African Field Epidemiology Network (AFENET) Public Health Participatory Epidemiology Introductory Training Module

MANUAL FOR TRAINEES

Developed in collaboration with the Participatory Epidemiology Network for Animal and Public Health (PENAPH)

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Acknowledgments

The information presented in this manual is based on the work of a network of participatory epidemiology practitioners and trainers. It is for use in teaching the basic principles of participatory epidemiology, with a focus on public health. Although not exhaustive, this training, developed in collaboration with PENAPH and AFENET, does give interested practitioners the background and experience they need to plan and implement participatory epidemiology activities.

The PENAPH managing partners are ILRI, OIE, FAO, AU-IBAR, RVC, VSF-B, VSF-C, USCDC and AFENET. Further information can be obtained from:

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This is a participatory manual, and includes materials from many different sources. It can be downloaded from the PENAPH website:

http://penaph.net/

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Objectives, Priorities & Considerations

The goal of this training is to increase your awareness and use of participatory epidemiology. The training will also provide you with a valuable opportunity to become a public health advocate. Integrating *data for action* into your work comes with the responsibility to act on the information gathered. While responding to community needs is not within the scope of the training module, it is the responsibility of certain key stakeholders. In order to make the greatest use of the training and the participation of the communities, please share the findings and recommendations obtained during our field visits with individuals and agencies positioned to respond effectively.

Please keep a log of the names and locations of the villages you visit, their health concerns and your recommendations. Observations not discussed with the community may be included as appropriate (e.g. school aged children not in school).

At the end of this training, you will identify common themes, priority health issues and recommendations, and will summarize the findings into a presentable report format. You will also need to identify key stakeholders and responsible individuals or agencies that will be able to act on your recommendations. Contributing communities may also benefit from receiving your report. You are encouraged to complete the handout on Participatory Epidemiology Field Practice Recommendations in stages as you complete the field practices.

Training Learning Objectives

Having completed this training, participants will be able to:

- 1. Describe the roles, principles, and methods of participatory epidemiology
- 2. Improve outreach to the community
- 3. Plan and implement a participatory epidemiology study, including:
 - a. Develop and test a hypothesis
 - b. Develop a checklist
 - c. Lead a semi-structured interview
 - d. Apply participatory epidemiology tools, including visualization and scoring techniques
- 4. Carry out participatory disease surveillance (PDS)
- 5. Record PDS findings in a format suitable to contribute to a national surveillance system
- 6. Assess, analyze, and report participatory epidemiology data
- 7. Design interventions for disease control based on participatory epidemiology data

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Day One

1. Welcome and Introductions

Welcome to the Introductory AFENET Participatory Training Course!

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Introduced themselves, other participants and trainers
- 2. Describe the objectives of the training course
- 3. List the course ground rules

1.1. Icebreakers

Icebreakers are a great way for participants and trainers to get to know one another, and feel comfortable and relaxed in the training environment. Your facilitators will lead you through introductions and icebreakers.

1.2. Objectives of the training

Please review and be prepared to discuss the learning objectives for this training, found under 'Objectives, Priorities and Considerations'. Your facilitators will lead you through a review of our training objectives.

1.3. Ground rules & code of conduct for the training

Your facilitators will help you establish the ground rules for this training. What rules do you think will ensure that the training runs smoothly and that participants' expectations are met? Please take a few minutes to note your ground rules.

Exercise
Please use this space to note your training ground rules.
Examples: 1) Be on time. 2) Respect the opinions of others.
1)
2)
3)
4)
5)

1.4. Expectations

Your facilitators will also help you share with one another different expectations for this training. What are your expectations? What do you want to do with what you learn? What do you want to create or change once you complete this training? Please take a few minutes to note your expectations.

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Exercise

Please use this space to note your expectations for this training.

Examples: 1) I expect to learn more about how to implement epidemiological field investigations, so I am more prepared to rapidly and accurately diagnose a public health emergency. 2) I expect to meet other public health practitioners and widen my network of colleagues with whom I can share experiences and call on when I need help.

1)

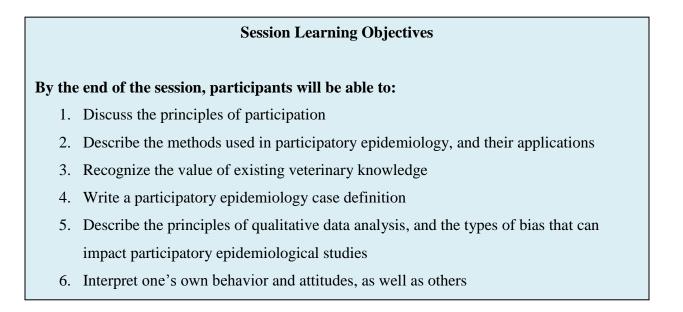
2)

3)

4)

5)

2. Introduction to Participatory Epidemiology



2.1. Participation

What do you understand by the word *participation*? Many people use the term in their work and personal lives in different ways, because they have different understandings. Please take a few moments to think about what participation is, and note your ideas.

PUBLIC HEALTH PARTICIPATORY EPIDEMIOLOGY 12

Exercise

Please use this space to note your ideas on what participation is.

Example: The process of involving people in projects, research or decision-making so as to empower them.

Participation empowers people to find solutions to their own development challenges. It is both an attitude and a philosophy that encourages learning, discovery and flexibility.

2.2. Types of participation

No type of participation is better than the others. Sometimes different types are required. In participatory epidemiology, the level of participation may range from information giving, where the focus is on data collection, to interactive, where the focus is on external agents and communities working together to identify problems, solutions and action plans.

What types of participatory projects have you been involved in? Do you have other examples of participatory projects and activities that you have heard about? What do you think about the level of participation achieved in each of these examples? Please take a few moments to list some participatory projects that you know about, and the level of participation achieved.

Exercise

Please use this space to list some participatory projects that you worked on or have heard about, and the level of participation achieved in each.

Example: We developed a list of priority diseases for children with HIV by asking mothers of HIV positive children in Kampala what diseases their children suffered from. This was extractive, because the participants gave us their responses and then we analyzed the data to write a report.

*Types of participation*¹:

- **Passive participation:** People participate by being told what is going to happen or has already happened. It is a unilateral announcement by an administration or project management without listening to people's responses. The information being shared belongs only to external professionals.
- **Participation in information giving**: People participate by answering questions posed by extractive researchers using questionnaire surveys or similar approaches. People do not have the opportunity to influence proceedings, as the findings of the research are neither shared nor checked for accuracy.
- **Participation by consultation**: People participate by being consulted, and external people listen to views. These external professionals define both problems and solutions, and may modify these in the light of people's responses. Such a consultative process does not concede any share in decision-making, and professionals are under no obligation to take on board people's views.
- **Participation for material incentives**: People participate by providing resources, for example labor, in return for food, cash or other material incentives. Much on-farm research falls in this category, as farmers provide the fields but are not involved in the experimentation or the process of learning. It is very common to see this called participation, yet people have no stake in prolonging activities when the incentives end.
- Functional participation: People participate by forming groups to meet predetermined project objectives related to the project; which can involve the development or promotion of externally initiated social organizations. Such involvement tends to occur after major decisions have been made rather than in the early stages of project development. These institutions tend to be dependent on external initiators and facilitators, but may become self-dependent.
- **Interactive participation**: People participate in joint analysis, which leads to action plans and the formation of new local institutions or the strengthening of existing ones. It

¹ From Pretty, J.N., Guit, I., Thompson, J. and Scoones, I (1995). A Trainer's Guide for Participatory Learning and Action, London: International Institute for Environment and Development (IIED)

tends to involve interdisciplinary methodologies that seek multiple perspectives and make use of systematic and structured learning processes. These groups take control over local decisions so people have a stake in maintaining structures or practices.

• Self-mobilization: People participate by taking initiatives independently of external institutions to change systems. They develop contacts with external institutions for resources and technical advice they need, but retain control over how resources are used. Such self-initiated mobilization and collective action may or may not challenge existing inequitable distributions of wealth and power.

2.3. Participatory appraisal

What is participatory appraisal? When can it be used? Do you have experience with it? If so, how was it used and what was your role? Please take a few moments to describe participatory appraisal and your personal experience with the methodology.

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Exercise

Please use this space to describe what participatory appraisal is, and what personal experience you have had with the methodology

Example: PRA is when a team of experts works with a community to develop descriptive information and a plan of action. I was the agronomist on a team of five experts that worked with coffee farmers in Kabarole District, Uganda, to find solutions to deforestation. I found out that harvests were decreasing because of climate change related temperature increases, so farmers were clearing more forest to plant more coffee. The physician found that respiratory disease in children was increasing, because of the increased burning to clear forest. As a result we are working with conservation and health NGOs to increase coffee/banana intercropping in Kabarole, so that the coffee trees are shaded and less heat stressed, and kids spend less time cutting and burning forest.

Participatory appraisal is a family of approaches and methods that enable people to present, share and analyze their knowledge of life and conditions, so as to plan and act. It is participatory, flexible, lightly structured, adaptable, exploratory, empowering and inventive. Some examples of participatory appraisal approaches are rapid rural appraisal, participatory rural appraisal, farming systems research, and participatory impact assessment.

Key principles of participatory appraisal:

- Behavior and attitude
 - Listen, learn and respect
 - Be prepared to unlearn negative attitudes and stereotypes
 - Act as facilitator, not an expert
- People are knowledgeable
 - On subjects important to their livelihoods
 - Certain individuals have unique and valuable perspectives
- Co-learning
 - Share knowledge, experience and analysis
 - Combine local and professional knowledge for effective acceptable action
- People are rational
 - There is an insider's and an outsider's perception of behavior
 - Based on the information available, most people make rational decisions
 - The appearance of irrational behavior means that a misunderstanding may have occurred
- Optimal knowledge/optimal ignorance
 - There is a balance between the need for information and the need for timely decision-making
- Action-orientated
 - Be prepared to take action rather than just collect data

2.4. Participatory epidemiology

Participatory epidemiology is the use of participatory approaches and methods to improve our understanding of the patterns of diseases in populations. The approaches and tools used are derived from participatory appraisal. It is based on conventional epidemiological concepts and allows for the investigation of interactions between host, agent and environment, but in a social context of disease transmission. It is based on what is called "existing medical knowledge."

Participatory approaches have been evolving since the 1960s. These methods have been used in adult education, social anthropology, action research, and community-based health initiatives. In the veterinary world, participatory epidemiology was first developed in pastoralist systems for active surveillance of rinderpest. It is now applied in many situations including active surveillance for endemic, epidemic and emerging diseases. Participatory epidemiology is increasingly being used for investigating human health events.

Applications of participatory epidemiology range from data collection to interactive participation where information is analyzed with the community and a joint action plan is developed. Participatory epidemiology can be applied to:

- Needs assessments
 - Priorities of and entry points into communities
- Participatory epidemiology research
 - Basic epidemiology studies
 - Disease modeling
 - Risk assessment
- Participatory disease surveillance (active)
 - Case finding
 - Demonstrating disease freedom
- Community-based disease reporting (passive)
- Impact assessment
 - Evaluation of disease control interventions

• Strategy and policy reform

What other applications can you think of? Please take a few moments to think of how you might use participatory epidemiology.

Exercise

Please use this space to describe how you might use participatory epidemiology in your own work.

Example: In Nigeria, an NGO was proposing to supply chickens as part of a livelihoods improvement program. After community meetings it was determined that goats were more useful, because chickens were used exclusively for ceremonial purposes and not for commercial gain.

