their current system of receiving notifications from their local volunteer organization (volag). Some found using an electronic notification system too cumbersome for the volume of refugees they resettle. Many others, however, stated they would like to or could envision using EDN for notification of new arrivals.
• The fact that EDN is an established system in many states argues for expanded use, which could enhance uniform collection of demographic and overseas medical information for new arrivals across the country.

It is of note here that only 50 percent of respondents thought EDN was a good venue for returning screening data to CDC. This issue will be addressed more fully in recommendations related to developing a national surveillance system.

**Recommendation 2:** Other mechanisms for flagging emerging health issues among newly arriving populations in a timelier manner should be explored by a joint CDC-ARHC committee.

These mechanisms could include:

• Increasing the use of Epi-X by refugee health programs.
• Utilizing the Refugee Health Technical Assistance Center (RHTAC) website and/or listserver.
• Utilizing the ARHC message board.

**Recommendation 3:** Since little is known about the long-term health outcomes of refugees resettled in the United States, CDC should fund a project to investigate refugee health beyond the initial resettlement period.

Domestic refugee health assessments generally occur within 90 days of a person’s arrival in the United States and thus are largely indicative of the person’s health status prior to arrival. With the exception of longer-term followup for certain infectious conditions such as tuberculosis, few refugee health programs have the capacity to assess and address refugee health needs for more than a few months after arrival.

Several states could be selected and funded as part of a pilot study to follow refugees for longer periods of time to better understand their evolving health needs post-arrival.

**Recommendations Related to Developing a National Surveillance System**

Of the 71 percent of the 14 refugee health coordinators (RHCs) who responded to Supplemental Survey indicated interest in being a surveillance site for CDC, all stated
that their agency’s data sharing policies permitted reporting de-identified raw and aggregate summary data files to CDC. Only four (29%) participating agencies indicated the ability to report identified raw data files to CDC. A national surveillance system of domestic refugee medical screening information coordinated and managed by CDC will provide a better understanding of refugee health concerns and opportunities to better assist refugees living in, or awaiting resettlement in, the United States.

**Recommendation 1:** Funding should be obtained to develop a national domestic refugee health surveillance system.

A more robust data set resulting from a national surveillance system could help states and CDC better identify population-specific health problems among resettled refugees, supplement information provided by state surveillance systems, and potentially allow states with limited surveillance capacity and/or small refugee arrival numbers to benefit from nationwide data. Such a system could be effective even if not all of the state refugee health programs were able to participate. For example, if only states resettling more than 500 refugees a year were to share refugee health screening data with a national refugee health surveillance system, information on approximately 95 percent of refugees resettled in the United States could be available for analysis.

CDC should be approached to fund and work with ARHC to develop a national domestic refugee health surveillance system. This will ensure that surveillance will include infectious and specific chronic diseases and place a high value on data quality and standardization. This will also enable flexibility to account for changing refugee populations with differing health issues and enhance the timeliness of the data collected.

The core functions of this surveillance system should be to:

- Better understand the changing health needs and trends in newly-arrived refugee populations.
- Identify health issues that are population-specific.
- Assist CDC in tailoring domestic refugee health screening guidelines based on data generated from this system.
- Help states to better prepare for the arrival of refugee populations by being informed of trends in nationwide data.
- Provide feedback on the health conditions of concern in refugee populations to the refugee camps from which they originated.

**Recommendation 2:** To develop a national surveillance system, resources and support must be directed to national, state, and county surveillance sites.

Public health infrastructure and personnel capacity varies by state, making it important to evaluate each state’s existing surveillance system. From the Supplemental Survey,
eight of 12 (67%) RHCs specified the need for additional capacity building resources as short- and long-term challenges.

The identification and allocation of financial, IT and personnel resources to national and participating surveillance sites by a consortium or work group would ensure execution of objectives as defined by the surveillance system stakeholders.

A successful national surveillance system would need the following:

- A coordinator to define roles and responsibilities for participating sites, provide them with feedback, develop and monitor data sharing protocols and user agreements, and report national data summaries to sites and stakeholders.
- Programming staff to implement and maintain the surveillance system, as well as to assist states that do not have the funds and/or personnel to have an IT professional of their own.
- An epidemiologist to analyze national level data and to provide support, education, and training to participating sites as well as to states that do not have the funds and/or personnel to have an epidemiologist of their own.
- A data manager to coordinate and audit incoming data and provide technical assistance to participating sites.
- A local surveillance epidemiologist/coordinator to assist in analysis and interpretation of data and to serve as a regional data analyst.
- A local or regional data manager to ensure that data are received from providers in a timely basis and entered into the local surveillance system.
- Local IT capacity/support to implement a robust surveillance system at the local level and potentially to serve as a regional IT support for sites using similar systems.

Recommendation 3: We recommend that this surveillance system should have the following technical characteristics:

a) Ability to upload de-identified data in common formats such as Microsoft Excel, comma separated, text, extensible markup language (XML) or hypertext markup language (HTML).

b) Web-based system with limited security requirements.

c) Accessibility by stakeholders at high, medium, and low capacity agencies.

d) Ability for users to export data for analysis and dissemination.

e) Ability for users to generate basic summary reports from data.
Recommendation 4: The committee proposes three potential surveillance models. The final mechanism needs to be decided upon by stakeholders.

Model A – A web-based system without a digital certificate (which is not required for de-identified raw data) operated and maintained by a refugee partner or stakeholder that is funded by a federal stakeholder through a cooperative agreement.

Model B – A web-based system without a digital certificate operated and maintained by CDC’s Division of Global Migration and Quarantine (DGMQ).

Model C – A module within the EDN system (not linked to identifying information) operated and maintained by CDC’s DGMQ.

Recommendation 5: We recommend the sharing of de-identified, raw data files for a national surveillance system.

Very few of the RHCs interviewed (29%) reported the ability to share raw identified data with CDC unless they had received the patient names and health information from CDC to begin with, or unless a Memorandum of Understanding (MOU) were drafted. All fourteen Supplemental Survey respondents indicated that de-identified and aggregate summary data files could be shared with CDC without an MOU. The benefits and limitations to sharing identified, de-identified, and aggregate data are listed in Appendix F.

Recommendation 6: We recommend that refugee health staff acquire a working knowledge of their data sharing policies in order to participate in any interstate or national disease surveillance activities.

Many of the RHCs who were interviewed were unfamiliar with or encountered difficulties interpreting their agency’s data sharing policies.

Recommendation 7: For states with lower capacity that would not be able to participate in a national surveillance system, we recommend that:

a) The Office of Refugee Resettlement (ORR)/ARHC should create permanent short-term state partnerships/mentorships between lower and higher capacity states to encourage data and idea sharing. The higher capacity states, in addition, could help train the other states on the new nationwide collection system so that all states involved collect and report data in the same manner.

b) States that do not have standardized reporting across multiple screening site clinics should develop a minimum standard of what information needs to be reported back and kept by the state in order to have a consistent data set.
c) ARHC, in partnership with ORR and CDC, can offer technical assistance to states that desire a data collection system but have not been successful in creating one.
d) ARHC and the Refugee Council USA (RCUSA) can partner to develop models of how Refugee Health Programs and local resettlement agencies can work together to ensure quality screenings completed in a timely manner.

Recommendations Related to Standardizing Data and Prioritizing Variables

Recommendation 1: ARHC, in partnership with ORR and CDC, can develop standardized screening forms that could be modified, if needed, by individual state programs (see the Universal Refugee Health Screening Form created by the Medical Screening Committee).
  a) One third of Capacity Survey respondents reported that their program does not have standardized forms across all providers performing health screenings. Without standardized forms, it is nearly impossible to have standardized data collection.
  b) ORR should encourage states that do not have standardized reporting across multiple screening site clinics to develop a minimum standard of what information needs to be reported back and kept by the state in order to have a consistent data set.

Recommendation 2: Any state with more than 200 refugee arrivals per year and with sufficient capacity and resources should create a refugee health data surveillance system that includes health-screening results. ARHC should develop a minimal standard for a formal data collection system by states. States with low numbers of arrivals (less than 200/year) would not be held to the same standard as states with a higher volume of arrivals. ARHC, in partnership with ORR and CDC, should offer technical assistance to states that desire a data collection system but have not been successful in creating one. The surveillance system should be easy to use and should allow for quality assurance and the possibility of data sharing. This could be achieved by adhering to the following requirements:

   Software
     o Utilizing software that includes query functionality.
     o Utilizing software/systems that allow data exports in a format that can be shared as well as imported into analysis programs (e.g., SAS, Stata).
     o Ensuring that surveillance systems include non-duplication features.

   Data Management
     o Including as many “checks and balances” as possible. For example, setting up the system to not allow blank fields, require follow-up answers, etc.
     o Ensuring that qualified personnel will be identified and assigned to maintain the database.
Ensuring that data are standardized.

Employing established software such as Microsoft Access or Excel or a web-based solution that is compatible with multiple computer networks and/or adapting existing surveillance systems that are in use by other state Refugee Health Programs, such as eSHARE or MAVEN, could facilitate the development of a surveillance system that meets the above requirements.

Assistance to any state wanting to develop or upgrade their current process or surveillance system should be provided by a funded ARHC liaison, who could help the state to benefit from the example and experiences of other state programs.

- Eighty-five percent of respondents are interested in collecting more comprehensive data on refugee arrivals and results of screening exams.
- Smaller programs do not perceive the need to track a small number of arrivals. They also report a lack of funding to track arrivals or build a database to maintain refugee arrival records.
- Smaller programs also do not have the time or manpower to collect data on newly arrived refugees. Most of these programs have either half-time employees or employees who share duties with other public health programs.
- By having a regional or national database the smaller refugee programs would not have to increase funding or staff because the system would be established and maintained at the regional or national level. For analysis, an epidemiologist could be implemented at a regional or national level. An added benefit to the states would be state-specific data that could prove beneficial in seeking funding.

**Recommendation 3:** We recommend standardization of data related to refugee health screening. This is essential for any national refugee health surveillance system to function effectively.

A joint CDC-ARHC committee should be formed to compare data dictionaries across states to serve as the basis for the development of a national data dictionary that would guide the documentation of health screening data elements across states. This should be completed early in the development of the national surveillance system so that states have sufficient time to allocate staff resources toward standardization of screening forms and surveillance system databases.

