INTEGRATED DISEASE SURVEILLANCE AND RESPONSE IN THE AFRICAN REGION A GUIDE FOR ESTABLISHING COMMUNITY BASED SURVEILLANCE

DISEASE SURVEILLANCE AND RESPONSE PROGRAMME AREA DISEASE PREVENTION AND CONTROL CLUSTER

August 2014



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1. INTRODUCTION

Emerging and re-emerging events with a potential to cause disease outbreak remain a constant threat to global health security. In Africa, community volunteers are supporting initiatives and programmes like polio eradication, onchocerciasis, guinea worm eradication, trachoma control, integrated community case management, maternal and child health integrated programme, and early warning and response to public health emergencies among others. In some communities structures are not functional or are still to be built to detect, prevent and respond to public health events, despite the fact that the first edition of the Integrated Diseases Surveillance (IDS) in the African Region advocated for countries to establish Community-based Surveillance (CBS) systems since 2001. Community representatives and health workers with instructions on how to recognise certain diseases or health conditions were to be used as contact persons in the community for the purpose of detecting and reporting suspected cases to the health facility. In the first edition of IDS, tasks at community level included:

- (a) Notifying the nearest health facility of the occurrence of disease or health conditions selected for community-based surveillance.
- (b) Supporting health workers during case or outbreak investigation, and contact tracing.
- (c) Using feedback from health workers to take action, including health education and coordination of community participation.

The first edition has been extensively revised, and the second edition (2010) is now titled Integrated Disease Surveillance and Response (IDSR). While WHO has been assisting countries to develop and implement the second edition, this effort has had mixed progress. Countries are at different levels of implementation. A critical gap is lack of community participation in detection of and response to public health problems. Recent events such as internal war in Central African Republic, cholera outbreak in South Sudan and the Ebola outbreak in West Africa underscores the need for urgent community action that can lead to timely interventions to limit their impact on the health of affected communities.

This document is intended to guide the establishment of Community-based Surveillance (CBS). Once in place, a CBS will, among other things, improve relations between communities and their local health system; function at a high level of sensitivity for reporting of the targeted diseases; and provide an active, rather than a passive, surveillance system. Eventually, a functioning CBS will benefit both the communities and the wider health system.

2. SCOPE AND OBJECTIVE OF THE GUIDE

This guide is intended for use as:

- (a) A general reference for establishing community-based surveillance activities.
- (b) A resource for community case definitions.
- (c) A guide for improving early warning and alert for outbreak response.

The information and recommendations in this guide are intended for use by the following:

- (a) Health Facility managers.
- (b) District Health Management Teams (DHMT) including those involved on the implementation of the IDSR strategy.
- (c) Disease surveillance managers and officers at all levels of health system.
- (d) Community based health workers.
- (e) IHR (2005) National Focal Point.
- (f) Education and Agricultural Officers.
- (g) NGOs and other relevant partners such as Red Cross.

This guide has two main objectives:

- (a) to build and strengthen the capacity of communities to conduct effective surveillance and response activities in line with the IDSR strategy by training local community representatives in the One Health Approach; develop and carry out plans of action; and advocate for and mobilize resources;
- (b) to improve the flow of surveillance information between the community and local health facilities.

3. KEY CONCEPTS AND PRIORITY CONDITIONS FOR CBS

In order to effectively implement community-based surveillance, it is crucial that community representatives are familiarized with key terms used in the IDSR strategy such as the definition of surveillance, public health risk, the integrated diseases surveillance including reporting system for priority IDSR diseases, conditions and public health events.

3.1 What is disease surveillance?

Surveillance is the ongoing systematic collection, analysis, and interpretation of health data. It includes the timely dissemination of the resulting information to those who need it for action. Surveillance is also essential for planning, implementation, and evaluation of public health practice.

Several types of surveillance are used in national programmes. The choice of method depends on the purpose of the surveillance action. In general, types of surveillance methods describe:

- (a) A focused location for surveillance (such as health facility-based surveillance or community-based surveillance).
- (b) A designated or representative health facility or reporting site for early warning of epidemic or pandemic events (sentinel surveillance).
- (c) Surveillance conducted at laboratories for detecting events or trends not necessarily evident at other sites.
- (d) Disease-specific surveillance involving activities aimed at targeted health data for a specific disease.