2.4.1. Methods used in participatory epidemiology

Participatory epidemiology is based on communication and transfer of knowledge, using a variety of tools. Different participatory epidemiology tools can be used to investigate the same issues or diseases. Although the methods are intended primarily to explore different aspects of the issue, there will be some overlap in the information generated. Three main groups of tools will be presented during this training:

- *Informal interviewing:* semi-structured interviews, key informant meetings, focus-group discussions
- *Ranking and scoring:* simple ranking, pair-wise ranking, proportional piling, matrix scoring
- Visualization: mapping, timelines, seasonal calendars, Venn diagrams

In a participatory epidemiology study, information gathered using these tools is complemented by:

- *Secondary information sources:* obtained before you go to your study area and as the study is conducted
- Direct observation: people, animals, housing, environment, etc. while in the study area
- *Laboratory diagnostics:* field diagnostic tests complemented by sample collection and analysis by a regional or national laboratory for confirmation

Participatory disease surveillance (PDS) is the application of participatory epidemiology to surveillance. Disease occurs due to the interaction between the host (human or animal), the agent (virus or bacteria) and the environment in which the host and the agent are present. PDS is a useful methodology for exploring the social context in which a disease is occurring, as well as other aspects of the host-agent-environment interaction.

2.4.2. Cross-checking data in participatory epidemiology

Qualitative research methods require data checking and analysis. In participatory epidemiology, this process begins during fieldwork. Throughout an investigation the practitioner is analyzing information, and as a result the hypothesis guiding the investigation is continually evolving. There are several ways in which data is crosschecked, validated and analyzed.

- *Probing:* during an interview, information provided by informants is explored for internal consistency. When an interviewee responds to a question, the interviewer usually asks additional questions to verify and deepen his or her understanding of the interviewee's viewpoint.
- *Triangulation:* an analytical process where data collected by different methods and from different sources is compared. Triangulation is used to explore patterns and coherence, as well as to understand the bias of different informants. Triangulation occurs during an interview, when comparing secondary information and interview results, and during final analysis.
- *Conflict of interest:* it is important to understand any potential conflict of interest your informants might have in order to interpret the information you gather.
- *Weighing of evidence:* the practitioner needs to weigh the evidence gathered from different sources to make a judgment on which to prioritize and investigate further.
- *Laboratory diagnostics:* results, particularly regarding a diagnosis, should be confirmed with biological testing.

2.4.3. Analysis in participatory epidemiology

Different types of data can be collected during an epidemiological study.

- *Quantitative:* a measure of "how much" of something, expressed as a specific quantity with a unit. For example, a distance of 10 km is a quantitative measure.
- *Qualitative:* descriptive and considered more subjective than quantitative data. Instead of a specific quantity and unit of measure, in qualitative terms a distance might be described as "farther" than another.

• *Semi-quantitative:* information that has been assigned a numeric quantity but the unit of measure may be irregular. Semi-quantitative data is often created from qualitative data by using systems of ranking or prioritization.

Participatory epidemiology allows for the collection of all types of data. What are the pros and cons related to each type of epidemiological data? Please take a few minutes to complete the following table.

Exercise

Please indicate below the advantages and disadvantages associated with each type of data that is generated in epidemiology.

Quantitative Qualitative		Semi-quantitative			
Advantages	Disadvantages	Advantages	Disadvantages	Advantages	Disadvantages
Example:	Limited in the	Can record	Hard to	Allows for	May be hard
Statistical	type of data	why	analyze	some	to interpret
analysis is	that can be	differences in		statistical	magnitude
easy	collected	responses		analysis	
		occur			

Advantages of the integration of participatory with conventional methods in epidemiology.

Every epidemiological study has qualitative elements. Whereas statistics measure association, causality is a subjective judgment. Quantitative data should always be interpreted in a context. In quantitative epidemiology, data is validated by probabilities whereas in qualitative epidemiology, the researchers weigh the evidence.

The strength of participatory epidemiology is that it allows for the rapid collection of data and is flexible enough to allow the investigators to fill in gaps in knowledge that might be missed in a study utilizing only quantitative methods. With participatory epidemiology, we can contextualize associations and improve the data available for assessments of causality. Participatory epidemiology is complementary to conventional epidemiology. It can be used as a hypothesis generation tool, as a complement to quantitative methods or as a stand-alone discovery process.

Participatory epidemiology is best conducted by trained field personnel who are able to contextualize information on the spot and direct questioning in ways that expose sources of bias. Data analysis begins during fieldwork in participatory studies.

2.5. Bias

As scientists, what do we mean when we speak about bias? What may be sources of bias in fieldwork? Have you conducted fieldwork where you suspect bias was introduced during the study?

Exercise

Please use this space to develop a definition for bias. List sources of bias in fieldwork, and provide examples from your own work where you suspect bias was introduced and how. Bias affects all human observations and perceptions. It is a propensity to present one perspective, or a partial perspective, even though there are other equally valid alternatives. In research bias is a deviation from the truth, or a systematic tendency in the collection, analysis, interpretation, publication, or review of data that leads to conclusions that are different from the truth. This does not imply that the deviation is intentional. As scientists we must always be aware of the potential for bias in our work. Understanding bias is a key requirement for being an effective participatory epidemiology practitioner.

Randomization of informants is difficult during an investigation, and can make selection bias (systematic differences in participants included in the study) an important problem. It is critical that practitioners of participatory epidemiology understand this from the beginning, so that they are able to probe for information and understand the motivators driving informants to respond the way they do. Practitioners can seek to balance the perspective of one informant by seeking information from someone who may have a different opinion. For example, if after interviewing three middle-class community members and finding that their highest disease priority is high blood pressure, you might interview three poor members of the community. You might find their disease priority is different, perhaps diarrhea. Practitioners of participatory epidemiology seek to understand bias rather than to eliminate it. Why are the viewpoints of the middle class and poor different in the community? By answering that you can begin to understand the drivers behind the different disease problems.

Understanding the different types of bias that may affect a study can decrease the likelihood that bias will affect the overall conclusions drawn by the investigator. Selection of a variety of informants, as well as cross checking data through probing and triangulation, will decrease the likelihood that a systematic deviation from the truth will affect the results of a study. How participatory epidemiology tools are designed to reduce bias will be discussed further during this course. In participatory epidemiology we take into consideration how some kinds of bias tend to influence participatory work. These types of bias are²:

² From Robert Chambers (1983) Rural development: putting the last first. Longman, London. Available online: <u>http://www.eou.edu/socwomen/support/articles/chambers.pdf</u>

- Spatial bias: The selection of a study area based on convenience and access.
 Investigators often travel by road, leading to study areas identified by proximity of villages to good roads. The people in more remote communities (often the poorest) remain unrepresented in the study.
- *Project bias:* The selection of a study area based on the presence of other projects, because of the increased level of activities in the village and comfort with outside investigators. Visitors and researchers are often channeled to areas where projects have been active and most of the work will then concentrate on these places.
- *Person bias:* The selection of respondents who are easy to access and interact with. The views of certain types of people (influential, rich, vocal, etc.) can overrepresented in the interviewing process, and those people may be biased against poor people, or ignorant of their needs. The "rural elite," while not at all representative of the cross-section of the community, is often the most vociferous during group interviews, drowning out the voices of others. The investigator must make a special effort to include marginalized members of the community in a study, such as women, approaching them in settings where they feel comfortable enough to express their views.
- *Seasonal bias:* The collection of data during one part of the year, which may not be representative of the pattern of disease during other parts of the year. For example, malnutrition, morbidity and mortality may be highest at the end of the dry season. Surveys carried out at other times of the year may miss these phenomena.
- *Diplomatic bias:* The reporting of information by informants that hides certain problems, out of respect or embarrassment because the problem may have a negative social stigma. For many communities, poverty is the subject of shame, and the needs of the poorest are sometimes glossed over or even concealed, either by the poor themselves or by officials working with them.
- *Professional bias:* The filtering of information through the lens of one's professional training, rather than objectively considering it as reported. Health professionals may introduce bias, preventing them from really understanding what informants are trying to tell them. In epidemiology, professional bias can cause problems at the technical level, preventing study teams from correctly understanding the traditional knowledge base.

Exercise

In the blank spaces provided below, please identify the type of bias associated with each situation.

- A mother says that there is a new disease affecting her children. She describes clinical signs similar to those seen in kwashiorkor, which has been in the area for quite some time. The investigator assumes that the mother is incorrect about this being a new disease. *Type of bias*: ______.
- An investigator asks a Ministry of Health official for locations of communities experiencing elevated incidences of childhood pneumonia. The official points the investigator in the direction of villages on a main road between two major towns. *Type of bias*: ______.
- Fieldwork is conducted between the months of June and August. The investigator asks community members about the disease problems that occur in their village. *Type of bias*: ______.
- A village leader is asked about a zoonotic disease that is associated with poor hygiene and poverty. He denies that it exists in his village, but says that it has occurred in a nearby village. *Type of bias*: ______.
- 5. An investigator conducts a focus group interview where she suspects a new disease is affecting women. The men answer the majority of the questions with confidence, while the women sit on the periphery and do not offer their opinions. *Type of bias*:
- 6. Several villages in a region have community health workers (CHW) who have been trained by an NGO to conduct childhood vaccination. A health official recommends that these would be the best villages to include in a study, because the CHW are very knowledgeable about the childhood diseases in their village. *Type of bias*:

2.6. Attitude and behavior

It is important to be aware of our own attitudes and behavior, and how they might influence our work. Human beings communicate with all five of our senses: sound, sight, hearing, touch and smell. Most of us are used to communicating primarily with the sense of sound, by speaking. However, when we interact with others we are consciously or subconsciously communicating in other ways. Our attitudes are often displayed through these other means of communication; we exhibit behavior that the people become aware of and respond to in unanticipated ways. Our attitude and behavior may bias our study. Please take a few minutes to consider what types of bias can we introduce to a study simply because of our attitudes and behaviors?

Exercise

Please think about different attitudes, and what kinds of behaviors they elicit. List them below, and the type of bias they may introduce to a study.

Example: 1) Boredom. During an interview the scientist can look bored, looking around the room rather than at the respondent, interrupting the respondent, or talking to the interview team rather than listening to the respondent. This can lead to diplomatic bias, because respondents can see that you don't want to hear about something, and professional bias, because you might not even take notes on information you find boring.

1)

2)

3)

It is also important to be aware of the attitudes and behaviors of those with whom we are working. The attitudes and behaviors of our interviewees provide us important information for our study, as well as how well we are facilitating the interview! If you ask a chief about the sexual behaviors of young adults in a village, and his face shows anger, what does that tell you about how sexuality is regarded in that culture? Should you continue with that line of questioning, or change the subject? Please take a few minutes to consider how the attitudes and behaviors of respondents might influence the information you obtain during a study, how a respondent might communicate an attitude to you, and what you might do during an interview when you encounter certain attitudes and behaviors.

Exercise

Please consider the attitudes listed below, and brainstorm a few of your own. What type of behavior might you see in a respondent with that attitude? How might that attitude influence the information the respondent provides? What can you do to encourage or diffuse a situation influenced by the attitude?

Example: 1) Relaxed. The respondent might smile, sit comfortably, breath easily, look at the interviewer, and willingly answer questions. This is good during an interview because the respondent will provide detailed answers and welcome probing questions. To encourage a respondent to be relaxed, we should be relaxed ourselves, and treat the respondent as our equal.

- 1) Angry
- 2) Open
- 3) Suspicious
- 4)

5)

2.7. Indigenous knowledge

Existing medical or veterinary knowledge is the source of information from which participatory epidemiology practitioners learn. Community members know a lot about human and animal diseases and their clinical presentations. They likely have local names for disease manifestations, especially if the disease has been present in the area for quite some time. For some diseases with clear clinical signs, such as cholera, measles or plague, community members may be able to diagnose the disease and understand the pathology, vectors, reservoirs and other risk factors linked to the occurrence of disease. This type of information has also been called local knowledge, traditional knowledge, ethnoveterinary knowledge and existing knowledge.

When working with communities, we frequently seek to build a lexicon for local disease terms. The name for a disease in a local language can tell us a lot about the disease itself. For example, Somali pastoralists call Rift Valley fever *sandik*, which translates literally as 'bloody nose', because of the bloody nasal exudate they observe in some infected sheep. They even refer to the human form of Rift Valley fever as *sandik*, because they know it is the same disease affecting livestock and people. Please take a few minutes to reflect on experience you've had with existing knowledge in your work or family.

Exercise

Please think about names in local languages that you've heard for different diseases, and how their meaning can help you understand the diseases and their patterns in communities that use thge local names.