The inclusion of variables in a national refugee health surveillance system should depend not only on their importance in enhancing refugee health programs’
effectiveness, but also on the frequency with which they are collected by states and on the ease with which they could be standardized across states. For example, when screening forms from 31 states were analyzed, it was found that 100 percent of states document tuberculosis screening results. Of these, 84 percent record results as either TST induration or IGRA positive/negative. Conversely, determining standard data elements for parasites will likely take more time. Nearly all (97%) states collect parasite screening results in some format, but only 55 percent document specific parasites. Chronic conditions are often documented when indicating whether referrals were made.

**Recommendation 4:** States should prioritize which health screening data variables to collect based on proposed health screening priorities and on which variables would best inform programmatic priorities if analyzed at the national level.

One possible mechanism for guiding prioritization could be a tiered variable prioritization system, as is currently used by the CDC for nationally notifiable disease data submissions. (See Appendix D for an example of how prioritization might work for refugee health screening and examples of variables that are currently being collected as reported by the survey participants).

States would need to collect, at a minimum, the required variables to share data with the national data surveillance system. In order to use the data to assess prevalence of disease, both positive and negative results should be documented.

Though they are important to document, states would likely not be able to share certain identifying variables with a national system due to privacy concerns. Examples of these variables include alien number, date of birth, and arrival date. A way to overcome this could be to require a unique ID, age, and month and year of arrival for each individual instead.

Recommendations from the ASTHO Medical Screening Committee should be taken into account, and a joint CDC-ARHC committee should be formed to determine which variables should fit in which tier and to address any privacy concerns.

**Recommendation 5:** In addition to capturing health and demographic data, a refugee health data surveillance system should include data related to screening status. According to the Data Survey, though 84 percent of responding states indicated that they documented whether any screening was done and 81 percent documented the initial clinic date, only 59 percent documented screening completion date and less than half (44%) documented when screening results were received. More consistent collection and analysis of these variables could ensure timelier identification of health issues in newly arrived refugees as well as timelier disease followup.
In order for screening status variables to be used to gauge the effectiveness of a refugee medical screening program in terms of coverage and timeliness, a state should collect such information as:

- Whether or not any screening was done for each newly arrived refugee.
- The initial clinic date for a refugee who received medical screening.
- The screening completion date.
- The date screening results are received by the refugee health program.

The collection of these variables could allow state refugee health programs to calculate:

- The proportion of arriving refugees who receive medical screening.
- The average length of time between a refugee’s arrival and the initiation of screening.
- The average length of time between a refugee’s arrival and receipt of domestic health screening results.
- The average length of time between completion of screening and the receipt of domestic health screening results.

A recent ARHC data survey found that 66 percent of responding states documented a refugee’s country of origin. Given that a national refugee health surveillance system would be used to identify population-specific health issues, country of origin seems a crucial variable that states should be required to collect and that should be prioritized for standardization across states.

**Recommendations Related to Technical Assistance and Guidance for States**

**Recommendation 1:** ARHC can develop strategic guidance for state programs on retrieving and analyzing refugee screening results from screening clinics.

According to the Capacity Survey, close to 33 percent of programs do not know if health screening of the refugees was completed. For those that do know, 29 percent do not track completion rates at their programs. Reasons for this include lack of personnel and funding. Fifty percent of the programs surveyed do not receive lab or diagnostic results.

A majority of the Capacity Survey respondents track both demographic data and completion of screening, while only half keep track of lab results and screening diagnosis. About two-thirds of respondents do not track disease trend data such as tuberculosis, hepatitis B, etc. A national standard needs to be set across all refugee-accepting states to guide them in determining priorities in relation to data to be collected and tracked.

**Recommendation 2:** Assistance should be provided to refugee health programs that are prevented from developing high quality surveillance systems due to difficulties obtaining health-screening results.
Barriers may include general HIPAA concerns, concerns over providing results for non-reportable conditions, or medical screening funded by Medicaid, which provides states less leverage for obtaining screening results.

Several mechanisms could help address these difficulties:

- Noting the exemption of public health agencies from the Public Health Information Common Rule under HIPAA. The Privacy Rule expressly allows public health information to be shared with public health agencies for public health purposes without individual authorization, including reporting of disease, injury, and vital events and conducting public health surveillance, investigations, and interventions (Appendix B).
- In cases where the refugee health program is funding the health screening, this should entitle them to screening results. Stating that payment for services rendered includes the provision of screening results in contractual agreements could be a solution.
- Data use agreements (e.g., with Medicaid) could define how screening results will be shared and analyzed.
- CDC could send letters of support to states detailing the intended use of the data and the importance of analyzing screening results.
- Screening results could be transmitted to refugee health programs with protected health information removed.

In addition, a refugee health coordinator may not be located in the health department and may thus be bound by different privacy regulations. A recent CDC survey found that 71 percent (25 out of 34 respondents) of refugee health programs stated they were housed within state health departments. Others can be found in human service agencies, in the office of the state coordinator, or in resettlement agencies.

Given that surveillance is key to identifying pressing health issues among newly-arrived refugee populations, assessing the effectiveness of a refugee health screening program, and coordinating disease followup, a state refugee health program would ideally be located within a state health department in order to function effectively as a public health authority.

Barriers to obtaining screening results may be state-specific in nature. As such, further assistance to states should be provided by a funded ARHC liaison, which could assist the state with developing processes to obtain screening results while addressing privacy concerns. The liaison could also help the state to benefit from the experiences of other state programs.
In conclusion, ARHC strongly advocates for increased standardization of data collection across states, offering technical assistance to develop such systems in states without them, and the development of a national repository for refugee screening data to enhance both tracking of diseases and comprehensive healthcare to newly arrived refugees.
Committee Membership

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Appendix A: Capacity Survey

This survey was sent to 31 states. The survey was sent to a mix of states. Seventeen were states that did not respond to the ARHC Data Committee Survey done in 2010 and fourteen were states identified with smaller numbers of arrivals.

Eight states were interviewed by phone as a trial of the survey and the rest were asked to respond via Survey Monkey. Some states were contacted by phone after the survey was released to enhance response numbers. In total 21 states responded to the survey.

1. How are you notified about newly arrived refugees?
   a. EDN [SKIP to Qu. 5]
   b. WRAPS
   c. Volags
   d. Other ________________

2. Do you know about EDN as a resource for refugee notifications?
   a. Yes
   b. No

3. Are you interested in more information about EDN and what it might offer to your refugee health program?
   a. Yes
   b. No

4. Can you envision using EDN to report refugee health screening results back to CDC?
   a. Yes
   b. No

5. Is your state’s refugee health program integrated with your state’s TB program?
   a. Yes
   b. No

6. Is your refugee health program centralized or de-centralized?
   a. Centralized
   b. De-centralized

7. Do the volags play a role in helping arrange for refugee health screening?
   a. Yes
   b. No [SKIP to Qu. 13]
8. What role do the volags have in arranging for refugee health screening? [Circle all that apply]
   a. Referrals to health screening agencies
   b. Transportation
   c. Interpretation services
   d. Make the appointment
   e. All of the above
   f. Other ______________________

9. Do the volags track the appointments that are made for referrals to health screening agencies or facilities for the initial health screening (domestic health assessment)?
   a. Yes
   b. No

10. Do the volags track the appointments that are kept for referrals to health screening agencies or facilities for the initial health screening (domestic health assessment)?
    a. Yes
    b. No

11. Do the volags track the referrals that are made to primary care (medical home)?
    a. Yes
    b. No [SKIP to Qu. 13]

12. How do the volags track the referrals that they make to primary care (medical home)?
    a. Keep track of total number of referrals
    b. Keep track of specific referral types (e.g. cardiac, mental health, gynecological)
    c. Both

13. Does your program have an active working relationship with the volags in your state?
    a. Yes
    b. No

14. How do you choose the clinics that do refugee health screening in your state?
    a. ______________________
    b. ______________________
    c. ______________________

15. What types of clinics perform refugee health screening in your state? [Check all that apply]
a. Private Primary Care
b. Health Departments
c. Federally Qualified Health Centers (FQHC)
d. Immigration Clinics
e. Other _________________________

16. Do the clinics that provide refugee health screening in your state also offer primary care?
   a. Yes
   b. No

17. Do you have a standardized form for health screening in your state?
   a. Yes
   b. No [SKIP to Qu. 22]

18. Do the clinics that perform refugee health screening in your state return the health screening forms with all of the data elements completed?
   a. Yes
   b. No [SKIP to Qu. 20]

19. Do the screening clinics in your state return the screening form to your office?
   a. Yes [SKIP to Qu. 21]
   b. No

20. What is the primary reason that refugee health screeners in your state do not complete all of the data elements on the health screening form?
   a. Money
   b. Time
   c. Skill
   d. Protocol
   e. Inconvenience
   f. Other _________________________

21. How are the health screening forms returned to your office?
   a. Hard copy
   b. Web based system
   c. Other (please specify) ______________________

22. Are the clinics that perform refugee health screening in your state performing all of the services that you ask them to perform?
   a. Yes
   b. No
23. Do you collect demographic data (name, dob, ethnicity, etc) on newly arrived refugees?
   a. Yes
   b. No

24. Do you know if a refugee has completed their health screening?
   a. Yes
   b. No [SKIP to Qu. 27]

25. Do you keep track of what percentage of your refugees completes their health screening?
   a. Yes
   b. No [SKIP to Qu. 27]

26. What tools do you use to keep track of what percentage of your refugees completes their health screening? [Answer Qu. 26 then SKIP to Qu. 28]
   a. Access
   b. Excel
   c. Other (please specify)_______________________

27. Specifically, what would need to change to start tracking the completion rate of your new refugee screenings? [Answer Qu. 27 then SKIP to Qu. 37]
   a. Funding
   b. Increased Personnel
   c. IT Support
   d. Other (please specify) _______________________

28. Are screening lab test results reported to the refugee health program in your state?
   a. Yes
   b. No [SKIP to Qu. 31]

29. Do you collect data on the results of the screening lab tests?
   a. Yes
   b. No [SKIP to Qu. 31]

30. What tools do you use to collect the results of the refugee health screening lab tests? [Answer Qu. 30 then SKIP to Qu. 33]
   a. Infectious Disease Surveillance System
   b. Access
   c. Excel
   d. Other (please specify) _______________________