Regardless of the type of surveillance, the important issue is that the health data is used for public health action.

3.2 What is Community-based Surveillance

Community-based Surveillance (CBS) is an active process of community participation in detecting, responding to and monitoring health events in the community.

The scope of CBS is limited to systematic on-going collection of data on events and diseases using simplified case definitions and forms and reporting to health facilities for verification, investigation, collation, analysis and response as necessary.

CBS should be a routine function for:

- (a) the pre-epidemic period (to provide early warning or alerts);
- (b) the period during epidemic (to actively detect and respond to cases and deaths);
- (c) the post-epidemic period (to monitor progress with disease control activities).

CBS should also include a process to report rumours and misinformation of unusual public health events occurring in the community.

3.3 Integrated Disease Surveillance

The main basis of integrated disease surveillance is data collection for action. In this case, CBS is intended for improving public health surveillance and response by linking communities with their local health facilities. The health sector can then leverage community structures for better surveillance, disease prevention and disease control. Communities are well placed to detect and monitor health events in the community, mobilize community action, and request national assistance or access resources to protect the community's health.

3.4 Priority diseases for CBS

Depending on the local epidemiological profile, priority diseases for CBS can be selected to address local diseases and conditions including unusual events. The nationally adapted IDSR technical guidelines cover the key signs and symptoms to include in surveillance case definitions relevant for the community level. For a list of ISDR community case definitions, please see Annex 2.

4. KEY ELEMENTS FOR COMMUNITY-BASED SURVEILLANCE

CBS is encouraged to create a sense of responsibility, urgency and ownership and to ensure maximum coordination and cooperation. This could be done through sensitization meetings, training workshops, supervisions by IDSR team, advocacy campaigns and using different media channels, including piggy-backing of integrated diseases surveillance messages during intervention programme activities.

4.1 CBS Tasks

The tasks for CBS are in line with IDSR core functions namely:

- (a) Using lay simplified case definitions to identify priority diseases, events, conditions or other hazards in the community.
- (b) Participating in verbal autopsies to determine causes of death.

- (c) Sending notification, timely and regularly, to the nearest health facility of the occurrence of unexpected or unusual cases of disease or death in humans and animals for immediate verification and investigation according to the International Health Regulations (IHR) and in line with the IDSR strategy.
- (d) Involving local leaders in describing disease events and trends in the community.
- (e) Supporting health workers during case or outbreak investigation and contact tracing.
- (f) Participating in risk mapping of potential hazards and in training including simulation exercises.
- (g) Participating in response activities including home-based care, including sensitization of the community on the adoption of behaviour facilitating the containment of the outbreak.
- (h) Using feedback from the CBS Coordinator to take action, including health education and coordination of community participation.
- (i) Verifying if public health interventions took place as planned with the involvement the community.
- (j) Having a forum for feedback to the community on outbreak/event assessment.

4.2 Formalized CBS framework

CBS should be implemented in a formalized framework where participants are well versed in what constitutes an unusual type of event to report (e.g. unusual mortality in a village, high absenteeism at school) and how and when to report (e.g. through messages or calls from mobile phones). The framework should be supported by a trained facility or dedicated district staff and should be regularly evaluated.

4.3 Community representatives that can be members of CBS team

Any community member acceptable by the community can be a CBS focal point. Representation could be from basic village-level services such as trained birth attendants, community or village health agents, or similar care providers, village leaders (religious, traditional or political) or school teachers, veterinarians, health extension workers, pharmacists, and traditional healers.

Once selected, the CBS focal points should receive training and carry out supportive supervision of how to recognise certain diseases or health conditions for the purpose of reporting suspect cases.

4.4 Establishing a CBS

Every health facility is responsible for establishing a CBS in its catchment area. This requires that the facility:

- (a) Maps the catchment area and determines the number of CBS focal points needed.
- (b) Identifies community representatives willing to be CBS focal points and accepted by the community to play such a role.
- (c) Trains the focal points regarding the use of case definitions and actions, and timelines for reporting intervals.
- (d) Defines a mechanism for regular feedback and support to the CBS.