		1_	
English	Local	Language	Meaning
Name	Name		
Example:	Mukenenya	Luganda	Something that drains someone to loose so
HIV		(Uganda)	much weight

2.8. Clinical case definitions

A case definition is a set of standard criteria for classifying an individual or population as affected by a particular disease, syndrome or health condition. A *clinical case definition* provides a set of clinical criteria such as symptoms and other epidemiological parameters for

detecting a disease. A practitioner obtains all of the information for a clinical case definition from interviews and examinations of affected individuals. There are other types of case definitions. A *necropsy or autopsy case definition* provides a set of gross pathological criteria for detecting a disease. When animals are affected, a veterinary practitioner in the field can perform a necropsy, and the results can be triangulated with clinical information to help confirm a diagnosis. A *laboratory case definition* provides a set of laboratory criteria such as antigen detection or microscopic pathology for detecting a disease. A diagnosis based on a clinical case definition is confirmed by a diagnosis based on a laboratory case definition. A standard case definition helps ensure that all detected cases are equivalent, despite where and when they are identified or who identified them. Case definitions can be tailored for different situations.

 Example

 Clinical case definition for viral hemorrhagic fevers

 Any person who has an unexplained illness

 with fever

 and bleeding from any part of the body

 or who died after an unexplained severe illness with fever and bleeding

In participatory epidemiology, clinical case definitions are important tools for probing local medical or veterinary knowledge, and linking that knowledge to a practitioner's knowledge about diseases and syndromes. We use signs, symptoms and epidemiological criteria to arrive at a diagnosis. The case definition can be for an infected individual or population, or an outbreak. We may develop a clinical case definition for a particular study or investigation, or we may develop a standard case definition to search for a disease at national, regional or global scales. A clinical case definition should provide enough criteria so that the practitioner can arrive at the expected level of certainty in his or her diagnosis, while not being too prescriptive so that important cases go undetected. This will vary, depending on the objective of the study or investigation. For example, if the clinical case definition was the only diagnostic tool for

detecting an affected individual, the definition may be very specific. This may be possible when a disease has a pathognomonic sign, such as a pseudomembrane on the tonsils in the case of diphtheria. However, when a clinical case definition is being used for early detection of outbreaks, it may be quite broad so as to pick up all potential cases. Then a laboratory test is required to confirm the diagnosis. For example, a clinical case definition for the earliest possible detection of avian influenza in poultry might simply be sudden, rapid die-off in one or more birds. In such situations, a rapid laboratory diagnosis will be critical to confirming true outbreaks and controlling the disease.

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Exercise

In the space below develop a clinical case definition for an infectious disease that interests you. Begin by defining your objective, the situation that the case definition will be used in. Is it for a physician to diagnosis the disease in the exam room, a field team investigating a report of a potential outbreak of the disease, an epidemiologist determining the incidence of the disease in region, or all countries in Africa to rapidly discover outbreaks of the disease? Then think about clinical signs and symptoms that community members can easily observe as well as those you know are associated with the disease, epidemiological parameters, etc. Use this information to write a clear, simple clinical case definition that will help achieve your objective.

Objective:

Case definition:

3. National Public Health Surveillance Systems

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Understand national public health surveillance structures
- 2. Be knowledgeable of government public health policies and initiatives
- 3. Have a list of nationally notifiable diseases of public health concern

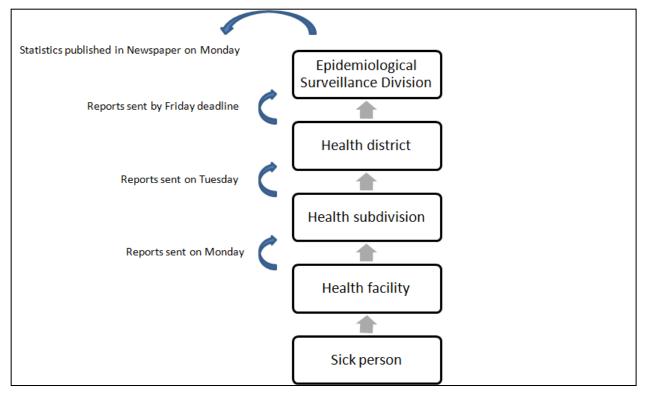
Surveillance is the collection of action-oriented information and intelligence within a realistic time frame. Surveillance is information for action! A national public health surveillance system provides for the continuous collection of information, leading to the prevention and control of diseases of public health importance. The structure of the system, what activities are undertaken and how action is implemented, is guided by national policies such as priority public health diseases. All health professionals have some role to play in a national public health surveillance system, and it is important that you have a good understanding of your role. Please take a minute to consider the notifiable diseases in your country. What is the reporting mechanism for these diseases, how does information move through the system, and what do national databases tell you and fail to tell you about these diseases?

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Exercise

Below, please list the diseases of public health importance that are notifiable in your country, the reporting mechanism, and the current national status for each disease.

Figure: Integrated Disease Surveillance and Response (IDSR) in Uganda showing information flow in a passive surveillance system for reportable diseases



It is also important for you to be aware of national programs and government policies for public health, such as provision of insecticide treated bed nets for infants, subsidized water treatment tablets, health center vouchers for peri-natal care, and universal access to HIV/AIDS antiretrovirals. Please take a minute to consider your own national public health policies. What constituencies do you serve that would benefit from knowing about these policies? Where can you go to find out more?

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Exercise

Below please list the national health policies of your country, and who the target beneficiaries are.

Consider the strengths and weaknesses of your current public health surveillance system. As you develop new skills and ideas during this training, take time to reflect on how participatory epidemiology can be used most effectively to fill gaps in the system.

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4. Tools: Semi-structured Interviews

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Describe the elements of a semi-structured interview
- 2. Describe the difference between open, leading, and probing questions
- 3. Demonstrate the semi-structured interview technique
- 4. Plan a good interview

Interviewing is a specialized skill that improves with practice. Although just about anyone can collect information through an interview, the amount and reliability of information obtained can be greatly improved with experience.

"At the heart of all good participatory research and development lies sensitive interviewing. Without it, no matter what other methods you use, the discussion will yield poor information and limited understanding. It may create feelings of suspicion, fear or even hostility in the local people. Semi-structured interviewing can be defined as: guided conversation in which only the topics are predetermined and new questions or insights arise as a result of the discussion and visualized analyses."³

An interview is a focused conversation between two or more people. It is a method of collecting data by talking to people and asking questions. In *structured interviews* the instrument used to collect data is a questionnaire. Questionnaires often use *close-ended* questions, which can

³ Pretty NJ, Guijt I, Thompson J and Scoones I. 1995. *Participatory learning and action: A trainer's guide*. IIED participatory methodology series. IIED (International Institute for Environment and Development), London, UK. 270 pp.

usually be answered with 'yes' or 'no' or a short response. Generally, questions are asked in a manner such that the answers fall within an expected range of answers. By restricting an interview in such a way, one risks loosing valuable information, viewpoints and context behind a response. Remember, if it appears that a response is not rational, then we have failed to understand some key factor in the situation. By avoiding closed-ended questions we provide the respondent the opportunity to explain to us the rationality behind a response. Interviews in participatory epidemiology are *semi-structured*, and the instrument used to collect data is a *checklist* or interview guide which reminds the interviewer about the subjects to be covered, but does not tell the interviewer what questions to ask.

Questionnaire	Checklist/Interview guide
Use a list of questions to be followed when collecting data	Generally bullet points of topics to guide the facilitator in capturing the main points during the interview. Can use questions.
Fixed questions - not changeable	Questions are not fixed, can vary depending on the situation
Generally closed ended questions or questions with limited answer choices	Open ended questions with unlimited potential responses
Enumerators collect information	Facilitators collect information
Not flexible in different situations	Flexible and suitable for all environments

Table: Differences between questionnaires and checklists/interview guides

Take a minute to think about all the things a team needs to do to prepare before leaving for the field to conduct an interview.

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Exercise

Please make a list of things that a participatory epidemiology team needs to do and prepare before leaving for the field to conduct an interview.

Examples:	1)	Agree	e on r	oles.	2)	Prepare bi	ological	sampli	ng kit.	
1)										
2)										
3)										
4)										
5)										
6)										
7)										
8)										
9)										
10)										

4.1. Checklists

A checklist allows the interview to be flexible and permits the respondents to express their thoughts in their own words within their own conceptual frameworks. It provides overall direction and ensures that no major points are missed in the interview. Respondents can discuss issues of special interest to them, and the appraisal team can investigate specific themes raised by the respondents. Not all items on a checklist/interview guide need to be covered with every group of participants; this is a matter of judgment.

Example

Checklist for the identification and prioritization of childhood health issues:

- 1. Introduce the appraisal team and purpose of the visit
- 2. Introduction of respondents
- 3. Different age groups of youngsters in the village4
- 4. Common childhood health concerns
- 5. Major diseases for <5 year old children
- 6. Local treatment for these diseases
- 7. Common health programs to improve child health
- 8. Questions from community
- 9. Advice/Add to local knowledge, clarify harmful beliefs

Mental checklists are a type of checklist that is not written down on paper. These are things you want to keep in mind in case certain subjects come up during an interview. They are commonly used when probing information about a disease, so that you can arrive at a diagnosis. For example, if respondents mention that they are afraid of a disease that caused several people to suddenly die in the village last year, you want to have a mental checklist of the different causes of sudden death in people, their symptoms and epidemiological patterns that will help you

differentiate between them: morbidity and mortality, seasonality, ages and genders affected, housing patterns, work patterns, treatments, survival rates, etc.

Exercise
You and your team have been asked to investigate a rumor of an outbreak of cholera. In the space below please develop a checklist to guide your investigation.
1) Introductions of team and community members
2)
3)
4)
5)
6)
7) Questions from the respondents

4.2. Place and time

The place and time when interviews are conducted influence their success. Unfortunately, the study team does not always have control over these aspects, but every effort should be made to arrange a quiet and comfortable location. Ideally, the interview team and respondents should feel relaxed and on equal footing with each other. Traditional community meeting places make good group interview sites. Although community and training centers may make acceptable interview sites, official offices or the appearance of an official enquiry should be avoided.

The best time for an interview varies from community to community, and an initial exploratory visit is often needed to make sure that you plan the interview for a suitable time. Always ask if it is a convenient time and if not, when you could meet. The interview should be planned to last 60-90 minutes. If it lasts too long, participants will begin to lose interest and the quality of information provided will decline. Learn to watch for signs of fatigue and boredom. Fidgeting and side conversations are a sign that either the interview needs to be enlivened by a shift to topics of greater interest or that it is time to wrap up and ask any key questions that may remain.

4.3. Introductions

The first step in any interview is introductions. The members of the study team should introduce themselves and ask the participants to introduce themselves, assuming that it is culturally acceptable. The introduction and the reason for the visit should be accurate, but should not bias the response of the participants. For instance, if you place emphasis on a particular subject such as diabetes or tuberculosis in your introduction, the respondents will frequently put undue emphasis on these topics in their replies.

The study team must be careful not to raise community expectations concerning future projects or services. The introduction is a good opportunity to diffuse some of these expectations by

stating that the appraisal is only a study and the members of the appraisal team are not the decision-makers for future programs.

4.4. Questions

Open-ended questions are designed to encourage full, meaningful answers using the responder's own knowledge and feelings. Typically, these questions begin with why, when, how, what, where, who? After listening to a response, the interviewer can *probe* further with clarifying questions. Imagine yourself at the top of a funnel, and the funnel is a new subject you would like to explore in an interview. Start exploring the subject at the top of the funnel with a nice open-ended question. Then, move with the respondent down the funnel by probing responses and asking clarifying questions. Save any closed-ended questions, if you have to use them at all, for the very end, at the bottom of the funnel, to make sure you completely understand. In the example below, why is the first question in each set better than the second?