31. Might it be possible to collect health screening lab test results data if things were different?
a. Yes
b. No [SKIP to Qu. 33]

32. Specifically what would need to change for you to start to collect health screening lab test results data?
   a. __________________________
   b. __________________________
   c. __________________________

33. Do you collect data on the results of the screening diagnoses?
   a. Yes
   b. No [SKIP to Qu. 35]

34. What tools do you use to collect the results of the refugee health screening diagnoses? [Answer Qu. 34 then SKIP to Qu. 37]
   a. Diagnosis Related Group (DRG) Database
   b. Access
   c. Excel
   d. Other (please specify) ________________________

35. Might it be possible to collect health screening diagnoses data if things were different?
   a. Yes
   b. No [SKIP to Qu. 37]

36. Specifically what would need to change for you to start to collect health screening diagnoses data? [Answer Qu. 36 and then SKIP to Qu. 37]
   a. Sharing of Electronic Medical Records
   b. Funding
   c. Increased Personnel
   d. IT Support
   e. Other (please specify) __________________________

37. Do you keep track of patterns of disease trends among your refugees (TB, Hep B, HIV, etc.)?
   a. Yes
   b. No

38. As things stand now, are you interested in collecting more comprehensive data about refugee arrivals and the results of their screening exams?
   a. Yes
   b. No
39. If money were not an issue, would you be interested in collecting more comprehensive data on your refugee arrivals?
   a. Yes
   b. No

40. Among your competing priorities, where would you put making the effort to collect data on refugee health screenings? (scale of 1-10 with 1 being least important and 10 being most important)

1 2 3 4 5 6 7 8 9 10

41. What are the barriers for you in collecting data on new arrivals?
   a. Funding
   b. Organizational structure
   c. IT
   d. All of the above
   e. Other (please specify) _________________________

42. Are there specific changes you’d like to make in terms of data collection on refugees for your state if resources were not a factor?
   a. Yes
   b. No [STOP]

43. Can you describe the specific changes you would like to make?
   a. __________________________
   b. __________________________
   c. __________________________
   d. __________________________
   e. __________________________
   f. __________________________

Thank the respondent for their time and input.
Appendix B: HIPAA Privacy Rule

The HIPAA Privacy Rule covers protected health information in any form.

**Protected health information** generally refers to specific pieces of Health Information that:
- include demographics about an individual
- are generated or received by a health care provider, health plan, employer, or health care clearinghouse
- are in regards to history of, presence of, or future information about physical or mental health or condition of any individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an individual
- identify the individual or can be reasonably assumed to allow for identity of the individual [45 CFR 164.501].

A **covered entity** is a health care provider that conducts certain transactions in electronic form, a health care clearinghouse, or a health plan [45 CFR 160.103].

A **public health authority** is an agency or authority of the United States government, a State, a territory, a political subdivision of a State or territory, or Indian tribe that is responsible for public health matters as part of its official mandate, as well as a person or entity acting under a grant of authority from, or under a contract with, a public health agency [45 CFR 164.501].

The Privacy Rule permits covered entities to disclose protected health information, without authorization, to public health authorities or other entities that are legally authorized to receive such reports for the purpose of preventing or controlling disease, injury, or disability. This includes the reporting of disease or injury; reporting vital events (e.g., births or deaths); conducting public health surveillance, investigations, or interventions; reporting child abuse and neglect; and monitoring adverse outcomes related to food (including dietary supplements), drugs, biological products, and medical devices [45 CFR 164.512(b)].

Generally, covered entities are required reasonably to limit the protected health information disclosed for public health purposes to the minimum amount necessary to accomplish the public health purpose. However, for disclosures to a public health authority, covered entities may reasonably rely on a minimum necessary determination made by the public health authority in requesting the protected health information [45 CFR 164.514(d)(3)(iii)(A)].
Public health authorities receiving information from covered entities as required or authorized by law [45 CFR 164.512(a)] [45 CFR 164.512(b)] are not required to enter into business associate agreements. Public health authorities that are not covered entities also are not required to enter into business associate agreements with their public health partners and contractors. Also, after protected health information is disclosed to a public health authority pursuant to the Privacy Rule, the public health authority (if it is not a covered entity) may maintain, use, and disclose the data consistent with the laws, regulations, and policies applicable to the public health authority.

References:


Appendix C: Data Collection Variables

These variables have been identified by the ARHC Data Committee as “core” variables that are recommended to be collected if a standardized data collection system was in place.

Please note: Variables are broadly defined below. In order to standardize documentation of results, more details would be needed in terms of the ways each variable should be documented.

DATA COLLECTION VARIABLES

(R= REQUIRED, P= PREFERRED, O=OPTIONAL)

Demographic Data
- R-ALIEN NUMBER (Or UNIQUE ID for de-duplication)
- R-ARRIVAL DATE
- R-ARRIVAL STATUS
- R-DOB/AGE
- R-GENDER
- R-NATIONALITY
- R-INITIAL CITY OF RESETTLEMENT
- R-STATE
- P-FAMILY FILE NUMBER (ex:TH-111111)
- P-INITIAL COUNTY OF RESETTLEMENT
- P-INTERPRETER NEED
- P-PRIMARY LANGUAGE
- P-SECONDARY MIGRANT STATUS AND ORIGINAL STATE/COUNTY OF RESETTLEMENT
- P-VOLUNTARY AGENCY (VOLAG)
- O-COUNTRY OF BIRTH
- O-SECONDARY LANGUAGE(S)

Infectious Diseases
- R-HEPATITIS B
- R-IMMUNIZATIONS GIVEN (by type and date given)
- R- PATHOGENIC INTESTINAL PARASITES (including Types)
- R-SYPHILIS
- R-TUBERCULOSIS SKIN TEST OR IGRA RESULTS
- P-HISTORY OF OVERSEAS IMMUNIZATIONS
- P-HIV
- P-LTBI or ACTIVE TB TREATMENT OUTCOME
- P-MALARIA
- P-OVERSEAS MEDICAL CONDITIONS
P-OVERSEAS TB CLASS STATUS
P-TUBERCULOSIS (LTBI, active TB, No TB infection)
O-CHLAMYDIA
O-GONORRHEA
O-HEPATITIS A
O-HEPATITIS C
O-PARASITE TREATMENT OUTCOME

Other Health Conditions
R-ANEMIA (as measured by Hematocrit/Hemoglobin)
R-DENTAL (e.g. caries, gingivitis, abscesses)
R-HEARING
R-LEAD (for children <17)
R-NUTRITION STATUS (as measured by Height and Weight/BMI)
R-PREGNANCY
R-REFERRALS (by specialty)
R-VISUAL ACUITY
P-CANCER/TUMORS
P-CARDIOVASCULAR (e.g. hypertension, heart disease)
P-DEFORMITIES/AMPUTATIONS
P-DERMATOLOGIC (e.g. eczema, fungal infection)
P-ENDOCRINE (e.g. diabetes)
P-GASTROINTESTINAL (e.g. gastric ulcer)
P-GENITOURINARY DISEASE
P-GYNECOLOGIC CONDITIONS
P-MUSKULOSKELETAL
P-OPHTHALMOLOGICAL (e.g. cataracts)
P-NEUROLOGICAL (e.g. seizure disorders)
P-PSYCHOLOGICAL
P-RESPIRATORY/NOT TB (e.g. asthma)
O-ALCOHOL USE
O-SMOKING (current)
### Appendix D: Data Variables Collected

<table>
<thead>
<tr>
<th>Variables Collected:</th>
<th>Documented on Form</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infectious Diseases</strong></td>
<td><strong>As:</strong></td>
</tr>
<tr>
<td>TB screening Results</td>
<td>100%</td>
</tr>
<tr>
<td>Domestic TB Classification</td>
<td>26%</td>
</tr>
<tr>
<td>Treatment for LTBI or Active</td>
<td>58%</td>
</tr>
<tr>
<td>Hepatitis B screening results</td>
<td>97%</td>
</tr>
<tr>
<td>Hepatitis C screening results</td>
<td>23%</td>
</tr>
<tr>
<td>Parasite screening Results</td>
<td>97%</td>
</tr>
<tr>
<td>Syphilis screening results</td>
<td>87%</td>
</tr>
</tbody>
</table>

#### Infectious Diseases

- **TB screening Results**: 100% (31)
- **Domestic TB Classification**: 26% (8)
- **Treatment for LTBI or Active**: 58% (18)
- **Hepatitis B screening results**: 97% (30)
- **Hepatitis C screening results**: 23% (7)
- **Parasite screening Results**: 97% (30)
- **Syphilis screening results**: 87% (27)

#### Documented on Form

- **As**:
  - TST Induration: 42% (13)
  - TST Induration or Pos./Neg. IGRA: 42% (13)
  - No TB, LTBI, old not treated, old treated, active TB, pending, incomplete eval: 88% (7)
  - Start Date or Reason why not started: 56% (10)
  - Start Date only: 22% (4)
  - Hepatitis B surface antigen, Pos./Neg: 63% (19)
  - Pos/Neg: 57% (4)
  - Treated? Yes/No: 52% (16)
  - Specify ID of Parasites - see below: 55% (17)
  - Ascaris: 100% (17)
  - Clonorchis: 71% (12)
  - E. hystolitica: 94% (16)
  - Giardia: 100% (17)
  - Hookworm: 100% (17)
  - Schistosoma: 76% (13)
  - Strongyloides: 94% (16)
  - Trichuris: 94% (16)
  - Pos/Neg: 44% (12)
<table>
<thead>
<tr>
<th><strong>Screening Results</strong></th>
<th><strong>Percentage</strong></th>
<th><strong>Number</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV screening results</td>
<td>61%</td>
<td>19</td>
</tr>
<tr>
<td>Reactive/Non-reactive</td>
<td>22%</td>
<td>6</td>
</tr>
<tr>
<td>Pos/Neg.</td>
<td>74%</td>
<td>14</td>
</tr>
<tr>
<td>Malaria screening results</td>
<td>52%</td>
<td>16</td>
</tr>
<tr>
<td>Not screened, screened - no malaria, screened - malaria (specify)</td>
<td>69%</td>
<td>11</td>
</tr>
<tr>
<td>Pos/Neg. or Normal/Abnormal</td>
<td>25%</td>
<td>4</td>
</tr>
<tr>
<td>Treated? Yes/No</td>
<td>69%</td>
<td>11</td>
</tr>
</tbody>
</table>