4.5 CBS Supervision

All activities for implementation by CBS should be coordinated by a surveillance officer or health facility manager in his or her locality. He or she will:

- (a) prepare a list of priority diseases or conditions for inclusion in the CBS based on the adapted IDSR technical guidelines;
- (b) share as appropriate a list of simplified community case definitions to facilitate case detection and monitoring;
- (c) build capacity of CBS focal points in all aspects of surveillance and response;
- (d) regularly strengthen the skills and practices of focal points in all appropriate aspects of surveillance and investigation particularly the handling and dissemination of data;
- (e) establish feedback loops, which is a critical action for ensuring that CBS continues to work because without the feedback, CBS volunteers will not see the importance of reliable performance;
- (f) disseminate posters of simplified case definitions to relevant places within the community, as appropriate;
- (g) monitor surveillance and response activities, including timeliness and completeness of reporting;
- (h) supervise activities of the CBS focal points in situations such as contact tracing;
- (i) identify and map key health determinants in the area;
- (j) provide regular and timely feedback to CBS teams.

5. SOURCES OF INFORMATION FOR COMMUNITY-BASED SURVEILLANCE

A functioning CBS should connect with key sources of information. This includes but is not limited to the following sources of information:

- (a) All community based health workers, including traditional birth attendants and school health masters: these constitute privileged sources of information due to their connections with the local community and their presence in the field, especially in remote areas where access to primary health care is scarce.
- (b) Community, traditional, youth or religious leaders and civil society: these individuals and groups may provide informal reports of unusual health events or health risks that they witness in their communities.
- (c) Media: local, national and international media are important sources of information for CBS. Events such as clusters of human cases, outbreaks or unexpected and unusual deaths may be covered by local newspapers (printed or available through the Internet) or radio reports before they are detected and reported by local health services.
- (d) Traditional medicine and traditional health practitioners and healers: in some African countries, a large number of the population depends on traditional medicine for primary health care. Traditional medicine has been used for thousands of years, and these practitioners may constitute a valuable source of information.
- (e) Alternative medicine (herbalists, for example) complementary medicine and nonconventional medicine: these include health care practices that are not part of that country's own tradition and are not integrated into the dominant health care system; they are gaining in

popularity and should be considered as a potential source of health information and contact with them provides opportunities for encouraging safe practices.

- (f) Faith-based Organizations (FBO) and Community-based Organisations (CBO) set ups as source of information on unusual events.
- (g) Families are also sources of information. Community health workers conducting door-todoor activities such as well-baby monitoring can collect information about whether anyone in the household has been ill.

6. STEPS FOR ESTABLISHING CBS

The process of establishing a CBS is coordinated by a health facility with support from district ISDR¹ or Surveillance Officer.

- (a) First establish who will be the designated health facility manager or surveillance officer to coordinate the CBS activities. He or she should have a clear understanding of the IDSR strategy. He or she will be responsible for coordinating the implementation of CBS in his/her locality.
- (b) Ensure that all necessary functions and capacities have been identified. These should cover the following IDSR core functions and activities at community level:
 - (i) identification of cases and events;
 - (ii) reporting suspected cases, conditions or events to the next level;
 - (iii) analysis and interpretation of findings;
 - (iv) investigation and confirmation of suspected cases, outbreaks or events;
 - (v) preparedness and response;
 - (vi) provision of feedback, evaluation and improvement of the system.
- (c) Identify and use locally available resources to support timely notification of priority illnesses.
- (d) Train selected CBS focal points.
- (e) Support the development of CBS plan of action.
- (f) Advocate for resources for the implementation of the CBS plan of action.
- (g) Coordinate the monitoring and evaluation of the implementation of the CBS activities.

7. TRAINING PACKAGE FOR CBS FOCAL POINTS

Suggested training outline for CBS focal points is as follows in line with the IDSR technical guidelines and training modules:

- (a) Lesson 1 Identifying cases and events: simplified community case definitions, priority diseases, conditions and events.
- (b) Lesson 2 Reporting suspected cases, conditions or events to the next level.
- (c) Lesson 3 Investigating and confirming suspected cases, outbreaks or events.
- (d) Lesson 4 Providing feedback to the community about the investigation outcome and the success of response efforts.