Example

Types of Questions

New Subject

Start with "What health problems are you experiencing?" (open-ended) Rather than, "Have you ever had diarrhoea?" (closed-ended)

Probing Question

Probe the response with, "Have you ever had diarrhoea before?" (open-ended) Is better than, "When was the last time you had diarrhoea?" (leading)

A good question does not make assumptions. For example, if the respondents have described a current disease problem that is consistent with diarrhea and you wish to know when previous

outbreaks occurred, you might wish to ask, 'When was the last time this disease occurred?' However, it would be better to ask: 'Have you ever seen this disease before?' The first question is *leading*. It assumes that the disease has occurred before and communicates the assumption to the respondents, who may state a year for the sake of being polite or out of fear of appearing uninformed. The second question allows the respondents greater freedom to state what they confidently know.

Questions should be ordered so that the interview progresses from general themes to specifics. As much as possible, the respondents should determine the direction of the interview. As a result, the majority of questions cannot be pre-planned. They must be designed on the spot in light of the information already presented, and the investigator must be able to think on his or her feet. The appraisal team may have a special interest in unraveling the local epidemiology of kwashiorkor, for example, and wish to ask about the last occurrence of kwashiorkor in every interview. This can be done, but very careful attention must be paid to when the question is asked in the flow of the interview to avoid leading the discussion. If the condition is endemic, the participants will probably raise the subject of kwashiorkor, and then the appraisal team can safely ask their standard questions. If the participants never introduce kwashiorkor, the kwashiorkor questions can be asked at the end of the interview. However, the appraisal team should note that the community did not introduce the subject and that this probably reflects that kwashiorkor is not a local priority.

In public health interviews, quantitative questions on subjects such as the number of people in a household or family size may not receive very accurate responses, and it may be best to avoid these questions. The number of people in a household may vary over time, and in many societies defining relationships is complex and may be seen as intrusive. For instance, 'sons' may actually be nephews or cousins. Clearly identifying which child belongs to which parent may be considered impolite. Amongst farmers, the number of animals is a sign of wealth. It is generally impolite to ask exactly how many animals a farmer owns. If farmers do respond, poor farmers may exaggerate and rich ones may depreciate their holdings. It is possible to collect accurate data on family or herd sizes to calculate mortality rates by triangulating owner information with direct

observation of the herd and information from neighbors about the subject's livestock holdings.⁴ In some societies, though, it is unacceptable to ask one person about another person's livestock holdings.

4.5. Probing

Probing means to ask detailed questions on a specific subject raised by a respondent. Probing is both a data gathering and quality control technique. Probing can be used to verify the internal consistency of information or simply to gather more detailed information on a particular subject. In participatory epidemiology, probing is often used to obtain a more detailed description of a particular disease entity volunteered by a respondent. For example, respondents might describe a disease that causes a child to cough. The appraisal team could inquire if there is an adult in the same household with a cough for more than two weeks and if so, does the adult have other symptoms like weight loss, evening fevers, loss of appetite, chest pain with or without productive cough and with or without blood in the sputum. A positive response is a characteristic description of pulmonary tuberculosis and further testing will confirm the diagnosis.

Verifying the internal consistency of information is an important means of data quality control. Probing helps to establish the plausibility of statements made by informants by gathering more detailed information about an issue. This does not mean that 'trick questions' or attempts to lead the participants into self-contradiction should be made. PRA is founded on enlightened respect for individual opinions and observations. The interviewer respectfully evaluates the quality and merit of all statements from all individuals.

⁴ McCauley EH, Tayeb A and Majid AA. 1983. Owner survey of schistosomiasis mortality in Sudanese cattle. Tropical Animal Health and Production 15(4):227-233.

Example

Cultural mishearing, Somalia 1988

During a socio-ethnographic survey of the Upper Juba Valley in Somalia, aimed at understanding the land tenure system of riverine farmers, initial questioning with official informants and interviewees seemed to confirm that ownership and rights to land were on an individual basis. However, the interviewers' personal observations of the ratio of people to land made them question the possibility that so many could own so little land. For verification, they measured every field and interviewed each individual claimant and discovered that many people had varying claims on the same piece of land. Believing they had misheard, the interviewers asked again about land ownership. Further probing clarified that claims were in proportion to the genealogical distance from the claimant to the farmer and hence, several people could be said to "own a particular piece of land. Contrary to official information as well as what the interviewers thought they had heard, land rights and tenure were fluid and evolving rather than fixed.

From Mitchell J & Slim H. 1991. Listening to rural people in Africa: the semi-structured interview in rapid rural appraisal. Disasters, 15(1):68-72.

4.6. Observation

It is very important to observe as well as listen. Are the respondents relaxed and confident? Is there eye contact? What types of body language are being expressed? Are some topics sensitive? Is everyone participating? Who is not participating? Are some people comfortable and others not? What are the differences in appearance between those participating and those who are not? Is gender, wealth or age the issue (don't ask, observe)? Follow-up interviews can be arranged with 'non-participating' respondents in groupings where they may feel more comfortable. With few notable exceptions, people will readily talk about their health concerns. Participatory epidemiology is about letting people share their knowledge and learning from them. Listen. Be patient and open-minded.

4.7. Teamwork

Usually a participatory epidemiology interview is conducted by a team. There are three important roles, the interviewer, the note taker, and the analyst.

A good *interviewer* is a good communicator. Remember communication involves two things, speaking and listening. When asking questions, the interviewer uses simple language. After asking a question, the interviewer gives the respondent all the time he/she needs to answer. Be diplomatic and adopt a positive attitude. Be informal, following the customs of your respondents, but also be confident and make sure that dominant personalities do not take over the interview and drown out the voices of other respondents.

A good *note taker* listens to both the questions and the response. Note the nature of the question. Was it open or closed? How was it asked? These things will influence the response. Monitor the respondents and note any interesting behaviours. Did they become uncomfortable when a certain question was asked? Observe group dynamics. Note who within the group is contributing to which questions and who is keeping quiet. Listen and note if bias is introduced during an interview, and potential underlying reasons. Don't judge responses, note exactly what respondents say even if it does not seem rational to you. Even before the interview starts, the note-taker is at work: date, location, setting, number of respondents, gender, ages, ethnicities, start and end times. Many of these notes about the interview setting and implementation will help the team when it comes time for analysis.

A good *analyst* listens closely to the interview, and is noting issues like subjects that have not been fully probed, subjects that may have been forgotten, confusing or conflicting responses, bias and discomfort among the respondents. The analyst does not interrupt the interviewer when

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an issue is noted. Often the analyst will find that an issue is rectified later in the interview and no intervention is necessary. Before the interview, however, the interviewer and analyst should agree on a protocol for how the analyst will notify the interviewer if something needs to be handled. For instance, the team may agree that at the end of each subject on a checklist the interviewer will stop and ask the analyst if there is anything else that needs to be clarified. Or the analyst might pass a small note to the interviewer to tell him or her of an issue or problem.

This means that *teamwork* is critical to the success of an interview. If the facilitator is acting alone, he or she should record only the main points during the interview. Full notes can be made at the end in order to not slow down or interrupt the interview process. Regardless of whether the facilitator is working with a team or acting alone, notes should be reviewed immediately following the interview and overlooked details should be added.

Tips

- Use open-ended questions (start with Where? Who? What? How? When? Why?)
- Order questions from general to specific
- Probe areas of interest when they arise
- Organize and prepare the interview team before heading out
- In general, the disease under investigation is not disclosed until part way through the interview. Some situations will require disclosure before the interview begins to allow participants to choose whether to participate (e.g. domestic violence).

Now take a minute to review the list of all the things a team needs to do to prepare before leaving for the field to conduct an interview. Do you need to add to or revise your list? What should the team do immediately together after the semi-structured interview?

Exercise

Please make a list of things that a participatory epidemiology team needs to do together as soon as they return from the field where they conducted an interview.

Examples: 1) Discuss the teamwork experience, including what was good, what was bad, and what we should do in the future. 2) Read through our notes adding any detail that was missed.

1) 2) 3) 4) 5) 6) 7) 8) 9) 10)

5. Communities

Session Learning Objectives

By the end of the session, participants will be able to:

1. Describe the elements of community structures, assets, organization and entry points

A *community* is a group of people who share the same norms, attitudes, culture, behavior, values or geographic location.

5.1. Introductions

Community structures are support mechanisms or systems within the community to help members respond to day-to-day issues. They can be formal or informal and be linked to social roles, such as age group mentors. Examples of political structures are councils and elders groups. Health examples include village health teams, community health workers and veterinary health teams.

Community *entry points* include: local authorities (politicians), religious leaders, elders, the chairlady of a women's groups, councilors, teachers, relief coordination mechanisms, aunties/Senga for HIV/sexual education (in Bantu culture) and celebrities.

5.2. Assets

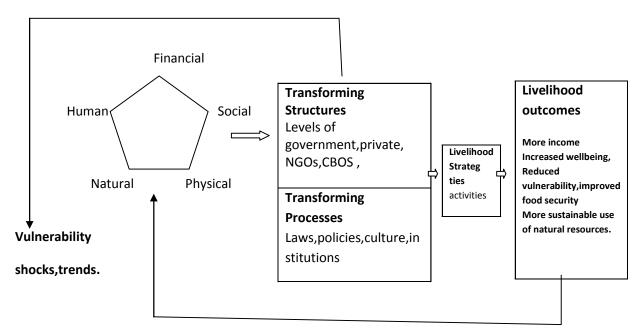
There are five forms of capital available within a community. Access to these assets by community members is mediated by different transforming structures and processes, which can either facilitate or hinder access and utilization by different sections of the community.

- Financial capital: banks, lending or credit facilities
- Physical capital: roads, buildings, vehicles, telephones
- Human capital: human skills within the community like trained personnel
- Social capital: social groups that people can resort to in times of stress
- *Natural capital:* natural resources, forests, water bodies, sand harvesting areas stones for construction

Livelihood strategies are the activities that community members choose in order to achieve desired livelihood objectives, namely more income, reduced vulnerability, food security and more sustainable use of natural resources. If community structures and processes act as barriers, then the result will be undesired outcomes like increased vulnerability and increased poverty.

Note that the five forms of capital are not fixed as one can be converted into another depending on needs. For example, sand, which is a natural capital, can be used in the construction of a health facility, which becomes a physical capital. Water and soil (natural capital) can be converted into crops and livestock, which are then sold and converted into financial capital. Financial capital is used for education, which becomes human capital.

Figure: Asset pentagon



A framework for analyzing community assets is called asset pentagon.

Please take a few minutes to imagine that you have been asked to carry out a survey of zoonotic disease problems in a remote pastoral community in your country. In particular, you are to focus on zoonotic diseases that women are exposed to because of their livelihood activities. How does knowledge of the community asset pentagon help you plan you study?

Exercise

You have been asked to carry out a survey of zoonotic disease problems in a remote pastoral community, focusing on diseases women and children are exposed to because of their livelihood activities. Please use your understanding about pastoralists to plan your fieldwork, including the following:

- How will you find an entry point into the community, so that you have freedom to interview different community members?
- 2) What forms of capital should you include on your checklist for discussion with community informants, and why?
- 3) What structures should you include on your checklist for discussion with community informants, and why?
- 4) What livelihood strategies should you include on your checklist for discussion with community informants, and why?
- 5) What key informants should you interview? What structures are they associated with, and what special insights do you expect them to have?

There are both advantages and disadvantages to the use of the asset pentagon as a framework for organizing one's work in a community. Therefore the use of this framework should be flexible and adaptable.

Advantages	Disadvantages		
Highlights core influences and processes and can	Two-dimensional representation of		
help the analyst order his/her thoughts. Key issues,	processes is limited and simplification		
questions and contradictions show area where	cannot capture the dynamic elements of		
action is possible.	livelihood systems.		
Good for analysis of micro policies relating to	It is only a tool for analysis. It can be taken		
poverty reduction as it emphasizes the links	too rigidly and not be adapted appropriately		
between various components that affect	to circumstances.		
livelihood.			
It points the effects of macro policies at local	It is complex and can be used even where		
level.	simpler tools are equally useful.		
It can be used at various levels, from individual	The framework may be too abstract for		
household to village to large geographical zone.	people working in the field.		
	There is danger of being overambitious in		
	using the approach.		