**Environmental**

<table>
<thead>
<tr>
<th><strong>Screening Results</strong></th>
<th><strong>Percentage</strong></th>
<th><strong>Number</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead screening results</td>
<td>87%</td>
<td>27</td>
</tr>
<tr>
<td>Actual Level</td>
<td>70%</td>
<td>19</td>
</tr>
<tr>
<td>Pos./Neg or Normal/Abnormal</td>
<td>30%</td>
<td>8</td>
</tr>
</tbody>
</table>

**Other Conditions**

<table>
<thead>
<tr>
<th><strong>Measurement</strong></th>
<th><strong>Percentage</strong></th>
<th><strong>Number</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Height</td>
<td>61%</td>
<td>19</td>
</tr>
<tr>
<td>in.</td>
<td>47%</td>
<td>9</td>
</tr>
<tr>
<td>ft. and in.</td>
<td>15%</td>
<td>3</td>
</tr>
<tr>
<td>cm. or in.</td>
<td>5%</td>
<td>1</td>
</tr>
<tr>
<td>cm.</td>
<td>5%</td>
<td>1</td>
</tr>
<tr>
<td>Normal/Abnormal</td>
<td>21%</td>
<td>4</td>
</tr>
<tr>
<td>Weight</td>
<td>68%</td>
<td>21</td>
</tr>
<tr>
<td>lbs.</td>
<td>52%</td>
<td>11</td>
</tr>
<tr>
<td>lbs. and oz.</td>
<td>4%</td>
<td>1</td>
</tr>
<tr>
<td>kg. or lbs.</td>
<td>4%</td>
<td>1</td>
</tr>
<tr>
<td>kg.</td>
<td>4%</td>
<td>1</td>
</tr>
<tr>
<td>Hematocrit/Hemoglobin</td>
<td>71%</td>
<td>22</td>
</tr>
<tr>
<td>Actual value</td>
<td>68%</td>
<td>15</td>
</tr>
<tr>
<td>Blood Pressure</td>
<td>68%</td>
<td>21</td>
</tr>
<tr>
<td>Diastolic/systolic values</td>
<td>62%</td>
<td>13</td>
</tr>
<tr>
<td>Sugar levels</td>
<td>48%</td>
<td>15</td>
</tr>
<tr>
<td>Blood glucose values</td>
<td>47%</td>
<td>7</td>
</tr>
<tr>
<td>Visual Acuity</td>
<td>74%</td>
<td>23</td>
</tr>
<tr>
<td>Normal/Abnormal</td>
<td>65%</td>
<td>15</td>
</tr>
<tr>
<td>Hearing</td>
<td>65%</td>
<td>20</td>
</tr>
<tr>
<td>Normal/Abnormal</td>
<td>65%</td>
<td>13</td>
</tr>
<tr>
<td>Gross Dental</td>
<td>77%</td>
<td>24</td>
</tr>
<tr>
<td>Normal/Abnormal</td>
<td>67%</td>
<td>16</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>87%</td>
<td>27</td>
</tr>
<tr>
<td>Yes/No</td>
<td>63%</td>
<td>17</td>
</tr>
<tr>
<td>Mental Health Status</td>
<td>55%</td>
<td>17</td>
</tr>
<tr>
<td>Referred Yes/No</td>
<td>65%</td>
<td>11</td>
</tr>
</tbody>
</table>
Appendix E: Supplemental Survey

Assessing the development of a national refugee health surveillance system
Survey Prepared by ASTHO/ARHC Surveillance Sub-Committee (Objective 3)

Terms and Definitions

*Identified raw data flat files*—this type of data would contain line-by-line record of each person’s information containing identifying information (each row could include: alien number, name, date of birth, Country of Origin, TB status, Malaria status, Lead level, etc.)

*De-identified raw data flat files*—this type of data would contain line-by-line record of each person’s information where variables have been transformed such that his/her identity could not be linked by CDC databases (each row could include: Random ID, Age at Arrival, Country of Origin, TB status, Malaria status, Lead level, etc.)

*Aggregate summary data*—this type of data would be summary table of outcomes. Examples of this data could be presented in a presentation or journal publication.

*Data Sharing Law/Policy*—Data sharing laws (federal, state) governing the sharing of public and private data. These data sharing policies are intended to protect the privacy and confidentiality of individuals’ data.

**Participant information**
1.) Name of your agency:

__________________________________________________________________________

2.) Agency Type

State Health Department
Local County Health Department
Other, specify: _____________________________________________________________

3.) State: ___________________
4.) Participant’s Name (Last, First):__________________________________________
5.) Telephone: ____________________________________________________________
6.) Email address: __________________________________________________________

Assessing interest and feasibility in reporting refugee health system in a national surveillance system
7.) Which of the following datasets would your agency be interested in reporting to CDC?

(Answer Yes or No for each question)

a. Identified raw data flat files
   Yes
   No
b. De-identified raw data flat files
   Yes
   No
c. Aggregate summary data
   Yes
   No
d. Another data format not listed
   Explain:
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
   ASTHO/ARHC Surveillance Committee-Assessing the development of a national refugee health surveillance system (objective 3)

e. None of the datasets above
   Please explain reason:
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

8.) If your dataset could be automatically uploaded into a CDC’s system, what data file format can be generated using your database or other applications available to you? (select as many)

Comma-separated values (csv) or other delimited values (can be read by spreadsheets or databases)
Microsoft Excel or Access
Text (txt)
Extensible Markup Language (XML)
HyperText Markup Language (html)
Other, list format(s):

9.) Who would be the primary person downloading and preparing data to be sent to CDC? (check all that apply)

Refugee Health Coordinator
Epidemiologist
Public health person in another program area
Other, specify position:

10.) Would your agency be willing to serve as a refugee domestic health screening sentinel surveillance site for CDC?

Yes
No

Data sharing policies

For Questions 5 and 6, some agencies might have data sharing policies or laws that can be a challenge to actually share disease surveillance data with CDC. We would like to get an understanding of your agency’s data sharing policies. Please be specific where possible.

11.) Can your data sharing policy permit you to report identified raw data files to CDC?

Yes, can share identified raw data per data sharing policy
If, yes: please document your agency’s data sharing policy permitting the sharing of “identified raw data flat files”:

No, cannot share identified raw data per data sharing policy
If, no: please document your agency’s data sharing policy preventing the sharing of “identified raw data flat files”:

12.) Can your data sharing policy permit you to report de-identified data files to CDC?
Yes, can share de-identified raw data per data sharing policy
If **yes**: please document your agency’s data sharing policy **permitting** the sharing of “de-identified raw data flat files”:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

No, cannot share de-identified raw data per data sharing policy
If, **no**: please document your agency’s data sharing policy **preventing** the sharing of “de-identified raw data flat files”:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

13.) Can your data sharing policy permit you to report aggregate summary data?

Yes, can share aggregate summary data per data sharing policy
If **yes**: please document your agency’s data sharing policy **permitting** the sharing of “aggregate summary data”:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

No, cannot share aggregate summary data per data sharing policy
If, **no**: please document your agency’s data sharing policy **preventing** the sharing of “aggregate summary data”:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

14.) Other data sharing policy, specify:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

ASTHO/ARHC Surveillance Committee-Assessing the development of a national refugee health surveillance system (objective 3)
15.) What are the short-term challenges that your agency has in regards to data sharing at state and national levels?

________________________________________________________________________
________________________________________________________________________

16.) What are the long term challenges that your agency has in regards to data sharing at state and national levels?

________________________________________________________________________
________________________________________________________________________

17.) What are possible solutions to alleviate short term challenges at the state and national levels?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

18.) What are possible solutions to alleviate long term challenges at the state and national levels?

________________________________________________________________________
________________________________________________________________________
Appendix F: Benefits and Limitations to Sharing Identified, De-identified and Aggregate Summary Data

Table 1. Benefits and limitations to sharing identified, de-identified and aggregate summary data

<table>
<thead>
<tr>
<th>Data file type</th>
<th>Benefits</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| Identified            | - Ability to contact persons in a timely manner should a multi-state outbreak occur  
                        | - Ability to analyze data to generate disease incidence and prevalence reports using demographic data  
                        | - Ability to match the overseas and domestic screening results to assess refugee health, and evaluate screening guidelines  
                        | - Data on location of refugees                                               | - Legally challenging if not impossible for individuals states to obtain permission to share such information with CDC  
                        |                                                                            | - Require challenging digital certificates to maintain data security  
                        |                                                                            | - Require additional personnel resources to states for data management and reporting? |
| De-identified         | - Digital certificate not required for data entry, allowing agencies with IT challenges the ability to participate  
                        | - Limited data sharing restrictions as most states authorize the sharing of de-identified data sharing for public health and surveillance purposes  
                        | - Ability to analyze data to generate reports on disease incidence and prevalence using demographic data | - Unable to match overseas and domestic health screening results by person  
                        |                                                                            | - Contact information would not be available impacting timeliness of investigation in the event of a multi-state outbreak of disease among refugees |
| Aggregate/summary     | - Ability to share summary reports highlighting disease prevalence; useful for stakeholders and policy makers  
                        | - Ability to identify possible outbreaks in certain populations               | - Unable to do detailed analysis                                             |
Appendix G: Resources

Pregnancy Risk Assessment Monitoring System (PRAMS):
http://www.cdc.gov/prams/

National Electronic Disease Surveillance System for TB (TB PAM):
http://www.cdc.gov/tb/programs/tims/NEDSS.htm

National Electronic Disease Surveillance System (NEDSS):

Surveillance systems supported by the division of HIV/AIDS Prevention:
http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/surveillance.htm

National Electronic Telecommunications System for Surveillance (NETSS):
http://www.cdc.gov/osels/ph_surveillance/nndss/netss.htm
Appendix H: Map of Agencies Set Up to Receive EDN Notifications
Appendix I: ARHC Data Survey

Developing Refugee Health Profiles
Assessment of State Data Collection, Management and Reporting Capacities

Survey Report
2010-2011

Prepared by:
Health Screening Protocol and Data Committee
Association of Refugee Health Coordinators
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AUTHORS

This report was developed by members of the Health Screening Protocol and Data Committee of the Association of Refugee Health Coordinators (ARHC). The members of this committee that participated in the development and execution of the survey and associated report are listed below.