¹ Please see ANNEX C for IDSR core functions and activities by health system level (community and facility) – 2010.

- (e) Lesson 5 Evaluation and improvement of CBS: reporting timeliness, quality of information, preparedness, and overall performance. Take action to correct problems and make improvements.
- (f) Lesson 6 Improvement of CBS post-evaluation: how to correct problems and make improvements.

The specific objectives of this training are to enable participants to:

- (a) identify cases and events of public health importance;
- (b) report suspected cases or conditions or events to the next level;
- (c) understand their role in:
 - (i) investigating and confirming suspected cases, outbreaks or events;
 - (ii) giving feedback to the community about the investigation outcome and the success of the response efforts;
 - (iii) evaluation and improvement of CBS;
 - (iv) being prepared for outbreaks or events of public health concern.

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The references below provided valuable information in putting together this guide for establishing a CBS.

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ANNEX 1: Preparing to conduct community surveillance and response

A designated health facility manager or surveillance officer responsible for coordinating CBS activities should:

- (a) Determine the availability and knowledge of standard community case definitions for reporting suspected priority diseases and conditions including events of public health concern.
- (b) Define the **sources of information** about health events in the district, including points of contact that the community has with health services.
- (c) Identify surveillance focal points for each source of information. Identify and specify the opportunities for community involvement in surveillance of health events.
- (d) Specify the priority events, diseases and conditions for surveillance within the catchment area and those directed by national policy. Compile a list of:
 - (i) epidemic-prone diseases;
 - (ii) diseases targeted for eradication and elimination;
 - (iii) other diseases of public health importance including noncommunicable diseases.
- (e) Define methods for informing and supporting focal points in the implementation of CBS, e.g.:
 - (i) list the current opportunities for training focal points in surveillance and response;
 - (ii) define the training needs including initial training in surveillance and response skills.
- (f) Describe how communication about surveillance and response takes place between the health facility/surveillance officer and the CBS focal points. Include methods such as monthly meetings, telephone calls and so on.
- (g) Review and update procedures and methods of feedback between the health facility and the community.
- (h) Describe the communication links between the community and health facilities with the epidemic management committee that can be activated during an outbreak and for routine activities.
- (i) State three or more objectives you would like to achieve for improving surveillance in your district over the next year.

ANNEX 2: Key simplified signs and symptoms for case definitions for use at community level

A designated health facility manager or surveillance officer will inform the CBS Focal Points (e.g. community leaders, community health workers, traditional healers, birth attendants, and health workers who conduct outreach activities) about the priority diseases and conditions under surveillance in your area. Use key signs and symptoms of case definitions such as the following to help the community to recognize when they should refer a person with these signs for treatment and notify the health facility. Examples of how key signs and symptoms of case definitions may be described at the community level. Please refer to your adapted IDSR technical guidance for more information.

- (a) Acute flaccid paralysis: Any child with a sudden onset of acute paralytic disease.
- (b) Acute watery diarrhoea: Any person with three or more loose stools within the last 24 hours and a danger sign *or dehydration (*danger signs include lethargy, unconsciousness, vomits everything, convulsions, and in children less than 5 years, inability to drink or breastfeed).
- (c) Acute jaundice: Any person with a sudden yellowing of the skin for not more than two weeks, with or without elevated body temperature.
- (d) Adverse event following immunization (AEFI): Any unusual event that follows immunization and is thought to be caused by the vaccination.
- (e) **Cholera:** Any person aged five years or more who has lots of watery diarrhoea.
- (f) **Diarrhoea in children less than five years of age:** Any child who has three or more loose or watery stools for a duration of 24 hours with or without dehydration.
- (g) **Diarrhoea with blood (Shigella):** Any person with diarrhoea and visible blood in the stool.
- (h) **Dracunculiasis:** Any person exhibiting or having a history of a skin lesion with the emergence of a worm.
- (i) **Hepatitis:** Any person with fever and yellowing in the white part of the eyes or yellowing of the skin within two weeks of onset of first symptoms.
- (j) **Influenza-like Illness (ILI)**: Any person with fever and cough or sore throat or nasal discharge.
- (k) Leprosy: Any person with light or reddish skin lesions with definite loss of sensation.
- (1) **Malaria**: Any person with fever in a malaria-endemic area. Any under-five child who has an illness with high fever and a danger sign*(*danger signs include lethargy, unconsciousness, vomits everything, convulsions, and in children less than 5 years, inability to drink or breastfeed).
- (m) Maternal deaths: Death of a woman during pregnancy or within 42 days of termination of the pregnancy.
- (n) **Measles:** Any person with elevated body temperature and widespread rashes on the face and the body.
- (o) Meningococcal meningitis: Any person with fever and stiff neck.
- (p) Neonatal death: Death of newborns within 28 days of life.
- (q) **Trachoma:** Any person with soreness of the eyes or watery discharge from eyes.
- (r) **Viral Haemorrhagic fever:** Any person with onset of fever, not responding to the usual treatment of fever in the area at risk of transmission, and with at least one of the following signs: bloody diarrhoea, bleeding from gums, bleeding into skin, bleeding into eyes and urine or sudden death.