 Table: Advantages & disadvantages of the asset pentagon framework

5.3. Overcoming obstacles to participation

Obstacles to participation may exist within community structures. Other obstacles can be norms and cultural rules, lack of organization and organizational skills, poor communication infrastructure, poverty and other issues that marginalize some members of the community, and corruption. All of these issues can throw up barriers to meaningful participation.

Please return to you study of zoonotic diseases that pastoral women and children are exposed to because of their livelihood activities. Think about the obstacles women and children in the community will face to participate in your study, and how you can help them overcome those obstacles so that your study is representative of all community members.

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Exercise

You have been asked to carry out a survey of zoonotic disease problems in a remote pastoral community, focusing on diseases women and children are exposed to because of their livelihood activities. Previously you planned your fieldwork by identifying possible entry points, key informants, forms of capital, community structures and livelihood activities to include on your checklist. Now think about obstacles that you target group, women and children, will face to participate in your study. List those barriers, and how they can be overcome.

Example: 1) Women likely won't speak English because they are less educated. I'll need a translator, who should be a woman from the same culture.

- 1)
- 2)
- 3)

4)

5)

Community level obstacles	Mechanisms for overcoming obstacles
Lack of appropriate community organizations	Spread awareness of the program and development needed
organizations	Strengthen existing organizations
Lack of organizational skills	Informal trainings by community organizations
	Helping leaders to plan meetings
	Bring issues to membership
	• Formal training in record keeping, etc.
Poor communication facilities	Organization builds communication networks within
	its membership
	Breaks down some tasks
	• Discussions for smaller groups
Factionalism and differing economic	Minimize the need for cooperation between
interests	conflicting groups
	• Design incentives to strengthen local organizations
	• Support processes that unify people who must
	cooperate.
Corruption	Develop mechanisms for system checks

Table: Obstacles within the community and possible ways to overcome them

5.4. Developing local community organizations

One strategy for developing an organization is to make it location specific, and either work with an existing organization or form a new one.

Issues to be considered while forming community organizations

- Type of activity or resources to be managed
- Level of forming groups (hierarchy)

- Size
- Relationships between existing social structures like tribes, clans or castes
- Nature of leadership (political, traditional, etc.)
- Role of project staff
- Social variables affecting group formation (settlement patterns, social heterogeneity, social strata, seasonal migration patterns and history of cooperative efforts)

Principles of forming community organizations

- Evolve around experience needs
- Socially limited
- Start with a village with the highest chances of success
- Leadership should encourage participation
- Gradual progression
- Initially informally constituted
- Diversity of group forms
- Accountability and financial viability
- Need for support
- Skills in record keeping

Day Two

6. Tools: Ranking & Scoring 1

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Demonstrate the use of simple ranking
- 2. Demonstrate the use of pairwise ranking
- 3. Demonstrate the use of proportional piling
- 4. Explain the advantages and disadvantages of each technique

On a questionnaire we might ask how many cattle a man owns, or how many children a woman has. There is a high risk that the response we get will not be true, because if the respondent gave true information he or she would violate norms and traditions regarding giving others such information. The advantages of using ranking and scoring techniques include:

- They do not require actual numbers to be revealed, because the scores given are relative. Therefore, potentially sensitive questions such as, 'how many children live in this household?' are not necessary.
- Like other participatory epidemiology tools, the method does not require literacy on the part of the informants.
- Semi-quantitative data is collected that can be evaluated statistically. Comparisons can be made between different regions and different categories of informants.
- Data collected can be used to triangulate information from the semi-structured interview.

When using any type of scoring technique, you will be able to group and analyze the data at the end of your study. Therefore, it is important that your question is quite specific and consistent, so different respondents don't end up scoring different things.

Example	
What are the health problems here?	
Is less specific than	
What kinds of health problems have your children experienced?	
Is less specific than	
What kinds of health problems have your children experienced over the last y	ear?

The first question lacks specificity. The respondent can answer for the village, her family or herself. She can give you current health problems, recent issues, or issues that she worries about because her mother told her that in the past they frequently occurred. And each respondent can interpret these things differently, so in the end you will not be able to compare their answers. The second question lets the informant know that you are interested in childhood diseases in her home, but still lacks specificity concerning time period. The third question lets the informant know exactly what your units of evaluation are: childhood diseases, household level, past 12 months.

Sometimes certain health conditions are a stigma, for instance AIDS, and you know that respondents will not admit to them occurring in their family. Then you need to clearly decide on a unit of evaluation that will allow you to gather useful information, but will not make the respondent uncomfortable. Your units of evaluation can be: diseases, village level, past 12

months. Your question, "What kinds of health problems have the people in this village suffered from over the last year?"

Also remember that the question of 'importance' can be interpreted in different ways. You may ask the question, "Which kind of animal is most important for your family?" The father answers goats, but the son answers sheep. When you probe by asking each man why, the father says that goats are more important because they reproduce quickly and therefore provide the most food for the family. The son says that sheep are more important because they can be sold at a premium price at festival times, thereby providing the most income for the family. Now you cannot group the responses together, because the respondents understood the question differently, and actually answered different questions. Were you interested in the asset that generates the most income? Then you question should have been, "What kind of animal is most important to your family in terms of the amount of income it generates?" If you are interested in the asset that is most important to a family's livelihood, you might ask, "What kind of animal does the most to support your family?" Or, you might ask your respondent both questions. Then you will have two sets of data, one about important livestock for livelihoods, and important livestock for income. You can see if there is a difference in the two results. Also, because you probed by asking 'why', you will have a rich body of information about why some livestock are kept, even if they are not the most important economically!

Example

1. You have told me that the children in this village experienced three diseases over the past year, diarrhea, ringworm and the wasting disease. Which is the most important?

Is less specific than

2. You have told me that the children in this village experienced three diseases over the past year, diarrhea, ringworm and the wasting disease. Which is the one that affected the most children?

Or

3. You have told me that the children in this village experienced three diseases over the past year, diarrhea, ringworm and the wasting disease. Which is the one that causes a child to miss the most school?

Or

4. You have told me that the children in this village experienced three diseases over the past year, diarrhea, ringworm and the wasting disease. Which is the one that killed the most children?

Exercise

In the example above, the same question is asked in four different ways. Please answer the following:

Why is the first question less specific that questions 2-4?

From your experience, which disease do you anticipate a respondent will say is most important for the following questions, and why:

Question 2, affected the most children

Question 3, causes a child to miss the most school

Question 4, killed the most children

Which question will give you a measure of morbidity?

Which question will give you a measure of mortality?

Always remember to probe responses. By probing you will have semi-quantitative data that you can analyze statistically, and you will have a rich body of qualitative data that will provide you background information for each result. Please take a few minutes to think about why it is important to have the qualitative information. In the exercise above you were given an example of a village in which respondents said three childhood diseases occurred over the past year, diarrhea, ringworm and a wasting disease. You were asked to anticipate which disease would have the highest morbidity, mortality and impact in terms of missed school days. Now put yourself in the shoes of a decision-maker, and consider how you will act on this information.

Exercise

You have learned that in a village ringworm has the highest morbidity (it affects the most children), but that diarrhea has the highest mortality (more children die from diarrhea than any other disease in the village). A wasting disease is causing the children to miss the most days of school. Because of the alarming nature of your results, you call together a provincial committee to take action. In addition to you, the committee has members from the provincial offices of health and education, as well as local government. Please answer the following questions:

What further information will the committee ask for?
1)
2)
3)
4)
4)
What concrete actions can the committee take now, while it is waiting for the above
information?
information? 1)
1)
1) 2)
1)
1) 2) 3)
1) 2)

Now lets' move on and learn how to carry out ranking exercises in three different ways.

6.1. Simple ranking

In simple ranking the informants are requested to order a list of items based on a defined set of criteria. Simple ranking is a fast and easy tool that allows many people to participate. It is an easy way to make sure there is a consensus among the group being interviewed, and gives the investigator the opportunity to probe more deeply into the meaning behind the ranking. Ranking criteria could include prevalence, mortality, impact on the household, and many others.

Method

- Have your ranking criteria clear in your own mind. You may want to write them down in your notebook. For example: common childhood diseases, village, past 12 months; do two rankings for comparison, one on morbidity and one on mortality.
- To develop the list of items for ranking, begin with an open-ended question: For example,
 "What are some common disease problems that affected children under five years of age in your village in the last year?"
- 3. Probe the responses. Ask for descriptions of the diseases and clarify details. Can you diagnose each disease, or are some syndromes that you cannot further diagnose?
- 4. Explain that you want to carry out an exercise to better understand what you are learning about their common childhood health problems. Have pictures, symbols or objects to represent each disease, or write the name of each disease on a card. Place the cards on the ground where everyone can see them, and remind the participants what each card represents. Remember, not everyone will be able to read or understand each drawing, so be careful to clearly explain what each card represents. Some of your respondents will memorize the cards in this way.
- 5. Ask the group to rank the diseases based on your defined criteria. For example, 'Please show me which of these diseases affected the most children in your village in the last year by placing that card on top, and continue ranking them until the disease that affected the fewest children is on the bottom."

- 6. Give them time to discuss and rank the cards by consensus. Encourage them to make adjustments if they want to. When they appear to have finished, ask them if they all agree on the result.
- Leave the cards in place. Summarize and crosscheck their ranking. For example, 'You have put pneumonia first, followed by diarrheal diseases, then malnutrition, then HIV/AIDS. Is this correct?'
- 8. Probe the results. "Why did you put pneumonia first and HIV/AIDS last, and why is malnutrition above HIV/AIDS?"
- 9. Record the ranking question, the results, and notes of any discussion during the ranking and probing.

It might help to think of participatory epidemiology tools in terms of steps the first few times you try them.

Simple ranking is a quick way of gathering data to help the researcher understand issues from the respondents' point of view. It is usually best to conduct this exercise with small groups, although it can be done with individuals or quite large groups. Respondents should discuss the ranking and arrive at their decision by consensus. Listening to the discussion and probing the results of the ranking provides as much or more information than the final ranking.

Tip

It is really important that all participants understand the ranking criteria during the exercise. For instance, it is easy to confuse prevalence with impact when ranking diseases.

Example

Community members in an irrigated village of Mwea division, Kenya, were asked to rank health and social problems in order of importance to them and other stakeholders. They provided the following results:

Rank	Health & Social problems
1	Lack of clean water
2	Diseases (malaria, typhoid)
3	High cost of medical services
4	Inadequate water for farming
5	Low productivity for crops & livestock
6	Poor roads
7	Alcoholism
8	School drop outs
9	Domestic violence

From Mutero CM, Kabutha C, Kimani V, Kabuage L, Gitau G, Ssennyonga J, Githure J, Muthami L, Kaida A, Musyoka L, Kiarie E, Oganda M. 2004. A transdisciplinary perspective on the links between malaria and agroecosystems in Kenya. Acta Tropica, 89:171-186.

6.2. Pair-wise ranking

Pair-wise ranking is a slightly more complex method than simple ranking. Each item is compared individually with all the other items one-by-one. In pair-wise ranking, the interviewer compares two items from the list and asks the participants to name the most important. This is repeated for every possible combination in the list. This is approach is considered more reliable than simple ranking as it assists the participants to consider every possible relationship. It is especially useful if informants cannot reach a consensus using simple ranking or if they score

two items nearly the same when using proportional piling. After the respondents rank each pair, they are asked why they made the choice they did. The criteria they specify are called indicators.

Method

- Have your ranking criteria clear in your own mind. You may want to write them down in your notebook. For example: common childhood diseases, village, past 12 months, morbidity.
- 2. To develop the list of items for ranking, begin with an open-ended question: For example, "What are some common disease problems that affected children under five years of age in your village in the last year?"
- 3. Probe the responses. Ask for descriptions of the diseases and clarify details.
- 4. Explain that you want to carry out an exercise to better understand what you are learning about their childhood disease problems. Have pictures, symbols or objects to represent each disease, or write the name of each disease on a card. Place the cards on the ground where everyone can see them and remind the participants what each represents.
- 5. Select one disease card and a second one. Ask, 'Which disease did you see most often in the last year? HIV/AIDS or pneumonia?' Once they have chosen, crosscheck the answer and then probe, 'Do you all agree? Why do you think pneumonia is occurring more often than HIV/AIDS?'
- 6. Repeat the question comparing the same disease with each of the other diseases one-byone, crosschecking and probing each pair. Then select the second disease and compare it with all the remaining diseases one-by-one, and so on until all the diseases have been compared with all the other diseases.
- The result of each comparison is recorded as well as the details of any discussion generated by crosschecking and probing.
- Count the number of times each disease was selected. The disease that was selected the most times is ranked highest.