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Jossie Lange, Tennessee  
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Karen Moore, Colorado  
Kate Penrose, Massachusetts  
Carrie Senseman, Arizona  
Laura Smith, Florida  
Kelly Browne, Florida

ACKNOWLEDGMENTS

The Health Screening Protocol and Data Committee would like to thank those who made this survey and report possible including the members of ARHC, refugee health coordinators (RHC), state refugee coordinators, and all other refugee services staff that participated in the completion of the national survey.

ACRONYMS

<table>
<thead>
<tr>
<th>ACF</th>
<th>Administration for Children and Families</th>
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</thead>
<tbody>
<tr>
<td>ARHC</td>
<td>Association of Refugee Health Coordinators</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>DGMQ</td>
<td>Division of Global Migration and Quarantine (within CDC)</td>
</tr>
<tr>
<td>DHS</td>
<td>Department of Homeland Security</td>
</tr>
<tr>
<td>DOS</td>
<td>Department of State</td>
</tr>
<tr>
<td>EDN</td>
<td>Electronic Disease Notification System</td>
</tr>
<tr>
<td>HHS</td>
<td>Department of Health and Human Services</td>
</tr>
<tr>
<td>OPE</td>
<td>Overseas Processing Entity</td>
</tr>
<tr>
<td>ORR</td>
<td>Office of Refugee Resettlement</td>
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<td>PRM</td>
<td>Bureau of Population, Refugees, and Migration</td>
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<tr>
<td>USCIS</td>
<td>United States Citizenship and Immigration Services</td>
</tr>
<tr>
<td>WRAPS</td>
<td>Worldwide Refugee Admissions Processing System</td>
</tr>
</tbody>
</table>
TERMS AND DEFINITIONS

Country of Birth: The country the refugee is born in; regardless of nationality; this could also include the host country

Derivative Asylee: Spouse or child of an asylee already living in U.S.

Electronic Disease Notification System (EDN): The web-based system developed by CDC which automates the process for notifying state or local health officials of the arrival of immigrants and refugees with notifiable conditions to their jurisdictions

Nationality: The country/nation the refugee identifies with as their origin; this nation may be different from the host country or country where the refugee camp is located

Overseas Processing Entity (OPE): funded by DOS/PRM to prepare the necessary casework for persons eligible for consideration by the USCIS under the U.S. Refugee Admissions Program and, for those approved, to provide assistance in completing the additional requirements for refugee admission under Section 207 of the INA. The OPE forwards the necessary data on all DHS-approved cases to the Refugee Processing Center (RPC) for distribution to Reception and Placement agencies

Primary Asylee: Applied and granted asylum status in the U.S.

Primary Refugee Arrival: A refugee that was initially resettled in a specific state/jurisdiction

Refugee: The term refugee includes refugees, asylees, Cuban/Haitian entrants (including parolees), Amerasians, Iraqi/Afghan special immigrants, and victims of trafficking as defined by Office of Refugee Resettlement (ORR)

Refugee Processing Center (RPC): center operated by the U.S Department of State Bureau of Population, Refugees, and Migration to provide the necessary technical, data and refugee processing support to assist DOS/PRM in achieving its annual U.S. Refugee Admissions Program objectives

Secondary Refugee Arrival: a refugee that was initially resettled in another state/jurisdiction and has moved to a new state/jurisdiction of residence

Visa Status: The immigration visa classification assigned by Department of Homeland Security (DHS), U.S. Citizenship and Immigration Services (USCIS); visa status is used to determine eligibility for refugee benefits

Worldwide Refugee Admissions Processing System (WRAPS): The computer system used to process refugees for resettlement in the U.S. The system is used by the OPEs and the RPCs to coordinate and standardize data entry for refugees into the U.S. Refugee Admissions Program
EXECUTIVE SUMMARY

The ARHC Screening Protocol and Data Committee conducted a survey of Refugee Health and/or Refugee Service providers from May 2010 through August 2010 to gauge the data collection and management infrastructure of Refugee Health Programs (RHPs) across the nation. The survey, developed by the Screening Protocol and Data Committee, covered a wide range of topics related to data infrastructure, collection, management and quality assurance, and data-sharing policies for refugee health-related information.

Among the 50 states and jurisdictions requested to participate in the survey, 34 responded, yielding a response rate of 68%. Respondents represented a strong mix of high, medium and low refugee arrival states, providing insight into the correlation between arrival numbers and data collection and management capabilities. Through the survey results, the committee found a connection between states with high and medium refugee arrival volumes and strong data collection and management systems. All states with more than 4,000 annual refugee arrivals demonstrated an increased capacity for refugee health data collection, along with 63% of the medium arrival volume states.

Survey participants were asked to detail the types of refugee demographic and health screening data collected. Many respondents indicated collection of at least some refugee demographic data prior to the provision of the refugee health assessment (RHA), although the data collected varies widely across the nation. Respondents identified the Center for Disease Control and Prevention’s (CDC) Electronic Disease Notification System (EDN) as the primary source for receiving refugee demographic information. The use of EDN also provides the refugee service provider with the most health-related data available and notifications of new arrivals to their state and/or jurisdiction, greatly assisting refugee health service providers in the scheduling process for RHAs.

The vast majority of survey respondents (94%) collect refugee health screening data, while the remainder of respondents does not collect any health screening data. Infectious disease screening results are among the most widely collected screening data, though there is little consistency across states in the specific diseases documented. Chronic and other health conditions, as well as laboratory results, are less frequently collected and demonstrate even greater inconsistency from state-to-state.

While many respondents indicated that they have a data collection and management system in place, only half (53%) have a quality assurance system in place for their system(s). The inconsistencies reported in the collection of refugee demographic and health screening data, paired with a low level of quality assurance protocols, highlight the need for standardized screening and data collection requirements and the development of a national-level data collection system that has adequate infrastructure and support to ensure data quality. Results from the survey also showed that data sharing policies across the nation impede a state’s ability to share aggregate or raw data for the purposes of developing refugee health profiles. The implementation of the aforementioned activities will allow states to share refugee health-related data with national refugee health partners, and create a mechanism for developing population-specific refugee health profiles.
INTRODUCTION

Background

The ARHC Health Screening Protocol and Data Committee was formed to review health screening protocols developed by ORR, advocate for regional or national health assessment data collection systems, and identify trends in health outcomes among new arrivals for the purposes of developing population-specific health profiles. The committee also aims to collaborate with CDC, DOS, and other federal and/or international partners to conduct refugee health studies and increase awareness about population-specific illnesses.

It is widely known that RHPs and the services provided differ, sometimes dramatically, from state to state. Similarly, the methods for providing services and collecting data on the outcomes of those services vary from state to state. The committee identified that even if the collection of data regarding refugee health outcomes were standardized across states, there is currently no central repository or system in place for data sharing. Pooling refugee health data from multiple states would provide a more statistically robust means of identifying health issues specific to particular populations as well as health issues that cut across refugee populations.

Based on the knowledge of data collection inconsistencies and on the desire to gain an understanding of each state’s ability to share information and data, the committee developed a survey to assess the current landscape in data collection, management, and reporting of domestic health screenings for new refugee arrivals. The main objectives of the survey were to assess each state’s capacity to (1) collect refugee demographic and/or domestic refugee health screening data, (2) manage and analyze data, and generate associated reports, and (3) share data with third parties.

The purposes of gauging a state’s capacity to collect, manage and generate data reports are to gain an understanding of their ability to share information and data for the purposes of developing refugee health profiles. In order to develop a population-specific refugee health profile, the committee will compile state refugee health profiles from those states with the capacity to participate in this endeavor. State health profiles include de-identified, basic demographic and health outcome data for refugee populations that received a health assessment in each participating state refugee health program. These state health profiles will allow the committee to identify:

- Components of health services that are offered, and collected for data purposes, from each state RHP;
- Trends in health outcomes in refugee populations across the nation; and
- Best practices in data collection and reporting strategies.
Methodology

Eligibility and Recruitment

Primary staff from the organizations and/or agencies, designated as the responsible party for refugee demographic and/or health screening data in the state or jurisdiction, were eligible to participate in the survey. The committee identified the entities which collect both refugee demographic information and/or domestic health screening data using the ARHC’s member list and the ORR RHC listing located on ORR’s website (http://www.acf.hhs.gov/programs/orr/partners/hthcoord.htm). In states or jurisdictions where separate entities collect these data, staff from each office collaborated to determine which organization(s) would take the lead to avoid duplication of efforts and responses. Representatives from all 50 states and Washington, DC were encouraged to respond during ARHC conference calls and by e-mail.

Survey Instrument and Administration

E-mail invitations were sent to the primary staff, identified through the aforementioned process, requesting survey participation on May 24, 2010. Participants were asked to submit their survey responses via Survey Monkey by June 1, 2010. Upon preliminary presentation of the survey data at a national ARHC meeting in June 2010, participants indicated confusion regarding questions related to data management, analysis, and sharing capabilities. These questions were later clarified using a supplemental survey. The supplemental survey was emailed to previous respondents, and follow-up phone calls were made to ensure full participation and completeness of the data collection. Data collection was completed on August 8, 2010.

Analysis

Descriptive Analysis

The results of the survey were summarized using a combination of proportions and percentages. Results have been displayed using graphs and charts to depict the outcome of the respective survey question. Respondents who skipped questions during the survey were placed in an “unknown” category. It should be noted that the respondent may have inadvertently skipped the question rather than not knowing the answer to the question.