ANNEX 3: IDSR core functions and activities by health system level-2010

1. Community

1.1. Identify

Use simple case definitions to identify priority diseases, events, conditions or other hazards in the community.

1.2. Report

Report essential information on priority diseases, events, conditions or hazards to health facility and appropriate authorities.

1.3. Analyse and Interpret

- (a) Involve local leaders in observing, describing and interpreting disease patterns, events and trends in the community.
- (b) Undertake verbal autopsies on causes of deaths.

1.4. Investigate and Confirm

Support event investigation activities.

1.5. Respond

- (a) Assist local authorities in selecting response activities.
- (b) Ensure the community seeks care immediately in case of emergency and danger signs of disease, events and conditions.
- (c) Participate in response activities including home-based care.
- (d) Mobilize resources appropriate for the activity.
- (e) Carry out community health education for behaviour change.

1.6. Communicate(Feedback)

Give feedback to community members about reported cases, events and prevention activities

1.7. Evaluate

- (a) Verify if public health interventions took place as planned.
- (b) Verify the community response to the public health action.

1.8. Prepare

- (a) Participate in disaster or emergency preparedness and management committees.
- (b) Participate in risk mapping of potential hazards.
- (c) Conduct community-based surveillance.
- (d) Manage eventual contingency emergency stock.
- (e) Participate in training including simulation exercise.

Health Facility

1.9. Identify

- (a) Use standard case definitions to detect, confirm and record priority diseases or conditions.
- (b) Collect and transport specimens for laboratory confirmation.
- (c) Use local laboratory capacity to confirm cases or to initiate confirmation of cases if possible.

1.10. Report

- (a) Report case-based information for immediately notifiable diseases.
- (b) Report summary data to next level.
- (c) Report laboratory results from screening of sentinel populations.
- (d) Report laboratory results to next level.

1.11. Analyse and Interpret

- (a) Prepare and periodically update graphs, tables, and charts to describe time, person and place for reported diseases and conditions.
- (b) From the analysis, report immediately any disease or condition that:
 - (i) exceeds an action threshold;
 - (ii) occurs in locations where it was previously absent;
 - (iii) presents unusual trends or patterns.
- (c) Interpret results. Initiate possible public health actions with local authorities.

1.12. Investigate and Confirm

- (a) Take part in investigation of reported outbreaks.
- (b) Collect, package, store and transport specimens for laboratory confirmation.

1.13. Respond

- (a) Manage cases and contacts according to standard case management guidelines.
- (b) Take relevant additional control measures.

1.14. Communicate(Feedback)

Communicate with community members about outcome of reported cases and prevention activities.

1.15. Evaluate

- (a) Assess community participation.
- (b) Conduct self-assessment on the surveillance and response activities.
- (c) Monitor and evaluate programme targets and indicators for measuring quality of the surveillance system.
- (d) Monitor and evaluate programme timeliness and completeness of reporting from health facilities in the district.
- (e) Monitor and evaluate timeliness of response to outbreaks.
- (f) Monitor and evaluate prevention activities and modify them as needed.

1.16. Prepare

- (a) Participate in disaster or emergency preparedness and management committees.
- (b) Participate in Rapid Response training.
- (c) Conduct risk mapping of potential hazards.
- (d) Conduct training of community.
- (e) Participate in simulation exercises.