Pair-wise ranking of community concerns for their participation in an HIV microbicide trial, Mwanza, Tanzania.

	Blood collection for tests (B)	Range of services in clinic (ROS)	Travel allowance (TA)	Waiting times in clinic (WT)	Speculum exam (S)
Blood collection for tests (B)		В	В	В	В
Range of services in clinic (ROS)			ТА	ROS	S
Travel allowance (TA)				ТА	ТА
Waiting times in clinic (WT)					S
Speculum exam (S)					
	4	1	3	0	2

The most significant concern was blood collection for tests (score of 4), followed by travel allowances for the study (score of 3), speculum exam (score of 2), range of services in clinic (score of 1) and waiting times in the clinic (score of 0). Probing questions asked were: Why is blood collection the greatest concern? Why are waiting times least important? What aspects of travel allowance are of concern?

From Valley A, Shagi C, Kasindi S, Desmond N, Lees S, Chiduo B, Hayes R, Allen C, Ross D. 2007. The benefits of participatory methodologies to develop effective community dialogue in the context of microbicide trial feasibility study in Mwanza, Tanzania. BMC Public Health, 7:133.

	Exa	ample	
Pair-wise ranking to elucidate sir	nilarly ranked drivers of HIV/A	IDS transmission in Uganda.	
	Commercial sex workers (CSW)	Cross-generational sex (CGS)	Poor attitude towards prevention (Attitude)
Commercial sex workers (CSW)		CGS	Attitude
Cross-generational sex (CGS)			Attitude
Poor attitude towards prevention (Attitude)			
	0	1	2
The most significant driver to HI From AFENET and PENAPH, 20 25 March 2010.			towards prevention. epidemiology. Arua, Uganda, 15-

6.3. Proportional piling

Proportional piling is a tool that allows respondents to give relative scores to a number of different items or categories according to one criterion. The scoring is done by asking participants to divide 100 counters (beans, stones or similar items that are familiar to the community and locally available) into different piles that represent the categories. For example, the community could give scores to a set of disease problems (the categories) according to the impact the diseases have on their livelihood (the parameter). Alternately, the community could be asked to score the diseases according to how commonly they occur. Semi-quantitative data is collected by recording the number of counters in each category.

In veterinary participatory epidemiology, uses of proportional piling during a semi-structured interview include the demonstration of:

- Relative populations of livestock species in the village
- Relative quantities of feed types provided to a type of livestock
- Sources of farm inputs (day old chicks, calves, feed, medicines, etc.)
- Relative incidence of goat diseases in the village
- Relative impact of goat diseases on the livelihoods of farmers

In the human health field, proportional piling can be used to investigate different age groups of children, patterns of health service usage, health care resources, relative incidence of diseases, relative importance of health and nutrition problems, relative success of types of treatment, characteristics of health care providers, etc.

Method

- 1. Have your ranking criteria clear in your own mind.
- To develop the list of items or categories for scoring, begin with an open-ended question. For example, 'what are the health problems that affected the adults in the community in the last year?'

- 3. Probe the responses. Ask for descriptions and clarifications.
- 4. Explain that you want to carry out an exercise to better understand what you are learning about their health problems. Draw circles on the ground, one circle for each disease mentioned, and place a drawing or card next to each circle that illustrates the disease. Circles can also be made from construction paper or drawn on flipchart paper.
- 5. Make sure everyone recognizes each category by its drawing or card.
- 6. Place 100 counters in a pile, and ask the respondents to divide them according to a particular characteristic or parameter. Respondents should not count the counters, but divide them visually. Record the question now if you haven't already. For example, 'Please divide these beans to represent the impact each disease had on your livelihood in the past year'.
- 7. Allow time to discuss and divide the piles by consensus. When the group appears to be finished, summarize and crosscheck the result. "Does everyone agree? Does anyone disagree that tuberculosis has such a big impact?"
- 8. Count the counters, but leave them in place so that the result can be discussed.
- 9. Probe the results. Why did they make these choices? For example, 'HIV/AIDS ranks second with 20 beans and malaria third with 5 beans, but there is a big difference between 20 and 5. Why do you say that tuberculosis had such a greater impact on your livelihoods than malaria in the past year?'

It is usually best to conduct this exercise with small groups, although it can be used with larger groups or with individuals. The group should discuss the division of the counters and arrive at their decision by consensus. Listening to the discussion and probing the results of the piling provides as much or more information than the final score. This information tells you why the respondents gave the scores that they did and tells a lot about how they view the problems. Have your proportional piling question clear in your own mind and write it down in your notebook.

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Example

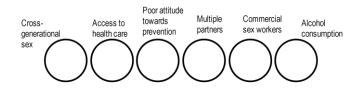
Proportional piling to demonstrate relative sources of household income or food during wet and dry seasons, Turkana, Kenya.

Activity	Dry Season	Wet Season Score	
receivity	Score		
Charcoal/wood selling	35	13	
Gifts from relatives	24	8	
Livestock products	18	30	
Fishing	16	15	
Wild fruits & berries	5	6	
Sorghum gardening	1	27	
Friends	0.5	0	
Purchased sorghum	0.5	1	
Total	100%	100%	

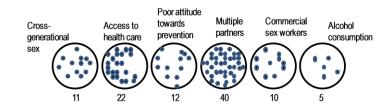
From Watson C. 1994. Proportional Piling in Turkana: a case study. RRA Notes, 20:131-132.

Example

A group of Ugandans were asked to list the major drivers for new HIV infections. They listed: cross-generational sex, lack of access to health care, poor attitude towards prevention, multiple partners, commercial sex workers and alcohol consumption. We drew six circles and label them with words representing the participants' responses.



The group was asked to distribute 100 counters relative to the degree that each parameter drives new HIV infections. The results are below.



Probing questions included:

- Why are multiple partners the biggest driver?
- Who is most affected by having a poor attitude towards prevention?
- Do all of the commercial sex workers practice safe sex?

From AFENET and PENAPH, 2010. Report of the introductory training course in participatory epidemiology. Arua, Uganda, 15-25 March 2010.

Tips

- For all ranking and scoring tools, make sure the *ranking criteria* are clear. Ranking fruits based on which is most preferred by children will be different from which fruits are more expensive. Similarly for diseases, if you ask, 'which disease is more common?' you are likely to get a different result than if you ask, 'which disease kills the most animals?'
- Make sure when you record the results of a ranking or scoring exercise in your report, you indicate what question you asked, namely the ranking criteria.

6.4. Analysis

The results of proportional piling exercises from different groups can be averaged to derive an *aggregate* score. You should pay close attention to the types of stakeholders or key informants who participate in the interviews. Often different stakeholders or key informant groups will provide very different scores and probing differences provide a lot of insight into the different perceptions and priorities of the groups.

Probing differences and calculating average scores for different segments of the community is known as analyzing the *disaggregated* results. For example, women often score diseases very differently from men because their needs and concerns differ from men.

More information about analyzing ranking data will be provided later in the training.

6.5. Practice

Are you ready to give it a try? During your training you will have sessions where you will practice these three ranking techniques. But why not try them out beforehand? Look for opportunities in your home, office or club. At home, can you use ranking techniques to find out what food you family thinks tastes the best? What food is most nutritious? What food is most economical? Has answering these three questions given you any new ideas about what meals you will prepare in the future? At the office, can you use ranking techniques to find out what

office improvements would most help the employees do their job better? But what improvements are most economical? In your club, can you use ranking techniques to find out what activities the members should support next year? Bring these results to the training to share with everyone!

7. Tools: Visualization Techniques 1

Session Learning Objectives

By the end of the session, participants will be able to:

- Demonstrate the use of participatory mapping, including geographical features and risk factors for disease
- Explain how visualization methods can help improve understanding and participation of all respondents during an interview

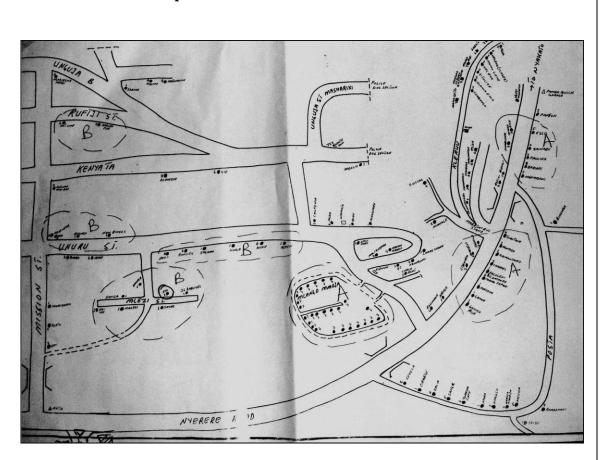
Visualization techniques demonstrate information that cannot be easily communicated orally. The information collected can be used to triangulate information from the semi-structured interview.

7.1. Participatory mapping

Participatory mapping is a technique for diagramming key physical resources, hazards, and land use patterns. It is one of the most useful tools of participatory epidemiology because sometimes it is easier to draw a map than to describe spatial relationships orally. Mapping can be used at the beginning of an interview to define the spatial boundary of the area under investigation. It can also be referenced through the rest of the interview whenever spatial issues arise. Once a map has been drawn it can be used to demonstrate the location of disease outbreaks, the spread of disease through an area over time and to show risk factors for disease occurrence or spread.

A simple map where informants identified neighborhoods around traditional bars and modern bars, guest-houses, groceries, hotels and restaurants to highlight differences in the demographic, sexual behavior characteristics and HIV and sexually transmitted disease risk profiles between women working in these different types of establishments.

Example



Credit: Shagi C, Vallely A, Kasindi S, Chiduo B, Desmond N, Soteli S, Kavit N, Vallely L, Lees S, Hayes R, Ross D; Microbicides Development Programme. 2008. A model for community representation and participation in HIV prevention trials among women who engage in transactional sex in Africa. AIDS Care, 20(9):1039-49.

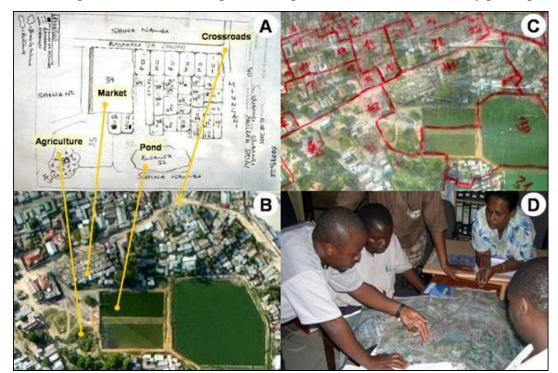
Key points to remember:

- Spatial information on human and animal population density, distribution, movements, interactions, diseases and disease vectors is extremely useful in epidemiology.
- Some information is easier to describe and analyze visually than in written form. It is easier to draw a map than describe a map in words.
- Mapping is useful at the beginning of an inquiry as an icebreaker to get many people involved right from the start.
- Maps produced on the ground using locally available materials are easy to adjust until informants are happy that the map is correct.
- Maps do not need written words or labels, and therefore non-literate people can participate.
- Possible uses include: mapping people (habitation density, human movements, health practitioners and specialists, traditional birth attendants, herbalists, sick individuals, social groupings, pregnant women, deaths and malnourished children), natural resources (land use, water sources, vector prone areas), facilities (clinics, health posts, medical shops, water supplies and chemists), hazards (mosquito breeding areas, toilet facilities, pollution, drains), social issues (trade and market movements, wellbeing status, asset ownership) and of course, physical features (main roads, habitation areas, waterways, meeting places, schools, community boundaries, infrastructure, disposal areas).