Data Collection and Reporting Capacity

In order to determine the data collection and reporting capacity of responding states, the committee developed an algorithm based upon nine responses contained in the questionnaire. The nine questions related to the state’s ability to collect, manage, download, and share data on refugee health outcomes. (Please see Appendix A for the complete algorithm.) The algorithm allowed for up to 5 points per question, with the highest possible score being 45.
The algorithm evaluated if a state has a standardized Refugee Health Assessment form for collection of health outcomes, as well as an electronic data collection system. The committee determined collection of the following variables to be important in assessing a state’s capacity to develop and contribute to refugee health profiles:

- Refugee Demographics
- Infectious Disease Screening Results
- “Other” Health Conditions
- Laboratory Tests

Other important components for developing a refugee health profile include the functional capabilities of a data collection system, such as the ability to extrapolate and share data. Therefore, the algorithm included questions that related to a state’s ability to:

- Analyze and Summarize Data
- Share Aggregate Data Sets
- Share Raw Data Sets

The capacity level of a state was determined by their total score within the algorithm. The breakdown of scores that determine a state’s capacity are:

<table>
<thead>
<tr>
<th>Capacity Level</th>
<th>Score Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>High capacity</td>
<td>31 – 45</td>
</tr>
<tr>
<td>Medium capacity</td>
<td>16 – 30</td>
</tr>
<tr>
<td>Low capacity</td>
<td>0 - 15</td>
</tr>
</tbody>
</table>

The committee utilized the two-year average (October 1, 2007 – September 30, 2009) of arrivals listed in Table 1 of the Department of Health and Human Services Administration for Children and Families ORR Notice of Final FY 2010 Formula Allocations to State for Refugee Social Services to designate states as high, medium, or low arrival states. The two year average was divided into a one year arrival average and natural breaking points in the volume were used to set arrival categories of high, medium, and low. The committee utilized these data to determine if a correlation exists between arrival volume and the data capacity of survey respondents.
SURVEY RESULTS

I. Participants

The survey was sent to 49 states and Washington DC (Wyoming does not have a refugee resettlement program); of those, 68% (34) states and/or jurisdictions responded.

The survey responses of 34 participants representing various types of organizations that manage refugee domestic health screening were gathered and analyzed. The majority (74%) of survey respondents represented the state RHP, while 12% represented the State Refugee Coordinator (SRC). The remaining 9% represented refugee resettlement agencies, local public health agencies, private contractors, or refugee services offices.
II. Data Collection Roles and Responsibilities

Who in your state/jurisdiction collects refugee demographic data?

Of the 34 respondents, 94% (32) collect refugee demographic data; 62% (21) identified the state RHP office as the primary responsible entity for the collection of refugee demographic data. The remainder of respondents primarily relies upon the SRC’s office, resettlement agencies, and other agencies not affiliated with the aforementioned entities to collect these data. In two cases, demographic data are not collected.

<table>
<thead>
<tr>
<th>Survey Participant</th>
<th>State Refugee Health Program</th>
<th>State Refugee Coordinators Office (not Health)</th>
<th>Resettlement Agency</th>
<th>Other Agency*</th>
<th>Demographic data not collected</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local/County Public Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Resettlement Agency</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>State Refugee Coordinators Office (not Health)</td>
<td></td>
<td>4</td>
<td></td>
<td></td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>State Refugee Health Program</td>
<td>21</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>25</td>
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<tr>
<td>Other</td>
<td></td>
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<td></td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>34</td>
</tr>
</tbody>
</table>

*State Health Department (not refugee health), State DHS (not refugee), Private Contractor (Refugee)

Who in your state/jurisdiction collects refugee domestic health screening data?
Among the 34 respondents, 70% (24) answered that domestic health screening results are collected by the state RHP or the state Department of Public Health. Comprehensive health screening results are not collected by 11% (4) of the entities that completed the survey (2 of these 4 responded to some “screening status” questions”).

### Agency Collecting Domestic Screening Data

<table>
<thead>
<tr>
<th>Survey Participant</th>
<th>State Refugee Health Program</th>
<th>Resettlement Agency</th>
<th>State Refugee Coordinators Office (not Health)</th>
<th>State Dept. Public Health</th>
<th>Other Agency*</th>
<th>Screening data not collected</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local/County Public Health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Resettlement Agency</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>State Refugee Coordinators Office</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Office (not Health)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>State Refugee Health Program</td>
<td>19</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>25</td>
</tr>
<tr>
<td>Other</td>
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<td></td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>34</td>
</tr>
</tbody>
</table>

*2 Local public health, 1 Private Contractor, 1 not available

### III. Refugee Notification & Health Screening Data Sources

In order to develop robust refugee health profiles, entities which manage and analyze refugee demographic and health screening results need comprehensive, accurate and timely data. The committee aimed to understand the various data sources, accessibility, and timeliness of the information that is being collected to identify commonality and gaps.

**What electronic systems can you access to view or download refugee related data?**

Refugee demographic and health information are contained in multiple data systems that are intended for use by various refugee resettlement entities. The Electronic Disease Notification System (EDN) maintained by the Centers for Disease Control and Prevention is the primary system used for obtaining overseas refugee health-related information while the Worldwide Refugee Admissions Processing System (WRAPS) is the primary system used for obtaining...
refugee demographic and sponsorship information. The SRC’s data system is typically unique to each state and collects refugee information that may be used for reporting to federal, state, and local refugee resettlement partners. Each data system contains overlapping, as well as unique, information on refugee arrivals. Access to all three systems provides state RHCs with the most refugee health and demographic data available, although access to all systems is not always possible. To determine the level of information available to staff in the state RHPs, survey respondents were asked to identify the data systems with which they have regular access to. Most respondents had access to EDN, while fewer had access to WRAPS and the state RHC system as indicated by the graph above. It is important to note that some survey respondents may have access to one, two, or all three data systems while some respondents may only have access to one data system.
Primary Refugees

Respondents were asked to rank their top three sources for receiving demographic data for primary refugee arrivals. The largest source of demographic information for primary refugees is EDN. EDN allows users to download overseas paperwork, including demographic and medical information, for refugees arriving in their jurisdiction. Among the 34 respondents to this question, 50% (17) ranked EDN as the primary source of demographic information. Resettlement agencies followed EDN, as the top source with 24% (8) of respondents receiving demographic data from these entities. When respondents ranked the second and third most relied upon sources of demographic data, EDN and resettlement agencies continued to top the list, however CDC quarantine stations, local health departments, and WRAPS became more heavily relied upon sources of demographic data (See Appendix B).

Secondary Refugees

Respondents were again asked to rank their top three sources of demographic data for secondary refugee arrivals. EDN remained the primary source for receiving demographic data, although the sources of secondary refugee arrival information were much more evenly distributed than primary
refugee data. Among the 34 survey respondents, 26% (9) ranked EDN as the top source, while 18% (6) and 15% (5) ranked the SRC and local health departments as the top sources, respectively. Fewer respondents listed second and third sources of demographic data, although EDN and resettlement agencies were most commonly listed (See Appendix C). Refugees were consistently listed as a source of demographic data for secondary arrivals despite being the least relied upon source of information, comparatively.

What percent of refugee arrival notifications in your jurisdiction do you receive?

Primary Refugees

Most (25) survey respondents indicated that they received between 95 and 100 percent of the primary refugee arrival notifications that come to their jurisdiction. Only two survey respondents stated they received less than 85% of the primary refugee arrival notifications. Several (4) respondents indicated that it was unknown how many notifications they receive, which is likely due to the fact that it is difficult to gauge the percentage of refugee arrivals that RHCs are not made aware of.

Secondary Refugees

The responses received regarding notification of secondary refugees differed dramatically from those received for primary refugees. The vast majority (65%) of the 34 respondents stated that the percentage of secondary refugee notifications is unknown. This is likely due to the fact that there is no formal process for notifications of secondary refugee arrivals and many secondary refugees relocate without the assistance of refugee resettlement partners. Despite this fact, several
respondents were confident that they receive a high percentage of refugee arrival notifications as evidenced by the chart on the right.

**On average, how long after the “date of arrival” does your entity receive notification from EDN?**

Since EDN is the most relied upon source for refugee arrival and overseas demographic information, the survey sought to identify how soon notifications are available in this system after a refugee’s date of arrival into the U.S. Of the 25 respondents utilize EDN and responded to this question, 36% (9) indicated that they receive notifications within 0-15 days from the date of arrival, 56% (14) receive notifications within 16-30 days, and 8% (2) receive notifications within 31-60 days of a refugee’s date of arrival*. No respondents indicated notification times from EDN extending beyond of 60 days from date of arrival.

*Responses to this question were received from May 24 – June 1, 2010. Since this time, CDC has made a significant effort to minimize the length of time from date of arrival to date of notification through EDN. Therefore, it is possible that these results are not reflective of the current notification timeframe in EDN.

Where do you obtain your domestic health screening data?

Refugee domestic health screenings are done in a variety of settings across the country. This survey question served to identify the entities from which domestic health screening data are received. Respondents were
asked to rank their top three sources of health screening data for primary and secondary refugees. The survey results for both categories were quite similar. Domestic health screening results for primary refugees are collected by 88% (30) of the survey respondents; this number decreases to 74% (25) for secondary refugees. Fifty percent (15) of survey respondents collecting screening results for primary refugees and 52% (13) of those collecting screening results for secondary refugees indicated that the top source for receiving these data are local public health clinics. Community health centers are the next most relied upon sources of health screening data, followed by private and contracted providers. One respondent indicated that they rely upon the primary resettlement state for health screening data of secondary refugees (See Appendix D & E for second and third ranked sources of domestic health screening data).

**What is the average length of time between the refugee’s date of arrival and receipt of domestic health screening results?**

RHPs across the nation strive to complete the domestic health screening within 90 days from the refugee’s date of arrival. Of those survey respondents collecting screening results, 70% (21/30) have received the results of the domestic health screening within 90 days of the refugee’s date of arrival. This indicates that many of the survey respondents are completing the domestic health screening within 90 days from the refugee’s date of arrival. Only 23% (7) of the survey respondents stated that results are not received within 90 days from a refugee’s date of arrival.

**How soon after the completion of the domestic health screening are screening results/data received?**

Among the 30 agencies that collect screening results, 37% (11) receive domestic health screening results within 30 days from the completion of the health screening and 30% (9) receive results within 30-60 days.
31-60 days of completion. Far fewer respondents, 13% (4) and 17% (5), receive results within 60-90 days and after 90 days, respectively.

IV. Refugee Demographic & Screening Results Data Collection

What percentage of primary refugees in your jurisdiction completed their domestic health screening in FY 2009?

Nearly 80% (26) of the 34 respondents indicated that 70% or more of the primary refugees in their jurisdiction completed a domestic health screening in fiscal year 2009. This indicates that the majority of refugees entering the jurisdictions represented in this survey are receiving medical screenings upon arrival. Among the remainder of the survey respondents, only 9% (3) noted that less than 70% of primary refugees in their jurisdiction completed a health screening, while 15% (5) of respondents did not know the percentage of health screenings completed.