As with other activities, it is useful to prepare a mental or written checklist of items to be probed during the mapping exercise. Respondents should not only be asked to illustrate locations on the map, but to provide underlying reasons for movements and resource use. At the end of the interview, maps can be used to plan disease control activities.

Example

A mapping exercise to identify areas for malaria vector mosquito control through targeted larval source management in Dar es Salaam, Tanzania. The sketch map is linked to areal maps, with important boundaries defined by participants.



Credit: Dongus S, Nyika D, Kannady K, Mtasiwa D, Mshinda H, fillinger U, Drescher AW, Tanner M, Castro MC, Killeen GF. 2007. Participatory mapping of target areas to enable operational larval source management to suppress malaria vector mosquitoes in Dar es Salaam, Tanzania. International Journal of Health Geography, 6:37.

Method

- 1. Request the informants to draw geographic and physical features of their village or area on a map: the place of the meeting, main roads, rivers, lakes, important public places, health posts and clinics, fields, bore holes, etc.
- Make sure that features important to your study are included: health clinics, immunization centers, maternal-child services, family planning services, mode of delivery (no cost or need to pay), approximate distance, etc.
- 3. Once the map is completed, or while participants are drawing the map, ask probing questions, such as, 'what services are available to perinatal women? How far do they need to travel to the center? Are referral centers available for complicated pregnancies? Where did an outbreak of neonatal diarrhea occur?'
- 4. To finalize the map, find out which direction is north and mark it on the map. Also try to obtain an idea of scale by asking the distance between two key points, and then add an approximate scale. If symbols are used to represent features, add a key to the map.
- 5. Copy the map into a notebook or take a photograph of the map.

Tips

- Depending on the location of the meeting and the type of participants, the map may be drawn on the ground and features represented by objects such as stones or sticks, or it can be drawn on flip chart paper with colored markers. It is important that the map is large so that everyone can see it and contribute to its development.
- Maps can be drawn on different scales depending on the objective of the study being carried out. The map could be of a health center and its surrounding area, a village and its surrounding area, a district or even a country.
- The map can be drawn either interactively (with suggestions and probing questions from the investigator) or the informants can be left alone to draw the map and then asked to explain the map to investigator.
- A blank sheet of paper can be intimidating. If the participants have trouble getting going, start by adding a feature that the informants have mentioned and then ask where another feature is located relative to the first. Ask them to draw or place this feature on the map themselves.

- Some informants may not know the directions (north, south, east, west). You may ask them in which direction the sun rises and mark this on the map.
- If the informants cannot estimate approximate distances (in kilometers), ask them how long it takes to walk from one location to another and mark this on the map.
- The informants may appreciate if you leave a copy of the map behind for them to reference. This is a way of giving back to the community. Be sure that the results are adequately documented.

Please take a few minutes to think about a disease that recently occurred in your neighborhood, or in a village that you worked in. What aspects of that outbreak could have been mapped, particularly disease determinants, to help you better understand the pattern of the outbreak? A *disease determinant* is a variable, such an environmental factor, that influences the pattern of that disease or outbreak.

Exercise

Think of a disease outbreak that recently occurred in your neighborhood, or in a village that you worked in. It could be a flu outbreak in your children's school, an outbreak of Newcastle's disease in chickens in your neighborhood, or an increase in the prevalence of neurocysticercosis in a village where you are working. List all of the disease determinants that you can think of that are associated with the outbreak.

Disease determinants (example, flu outbreak started in the first grade classroom):

1)

2)

3)
4)
5)
6)
7)

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Exercise (continued):

Now draw a map of that outbreak, showing as many of the disease determinants as you can. When you are finished, review the map. How has visualization of the outbreak helped you to understand the pattern of the outbreak?

Map:

New learning about the outbreak pattern:

7.2. Risk factor mapping

A risk map is an image that shows the spatial distribution of disease risk. The principle behind risk maps is that the spatial distribution of a risk factor will influence the spatial distribution of disease risk. If different risk factors exist for a given disease, and they have different degrees of association between the risk factors and the disease, it becomes difficult to estimate the likely spatial distribution of the risk of disease. One option then is to overlay and combine the spatial distribution of multiple risk factors, in order to obtain a combined indication of disease risk. This is the approach used for creating risk maps. These days risk maps are often generated using geographic information software so that epidemiologists can identify areas that may be at high risk for a disease. However, risk factors for disease can be mapped without needing sophisticated equipment.

Disease risk is the probability of occurrence of new cases. *Risk of introduction* is the probability of occurrence of new cases in a population or area previously unaffected. *Risk of spread* is the probability of occurrence of new cases following an initial case in the population or area. Disease risk is influence by risk factors. Often we can identify different factors associated with introduction versus spread.

A *risk factor* is something likely to increase the chances that a particular event will occur. For example, smoking is a strong risk factor for lung cancer, and use of mobile phone while driving is a risk factor for accidents. The presence of *Anopheles* mosquitoes is a risk factor for malaria, because mosquitoes are vectors for malaria and transmission of the disease from human to human occurs by the bite of infected mosquito.

Method

Imagine, for example, you are conducting a study on highly pathogenic avian influenza (HPAI) in poultry, and you are interested in identifying risk factors for the introduction of HPAI to village poultry populations, risk factors for HPAI spread between different poultry populations, and risk factors for human exposure to HPAI. You have traveled to a village that recently

experienced an outbreak of HPAI in its poultry to study the outbreak and identify these risk factors.

- 1. Begin by creating a participatory map with the villagers, making sure that all the geographic and physical features are included.
- 2. Discuss with the villagers what animal diseases are important to them. Since they recently had an outbreak of HPAI in their poultry, they will likely mention HPAI, and then you can focus on your disease of interest from that point forward.
- 3. Work through the various disease determinants that you are familiar with. You might have them listed, or you might use a mental checklist. To name a few: first household affected, second household affected, spread of the disease through the village, types of poultry affected, nearest poultry market, homes of poultry traders, movement patterns of poultry traders on bicycles or motorcycles, location of commercial poultry farmers, movement patterns of suppliers (feed, litter, chicks, etc.) and buyers (eggs, manure, finished birds, etc.) for commercial operations, location of butchers, houses that own fighting cocks, location of rivers and gardens, which houses have poultry houses, where free range birds like to gather, etc.
- 4. Ask probing questions as details develop on the map. For example, once the first affected house is mapped, and the poultry market, you can ask: When was the last time people in this house visited the poultry market? Did they bring back any new birds and put them their flock?
- 5. Be sure to observe closely. When the path of the poultry trader is drawn, and the path of the outbreak spread, look to see if they are similar. If the are, ask questions to probe your suspicion. For example: When did the outbreak start? When did the poultry trader last pass?
- Through this process you are running through the risk factors that you are familiar with, but keeping your mind open to discovering new risk factors as the map and the discussion develops.
- 7. Remember that there may be sensitivities about an outbreak. Be careful not to create an atmosphere of recrimination, where some people begin blaming others for their disease problems. For example, the informants may want to hold the person in the first affected household responsible if they begin to feel that he is responsible for the outbreak. Make

sure the atmosphere of the interview is one of open discovery, so that what is learned can be used by both you and the members of the villagers to prevent outbreaks in the future, not to exact retribution for outbreaks in the past.

8. When the exercise is complete, discuss with the villagers what they have learned, and how this may help them prevent outbreaks in the future.

Risk factor maps can provide information for the development of risk maps. They can be used to facilitate the rational implementation of disease surveillance and control activities. It makes sense to focus surveillance and control efforts on places where an outbreak is most likely to occur. Health services often have scarce resources for surveillance and control activities, and are thus unable to check for disease everywhere at all times. Used critically, and in conjunction with other tools (such as risk assessment), risk maps can help policy makers target areas for strengthened surveillance or control activities.

Please take a few minutes to return to your outbreak map in the previous exercise. Can you think of any determinants of disease that you did not include? If so, go ahead and include them now. Does your map help you identify any risk factors for how the disease was introduced, or how it spread? For example, if your map is of a flu outbreak in your children's school, can you determine from you map where the outbreak started? Do you know why it started there? Can you see how the outbreak spread? Can you identify any risk factors associated with this spread?

8. Communicable Diseases of Adults

Session Learning Objectives

By the end of the session, participants will be able to:

1. Discuss and advise others on common and important communicable diseases of adults

It is important that you have a reasonable understanding of communicable diseases, and are conversant to the degree that you can comfortably and accurately address the concerns of stakeholders when they arise during your work. If you are a physician, this may not be challenging. But if you are veterinarian or wildlife ecologist, it may be very intimidating indeed!

Please take a minute to think about human communicable diseases in the area where you work. Can you list them, their disease determinants, and prevention and control measures?

Exercise

Please think about the four or five most common communicable diseases that adults suffer from in the area where you work. In the table below list them across the top. Then write into each cell what you know about the different determinants for each disease. Are you missing information? Where can you go to learn more? What organization is working on that disease problem in the community?

ium os veating, romiting,		
os veating,		
veating,		
-		
omiting,		
e, etc.		
fever,		
sing,		
uine,		
g, etc.		
o netting		

Please make a note to familiarize yourself with government policy regarding specific diseases, such as HIV/AIDS treatment or access to mosquito nets. Also familiarize yourself with the public and non-governmental initiatives for disease prevention and control that are being implemented in the area where you work. Questions regarding resources and policy often come up during interviews in communities that have public health problems. Make sure to discuss your work with public health resource persons in your area, and have their contact information on file, so that if you cannot address the questions of community members you can put them in contact with resource persons who can. Colleagues in your training program will likely be able to point you in the right direction, or even be the resource people you need!

9. Behavior Change Communication

Session Learning Objectives

By the end of the session, the participants should:

- 1. Describe the principles of behavior change communication
- 2. Identify barriers to and facilitators of behavior change
- Incorporate behavior change communication into their practice of participatory epidemiology

Sometimes it is not in the scope of our activities to target behavior change, and we simply provide information. However, our impact is lasting when we target changing the behaviors that lead to a disease or problem. Behavior change communication is about facilitating change, assisting people to identify determinants of their behavior (e.g. why people smoke) and strategies to adopt more healthy behaviors (e.g. quitting smoking).

For example, for Guinea worm disease eradication, we could inform people to filter all their drinking water, and even demonstrate how to filter water. A behavior change communication approach would engage the community in identifying why people don't filter their drinking water, as well as how the community could act to ensure everyone always filters their water.

Providing education and information about how to prevent diseases is important. However, where people already have the information and the disease still occurs, giving more information will not prevent more infections. This is where facilitation is required to change the behaviors that lead to disease. In the case of Guinea worm, behaviors which help disease transmission are not filtering water, not reporting cases, not keeping affected people out of water sources and not cleaning home water containers. If communities already know that by doing these things they

could prevent the disease, but they do not consistently do them, then facilitation is required to help communities and individuals identify the best methods to approach behavior change.

Behavior change communication can be difficult. It is easier to simply give information tan to facilitate a change process. What do BCC educators do in projects?

- Listen rather than give advice
- Encourage people to seek correct information
- Connect people to services and treatment
- Help people think about future situations
- Help people develop new skills
- Help people prioritize problems

Humans are complicated creatures. Getting us to change what we do is even more complicated. Changing behavior means changing how people think, speak, act and use resources. Change can occur at personal, social and environmental levels. The behaviors on the personal level are the ones with the most individual control. Again using the Guinea worm example, if a community believes God causes the disease rather than contaminated water, it is very unlikely that any one member of the community will be able to change his/her beliefs and behaviors in the context of the more widely held community belief.

9.1. Behavior models & theory

While there are multiple theories about behaviors that affect how we act, a few noteworthy models are outlined briefly below.

• **Health Belief Model**: Health-related behavior change is based on the perceived severity of the threat to health.