Which immigration visa statuses does your state/jurisdiction document?

Of the 34 respondents, 85% (29) noted that their state or jurisdiction documents visa status for refugees and 82% document Iraqi/Afghan special immigrants. While documentation of other visa statuses was less common, the majority of respondents are collecting a wide variety of visa statuses. Although derivative asylee notifications are received through EDN, only 53% (18) of respondents indicated that this status is documented, while 79% (27) of respondents indicated that primary asylee status is documented.
What screening data do you currently collect?

Respondents were asked to indicate which domestic health screening components are being collected by their organizations, with the aim of determining which data are most commonly collected across states and could be used to create refugee health profiles. Results were categorized in three sections: demographics, screening status, and screening results. Screening results were further subcategorized into three sections: infectious disease, other health conditions, and labs. Thirty-two of the 34 survey respondents indicated that screening data are collected; fewer survey respondents collect all categories and subcategories of screening data, thus the denominator varies depending on the category. The percentage of survey respondents collecting these data are depicted in the tables below.

Demographics

All of the 32 respondents who indicated that they collect demographic data noted collection of date of birth, gender, and arrival date information for primary refugee arrivals. Alien number and resettlement agency were the next most commonly collected variables (94% and 88%, respectively). While 81% of respondents collect information about country of birth, fewer collect information about nationality (66%). Information about nationality is an important factor to consider when identifying health risks for particular populations. State information was noted as being more commonly collected (91%) in comparison to initial county (69%) and city (66%) of resettlement information. While county and city information is not frequently collected, it is beneficial for cross-state and in-state comparisons. Family file number was among the least collected pieces of demographic information (44%), which can be useful for identifying refugee individuals who arrived together and live together in the U.S.
Note: Twenty-three respondents to this question indicated collection of visa status information while 29 respondents noted above that they document refugee status. It is not clear what could account for this discrepancy.

Screening Status

Among the 32 respondents who indicated that they collect screening status information, 84% (27) indicated that they document when medical screening is done for a new arrival but only 59% (19) document the screening completion date. While respondents do not frequently collect the screening completion date, 81% (26) do document the initial clinic date when the screening was started. Even fewer (44%) document the screening results submission date. Only 34% (11) document when medical screening is not done for a new arrival, though 53% (17) noted that if screening is not done, they indicate a reason. This discrepancy is likely due to the fact that many respondents do not collect if a screening was not done, since one may have been completed by a provider not affiliated with the RHP.

Screening Results

Of the 30 survey respondents who indicated that they collect screening results, 29(85%) responded to some or all of the various questions related screening results.

Of the screening results that 29 survey respondents indicated they collect, the majority fall within the infectious disease category. Among the 29 respondents collecting infectious disease results,
100% indicated that they document screening results for tuberculosis, while only 69% (20) document the treatment outcome for those refugees with latent or active tuberculosis. Similarly, 79% (23) of respondents noted that they document screening results for parasites but only 30% (7) document the treatment outcome for refugees with a positive test result. After tuberculosis, hepatitis B and syphilis were the most common diseases for which screening results are collected. Immunization history and test results for HIV and other STDs are also documented by more than half of the survey respondents. Fewer than half of the respondents noted collection of test results for hepatitis A and C. Among the 10 respondents who indicated that they collect other infectious disease results, 70% (7) noted documentation of screening results for malaria.

Twenty-eight of the 29 respondents indicated that they collect non-infectious health screening results. Among these respondents, the most commonly documented results for new arrivals are lead levels (96%) and pregnancy test results (93%). More than half of the respondents indicated documentation of results for dental, vision, and hearing screening, anemia, growth and development, and malnutrition. Fifty-seven percent of respondents also indicated that they document when referrals for follow-up services are made. Of the 4 respondents who indicated that they collect results for other non-infectious conditions, documentation of general appearance, breast exams, pap smear results, and past surgeries were noted.

Laboratory results are the least commonly collected results, though 25 (86%) of the 29 respondents indicated documentation. Among the 25 respondents, almost all (96%) indicated that they document the results of the complete blood count with differential. More than half (68%) also document urinalysis results. Documentation of serum chemistries and glucose and serum lipid profiles was less commonly indicated, and no respondent indicated documentation of infant metabolic screening for newborns. Among the 4 respondents who

<table>
<thead>
<tr>
<th>Other Health Conditions</th>
<th>Results (N)</th>
<th>% of states/jurisdictions documenting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead</td>
<td>27</td>
<td>96</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>26</td>
<td>93</td>
</tr>
<tr>
<td>Dental</td>
<td>20</td>
<td>71</td>
</tr>
<tr>
<td>Anemia</td>
<td>18</td>
<td>64</td>
</tr>
<tr>
<td>Visual acuity</td>
<td>17</td>
<td>61</td>
</tr>
<tr>
<td>Hearing</td>
<td>17</td>
<td>61</td>
</tr>
<tr>
<td>Growth and development</td>
<td>16</td>
<td>57</td>
</tr>
<tr>
<td>Referrals</td>
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<td>57</td>
</tr>
<tr>
<td>Malnutrition</td>
<td>15</td>
<td>54</td>
</tr>
<tr>
<td>Mental health status</td>
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<td>Diabetes</td>
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<td>Gynecologic conditions</td>
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<tr>
<td>Deformities/amputations</td>
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<td>29</td>
</tr>
<tr>
<td>Asthma</td>
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<td>25</td>
</tr>
<tr>
<td>Gastric ulcer</td>
<td>7</td>
<td>25</td>
</tr>
<tr>
<td>Genitourinary disease</td>
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<td>25</td>
</tr>
<tr>
<td>Scoliosis, kyphosis</td>
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</tr>
<tr>
<td>Seizure disorders/neurological</td>
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<td>21</td>
</tr>
<tr>
<td>Cataracts/other eye disease</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Emphysema/non-TB respiratory</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Cancer/tumors</td>
<td>6</td>
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<tr>
<td>Smoking</td>
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<td>21</td>
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<tr>
<td>Drug abuse</td>
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<td>21</td>
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<tr>
<td>Alcohol abuse</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>14</td>
</tr>
</tbody>
</table>

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indicated that they document other laboratory results, 2 document complete metabolic panels. Other results noted include the T-spot test for tuberculosis, thyroid and liver function tests, and antibody titers.

<table>
<thead>
<tr>
<th>Laboratory Tests</th>
<th>Results (N)</th>
<th>% of state/ jurisdictions documenting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete blood count with differential</td>
<td>24</td>
<td>96</td>
</tr>
<tr>
<td>Urinalysis</td>
<td>17</td>
<td>68</td>
</tr>
<tr>
<td>Serum chemistries and glucose</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>Serum lipid profile</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>Infant metabolic screening for newborns</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
V. Data Management & Quality Assurance

What data collection methods does your state/jurisdiction have in place for refugee health data?

The committee aimed to determine the methods by which RHCs are collecting domestic health screening data, if at all. Strategies for data collection include a standardized data collection form, an electronic data collection form, and a refugee health data collection system or database. Among the 34 responses received for the questions regarding these methods, 71% (24) of the respondents indicated that they do have a standardized data collection form in place, although only 41% (14) indicated that they have an electronic data collection form. While states and jurisdictions vary in the methods used to collect screening results, a great majority (76%, 26) are inputting these data into an electronic system or database for management of the data. Respondents that indicated they had a data collection system or database in place provided a brief description of the system that is utilized. The majority of the 26 respondents were evenly distributed between those utilizing web-based systems (11) or Microsoft Access (9) for data collection, while far fewer utilized Microsoft Excel (3) or the CDC-provided application, EpiInfo (2). One entity collected hard copies of the screening results and manually entered the data into a data system. Some respondents noted that while they may have a data collection system in place, it primarily collects demographics or payer/insurance information for the refugee, rather than health screening results.
The map below highlights the states and/or jurisdictions that provided the committee with a copy of their standardized data collection form as a part of the survey.

Does your state/jurisdiction have the ability to download and analyze and summarize data?

As a prerequisite for sharing refugee health data across the country and developing state refugee health profiles, states must have the ability to download, analyze and summarize their data. Among the 34 respondents, only 71% (24) indicated that they have the ability to
download their data while 29% (10) do not have the ability to download data. When these data are linked to the above question regarding an electronic data collection system, the data indicate that 92% (24) of those entities with a data collection system or database are able to download their data. The ability to analyze and summarize data may not be easily tied to the previous question regarding electronic data systems, as some states may have the ability to analyze and summarize data using paper records and files. Of the 34 respondents, 76% (26) indicated that they are able to analyze and summarize their data.

Personnel capacity, among those with the ability to generate electronic summary reports from their data collection systems, varied by entity. While not all respondents (8) have the capacity to generate electronic summary reports, 5 indicated that they maintain some form of data collection. The personnel utilized for these functions are detailed in the graph on the right.

What is your IT infrastructure to maintain your data collection system and utilize your data?

The committee sought to assess the level of IT infrastructure available within states/jurisdictions to assist with the maintenance, modification, or upgrade of their current data collection system. Of the 34 respondents, 75% (24) had the technical capacity to modify their application for data downloads and the data summary reports. Slightly fewer (68% or 23) had the technical capacity to capture additional data within their data collection system.
What quality assurance protocols do you have in place?

Quality assurance procedures are extremely important to develop accurate and useful refugee health profiles. The committee aimed to gauge the presence and use of quality assurance protocols for refugee health data collection and management. To evaluate this component of data management, survey participants were asked to indicate if they have a procedure or protocol in place for ensuring quality and accurate data. Fifty-three percent (18) of respondents indicated that they did have quality assurance protocols in place. Since just under half (16) of the survey respondents stated that they do not have a quality assurance protocol in place, ensuring the quality of the data contained in some state refugee health data systems will be challenging, if not impossible.

Respondents were asked to expand upon their data quality assurance protocols to determine the types of checks and balances in place for maintaining complete and accurate data. The majority of respondents who do not have data quality assurance protocols in place skipped these questions. Of the 24 who did respond, 71% (17) utilize record de-duplication methods, 67% (16) use trained data entry staff, and 54% (13) have a protocol in place to verify the screening results. Respondents who verify screening results commonly do so by cross-referencing results with medical charts or other program areas at the health department.
VI. Data Sharing

Is your organization able to share refugee health data with third parties?

In recognition of the fact that many organizations’ abilities and policies for the sharing of data with third parties may conflict, the committee separated data sharing questions into two categories. The committee evaluated whether the organization represented through this survey has the ability to share data sets, both aggregate and raw (de-identified), and whether their organization’s policies allow for the sharing of those data sets.

Among the 34 respondents asked if their organization has the technical ability to share data sets, 65% (22) said they are able to share aggregate data, while only 50% (17) are able to share raw, de-identified data sets. Conversely, while only 26% (9) of respondents are unable to share aggregate data sets, a significantly greater number of respondents (47% or 16) are unable to share raw, de-identified data sets; 2 (6%) respondents skipped this question.

The responses received for the organizational ability to share data per the organization’s policies were similar to the responses received for the organization’s simple ability to share data; 62% (21) have policies in place that allow them to share aggregate data, 35% do not, and one respondent did not answer the question.
Those states/jurisdictions that are able to share data do so with multiple entities. A breakdown of the entities with which data is shared is shown in the graph below. Data is most frequently shared with the SRC (81%) and refugee resettlement agencies (77%), while 65% share data with ORR in compliance with the Preventive Health Grant. Data is also, less frequently, shared with local public health agencies (61%), health providers (55%), community stakeholders (45%), and with students or for research purposes (also 45%).
VII. Data Collection and Reporting Capacity Score

The data collection and reporting capacity score was calculated based on complete responses submitted by 33 entities. These participants represented states with varying volumes of primary refugee arrivals; 14 states had less than 1,000 arrivals, 16 had 1,000 - 4,000, and 3 states had greater than 4,000 arrivals per year.

<table>
<thead>
<tr>
<th>Low volume (&lt;1,000)</th>
<th>Medium volume (1000-4,000)</th>
<th>High volume (&gt;4,000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>[16 - 772]</td>
<td>[1,081 – 3,625]</td>
<td>[7,000-22,000]</td>
</tr>
</tbody>
</table>

Data collection and reporting capacity levels were determined using the algorithm discussed in the Methodology Section and attached as Appendix A. Among the 33 participating jurisdictions, 45% (15) are considered to have high capacity with a robust infrastructure to collect, manage and analyze refugee demographic and screening data. Thirty-six percent (12) have medium capacity and 18% (6) have low capacity. There appears to be a strong correlation between volume of refugee arrivals and a state’s capacity to collect, manage, and analyze data. All three states/jurisdictions with high volume also ranked as having high data collection and management capacity, based on their algorithm score. Medium volume states were also more likely to have high capacity while lower volume states were more likely to have low or medium capacity for data collection and management.

<table>
<thead>
<tr>
<th>Number of Arrivals</th>
<th>High Capacity</th>
<th>Medium Capacity</th>
<th>Low Capacity</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1,000 (N=14)</td>
<td>2 (14%)</td>
<td>6 (43%)</td>
<td>6 (43%)</td>
</tr>
<tr>
<td>1,000 – 4,000 (N=16)</td>
<td>10 (63%)</td>
<td>6 (38%)</td>
<td>0</td>
</tr>
<tr>
<td>&gt; 4,000 (N=3)</td>
<td>3 (100%)</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
LIMITATIONS

There were several recognized limitations to the survey and subsequent report. There are a total of 50 states and jurisdictions that resettle refugees in the U.S., although only 34 states responded to the survey. While more than 50% of the states did participate in the survey, several states with a high volume of refugee arrivals did not participate. Participation by those states would have allowed the committee to determine if there were enough high volume states with the ability to share refugee health data in order to develop robust refugee health profiles. Additionally, broader participation by both low- and high-volume states would have provided a better understanding of the current landscape of data collection and reporting capabilities of states.

While the survey suffered from a lack of participation by some states, many respondents skipped questions throughout the survey leading to a lack of uniformity in the number of respondents to each question. Consequently, there were difficulties in analyzing and comparing data from question to question. Respondents who skipped questions during the survey were placed in an “unknown” category, although the respondent may have inadvertently skipped the question rather than not knowing the answer to the question.

Additional limitations were realized in relation to the questions posed to survey participants. With this survey being the first of its kind, questions remained general in nature to gain a broad understanding of the data collection, management and reporting strategies in each state/jurisdiction. Follow-up surveys may need to be conducted to determine the specifics of the data collection methods. For example, participants were asked to identify the health screening results that are collected in their state/jurisdiction. Some states may collect absolute values while other states may simply document whether results were normal or abnormal. It will be important to understand the full range of data collection strategies in each state/jurisdiction to develop comprehensive refugee health profiles.
RECOMMENDATIONS

There are many recommendations that can be drawn from the results of this survey. First and foremost, the committee recommends the development of a standardized refugee health screening protocol and data collection system. Without a mandatory, standardized refugee health screening protocol in place the health services offered and collected will vary greatly from state-to-state, making the development of a national refugee health profile difficult, if not impossible.

Currently, many states are not collecting refugee health screening results because they do not have a data collection system in place, or do not have the staff and/or infrastructure to create and maintain a data collection system. The development of a national data collection system would allow states with little-to-no infrastructure to collect refugee health data, and provide the best opportunity for developing refugee health profiles. A national data collection system would also allow for data to be easily obtained and utilized by national partners including ORR, CDC, and DOS. Recognizing the limited ability of states to provide and share refugee health-related data, the committee further recommends that the sharing and input of these data be grant-mandated to ensure full participation and facilitate the development of robust refugee health profiles.

Given that the aforementioned recommendations would require a substantial amount of time, and potentially funding, the committee has developed interim recommendations for states and jurisdictions to increase their data collection, management and reporting capacity. The committee recommends that states strive to achieve the following:

- Obtain access to, and utilize, EDN, WRAPS, the SRC data system, and other refugee data systems in their state/jurisdiction to maximize data collection strategies
- Strive to make EDN the primary notification source for refugee arrivals and overseas medical documentation
- Ensure that all staff essential to the provision of refugee health services have access to EDN, including local-level medical staff
- Enhance and promote a notification and data collection system for secondary refugees including:
  - The use of the ARHC Secondary Refugee Transfer Protocol
  - Transfer of records in EDN
  - Enhance communication efforts between states/jurisdictions to facilitate the transfer of records
- Develop a standard data collection protocol and dictionary with specific demographic and health screening variables to be used in refugee health profiles
  - States should strive to capture demographic data that is essential to the development of a refugee health profile, including:
    - Date of Birth
    - Date of Arrival
    - Visa Status

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• Gender
• Nationality
• Country of Birth
• Overseas TB Status
• Primary Language
• State

• States should strive to capture health screening data that is essential to the development of a refugee health profile, including results of screening for:
  • Infectious disease
  • Lead
  • Pregnancy
  • Dental
  • Anemia
  • Visual Acuity
  • Hearing
  • Growth and development

• Encourage those entities who conduct health screenings, either by increasing the ease in reporting (e.g., web-based reporting) or contractual agreement, to report screening results as soon as possible
• Develop a state data collection system, if not already in place, using assistance from another state with a strong, established data collection system
• Create an environment within your organization that allows for the sharing of aggregate or raw, de-identified refugee health data sets, including adoption of data-sharing policies
• Develop quality assurance protocols to ensure accuracy and completeness of refugee health data
CONCLUSION

This survey demonstrated the diverse nature and structure of refugee health screening programs operated and administered throughout the U.S. In this regard, there are wide variations in the methods by which demographic and health-related data are obtained, as well as capabilities in data-sharing. The information gained from the survey indicates that those states with a high number of arrivals have been able to demonstrate a greater need for data management, thus developing data systems that capture many demographic and health screening variables. However, it is also noted that housing and maintaining a highly functioning system often requires additional personnel resources to manage and report the data.

Currently, there is no mandatory reporting of refugee health screening outcomes other than those required by states’ communicable disease reporting legislation. Should this aspect of the refugee health program operations change in the future, standardization of the type of data expected to be collected and reported may require additional financial resources, the availability of an interoperable system, and technical support for its maintenance across the nation.

The committee, associates, and members of ARHC, would like to utilize the results of this survey to assist in advancing towards the development of refugee health profiles at the state and national level. The committee encourages federal refugee health partners to implement standardized screening and data collection requirements to aid in this effort. Likewise, states and jurisdictions are encouraged to adopt the recommendations set forth in this report to facilitate participation in this endeavor. Through assistance from federal partners, collaboration by the states and jurisdictions resettling refugees, and the development of refugee health profiles, refugee health staff will be better equipped to identify trends in adverse health outcomes among specific refugee populations and better prepared to serve new refugee arrivals in the U.S.
APPENDIX A

Refugee Health Data Capacity Algorithm

State: ________________________________

II. 1. How many demographic variables are collected?

- 11-16 (5)
- 6-10 (3)
- 1-5 (1)
- 0 (0)

II. 3a. How many infectious disease screening results are collected?

- 11-15 (5)
- 6-10 (3)
- 1-5 (1)
- 0 (0)

II. 3b. How many “other health conditions” results are collected?

- 19-27 (5)
- 10-18 (3)
- 1-9 (1)
- 0 (0)

II. 3c. How many laboratory tests are collected?

- 4-5 (5)
- 2-3 (3)
- 1 (1)
- 0 (0)

III. 2. Do you have a standardized RHA form?

- Yes (5)
- No (0)
III. 1. Does your state have an electronic data collection form?

☐ Yes (5)
☐ No (0)

III. 5. Do you have the ability to analyze and summarize your data?

☐ Yes (5)
☐ No (0)

III. 4. Does your agency have the ability to share aggregate datasets?

☐ Yes (5)
☐ No (0)

III. 4. Does your agency have the ability to share raw datasets?

☐ Yes (5)
☐ No (0)

Total Points: ______/45

☐ High Capacity: 31-45
☐ Medium Capacity: 16-30
☐ Low Capacity: 0-15
APPENDIX B

Second and Third Ranked Sources of Demographic Data for Primary Refugees

APPENDIX C

Second and Third Ranked Sources of Demographic Data for Secondary Refugees

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APPENDIX D

Second and Third Ranked Sources of Domestic Health Screening Data for Primary Refugee Arrivals

APPENDIX E

Second and Third Ranked Sources of Domestic Health Screening Data for Secondary Refugee Arrivals

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