- Theory of Reasoned Action: Individuals consider a behavior's consequences before performing that particular behavior. Specifically, an individual's personal attitude and social pressures shape intention, which determines behavior and behavior change.
- **Theory Planned Behavior Model**: An extension of the Theory of Reasoned Action model, this theory includes the element of perceived behavioral control. As intention does not always lead to actual behavior, this theory realizes that volitional behaviors predict behavioral intention, with intention leading to whether or not an individual performs a given behavior.
- Learning Theories and Behavior Analytic Theories of Change: Individuals learn by duplicating behaviors observed in others, and rewards are necessary to ensure repetition of desirable behavior. While simple behaviors are established through imitation and reinforcement, complex behaviors are learned through the modification of simpler behaviors.
- Social Learning and Social Cognitive Theory: Behavioral change is determined by reciprocal interactions between environmental, personal, and behavioral factors.
- **Transtheoretical** and **Stages of Change Theory**: Change occurs through a process of stages. An individual's readiness to act on a new behavior is determined by the stage they are in when they hear a particular message. The stages of behavior change are: precontemplation, contemplation, preparation, action, maintenance and termination.
- **Perception of Divine Will**: The perception that all aspects of life are determined by Divine will (e.g. God's will).

The factor most predictive of the effort an individual will expend in initiating and maintaining a new behavior is *self-efficacy*, an individual's impression of their own ability to perform a task. Self-efficacy is shaped by previous success in performing the task, the individual's psychological state as well as external sources of influence.

Comparing those who do a behavior (*doers*) to those who do not do the behavior (*non-doers*) is one method of identifying the most important determinants on which to focus interventions. This

method helps identify specific barriers and facilitators for particular behaviors. Understanding the reasons why doers do a behavior can assist non-doers in modifying their own.

9.2. Behavioral determinants

A behavioral determinant is a reason why someone does or does not do something. They can be classified as either:

- Barriers: things that prevent a behavior
- *Facilitators:* things that promote a behavior

There are barriers and facilitators at personal, social and environmental levels. At the personal level, barriers and facilitators are affected by attitudes, beliefs, knowledge and perceptions. Three important elements that affect personal barriers and facilitators are:

- *Confidence* (self-efficacy): the belief in one's ability to perform a certain activity
 - Confident: "I know that if I put my mind to it, I can filter my water without exceptions"
 - Not Confident: "I will probably make mistakes while filtering my water"
- *Outcome Expectation:* Belief about what will happen if you adopt a certain behavior
 - Positive outcome expectation: "If I filter my water, my children won't get sick"
 - Negative outcome expectation: "The kids will still play in ponds and drink contaminated water, so why bother?"
- *Risk Perception:* An individual's belief that their behavior is unhealthy and will cause them problems
 - If one perceives risk: "letting infected people into the community water source could make ME sick!"
 - If one does not perceive risk: "letting infected people into the community water source is not my problem"

In designing behavior change communication projects, important factors to consider are:

- If a person knows what they should do, it does not mean they will do it
- If a person wants to perform a behavior, it does not mean they will do it
- The barrier to adopting a new behavior can be too little fear or it can be too much fear
- Many actions people do that improve health are not necessarily done for that reason
- Doers and non-doers may have similar reasons but different behaviors
- Assisting behavior change may require creative solutions
- Behavior change is a process, and relaxing expectations may be necessary to allow the behavior to improve in steps

Behavior change communication educators point people towards facilitators and show how barriers can be overcome.

9.3. Barrier analysis

This rapid assessment tool is used in community projects to identify behavioral determinants associated with a particular behavior, in order to develop more effective communication messages and support activities. Barrier analysis helps to identify determinants that block people from taking actions, and positive attributes of behavior in order for individuals to improve their lives. The framework⁵ consists of exploring and working with various behavioral determinants.

⁵ The framework here is adapted from Barrier Analysis, Food for the Hungry, accessed April 2010, http://barrieranalysis.fhi.net/background/background_info.htm

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Determinant	Question	Explanation	
Perceived	Can I get the disease? Could	Whether a person believes the problem	
susceptibility	that problem happen to me?	can happen to them	
Perceived	Is the disease very serious? Will	Whether the person believes a problem is	
severity	it kill me?	very serious	
Perceived action	Does the preventive action work?	Whether the person believes the	
efficacy		prevention action really prevents the	
cificacy	WOIK.	disease	
Perceived social	Is the preventive action socially	Whether the person believes the action is	
acceptability	acceptable?	acceptable to their community, family or	
acceptability		others important to them	
Perceived self-		Whether a person thinks the preventive	
efficacy	Can I do it? Is it easy to do?	action is easy for them to do (in terms of	
		skills, access, time and money)	
		Whether a person can remember to do	
Cues for action	Can I remember to do it?	the preventive action and can remember	
		the steps involved in doing the action	
Perception of	Is it God's will that I get sick?	Whether the person believes that it is	
divine will	Get healthy? Have the problem?	God's will that they have or that they	
	Overcome the problem?	overcome the problem	
Negative &	What is negative about the		
Positive	preventive action? What is	Characteristics of the preventive action	
attributes	positive about the preventive	which are negative and positive	
attibutes	action?		

Table: Barrier analysis framework

Day Three

10. Field Practice 1

It is now time for you to get out into the field and practiced what you have learned! The objective of your practice study is to determine the main communicable diseases that affect a community. During this first field practice you will be broken into teams of 3-4 people, with each team interviewing different groups of community members. There are three phases to fieldwork.

10.1. Preparation

Before you go to the field you need to make sure you are well prepared.

- Study objective: discuss the objective of the study in your team, and make sure you have a common understanding.
- Hypothesis: what is the hypothesis for you study? For example, it might be 'there are several communicable diseases that are common in this village, including HIV/AIDS'.
- Secondary sources of information: what sources of information would you like to consult before you start your fieldwork? These may include the World Wide Web, government records, laboratory results, published papers, ethnographic texts, health texts, etc.
- Checklist: develop a checklist for your study. Discuss it to make sure each member of the team has a common understanding of what information is to be gathered with each topic, the criterion for each topic, and what tools will be used for each. So far you have learned about semi-structured interviews, ranking and mapping.
- Team roles: determine what role each team member will play to start with, and when you will change roles. Come to agreement on how the interviewer and analyst will work together.

- Materials: do you have everything you need? Counters, markers, flip chart, notebooks, pens, copies of the checklist, materials to collect biological samples, personal protective equipment, etc.
- Community: what is the proper way to prepare the community for your visit? Does someone need to visit the community before the day of the study to arrange time, place and respondents? Who in the community needs to be notified? Do you need an official letter? When you arrive can you go straight into interviews, or do you need to make an official visit first?
- Key informants: Does you study include speaking with key informants? List who you would like to include. Do you need to notify them beforehand?
- Transport: Has a vehicle been arranged?

10.2. Field

While you are in the field don't hesitate to take a few minutes after each interview to communicate as a team. What did you cover on the checklist? What has not been covered? Have you gotten all the notes in the notebook? What was confusing and needs further clarification? Was bias introduced, and what can you do to correct it? Are the questions you planned to ask and tools you planned to use working, or do you need to modify your plan? Has something new and interesting cropped up that you would like to follow? Review your hypothesis, does it remain the same or would you like to modify it? What are the new team roles for the next interview?

10.3. Review

When you return from the field go through a routine review.

• Team debrief: What went well? What did not go well? What should we do in the future?

- Community: what was the comportment of the respondents during your fieldwork? Did their comportment change over time, or between interviews? Discuss: body language, posture, eye contact, talking time, active listening, attitude, language and phrasing of questions, seating/standing arrangements, fatigue, comfort/sensitivity, mood, judgments/impartiality, professionalism, dress code. Overall, how do you feel as facilitators after your first practice day?
- Notes: Review the notes to make sure they are accurate and complete. Make sure observations are also recorded in the notes: types of questions asked, when biased was introduced, the comportment of the respondents, etc.
- Hypothesis: review your hypothesis and determine if you would like to modify it.
- Planning: based on what you have learned, do you want to stick to your fieldwork plan, or do you want to change your plan for the remainder of the study?
- Analysis and reporting: analyze your data and be prepared to report to the rest of the training group on the following:
 - Team member roles
 - o Duration
 - Village name
 - Location (GPS & qualitative description)
 - Number of respondents $(\bigcirc \& \Diamond)$
 - Checklist
 - Tools used for what information
 - Existing knowledge
 - Local terms & meanings
 - Health seeking behavior & strategies (Px/Rx)
 - Advice discussed
 - Community level of participation
 - o Translator's role

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11. Tools: Visualization 2

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Explain the importance of direct observation in a participatory epidemiology study
- 2. Demonstrate the use of transect walks
- 3. Explain the purpose of conducting clinical and post-mortem exams and the etiquette of handling privately owned animals as a researcher

11.1. Transect walks

After years of neglect, there is a new trend in medical and veterinary schools – teaching the art of the physical exam! As new and better tests have become available, physicians and veterinarians are becoming more and more dependent on test results, and tend to pay less attention to taking a complete patient history and doing a through physical exam. Educators of health professionals have realized that the ability to speak to patients or their caretakers and carry out a physical exam is not inherent, and students must develop their skills in observing and examining their patients. Developing one's skills of direct observation takes practice, including the direct observation tools used in participatory epidemiology.

A transect walk is a tool that involves direct observation, informal interviewing, visualization of the location and observing distribution and accessibility of resources to gain a better understanding of a given cross-section of a village or area. It is useful for:

• Identifying and explaining the cause and effect relationships among topography, natural vegetation, human habitation and living conditions, and other human settlement patterns and production activities

- Identifying the relationship between human health problems and the environment
- Identifying major problems and the perceptions of different groups of participants in relation to features or areas along the transect
- Learning about local technology and practices
- Understanding certain behaviors
- Identifying the distribution and accessibility of resources, features, landscape and land use
- Triangulating data collected through an interview and other tools such as mapping
- Probing the information that has already been mentioned by the community. A transect walk is a tool for describing and showing the location and distribution of resources, features, landscape and main land uses along a given transect.
- Finding members of the community whose voices have not yet been captured in the study, and identifying other sources of bias

A transect refers to the process of obtaining a representative cross-section using a straight line (or as straight as possible) which cuts across the area of interest. The transect walk should not coincide with the main road, but should start on one side of the area, crossing the main road and continuing to the other side. In the case of a village, the transect should begin at the limit of the village land and continue straight forward, only deviating from the path when a physical obstruction (or cultural taboo) prevents direct passage to the opposite side. The idea is to directly observe community life in the side streets, backyards and a forgotten corner or two. The appraisal team should be accompanied by community members and should stop and ask questions of residents as the need arises. Residents to accompany the team on a transect walk should be selected based on their standing in the community, knowledge of local resources, and availability. If possible, both men and women should accompany the team to ensure gender sensitivity and balance.

However, in participatory epidemiology we can also use the term 'transect walk' loosely. We can conduct a transect walk in a straight line through a village or area of interest. Or we may decide we want to probe a certain issue deeply, like water sources. So we choose to visit each

water source in the village, making observations as we move towards and away from each point of interest.

Transect walks have been referred to as 'walking surveys' and 'mobile interviews'. Transects can be time consuming, but a lot of information is missed by field teams who drive into an area and drive out after an interview or questionnaire is administered. A wealth of information is available to a relaxed observer who takes the time to look around, allowing for a deeper understanding of the data gathered using other participatory epidemiology tools.

The following are regarded as some of the strengths of transect walks:

- Community members are able to demonstrate their knowledge of the local environment
- The investigator can corroborate informants' responses to questions
- The researcher becomes familiar with the community members, which may prompt them to be more open about the problems they face. You may even find yourself sitting down for another interview during or after the transect walk!
- Direct observation by the researcher allows for a clearer understanding of these problems

The following are regarded as some of the weaknesses of this tool:

- The presence of strangers in the community may bias normal activity
- Accompanying villagers may guide the researchers to see 'highlights' of the community that do not represent the community as a whole
- Expectations may be raised among the residents of the community without an opportunity to clearly explain the purpose of the visit
- Some areas being studied may have poor security and be unsafe for the research team
- Conducting an interview while walking and looking around may cause delays in note taking and loss of data

Exercise

Please think about the village you visited today to practice your new skills in participatory epidemiology. The objective for your visit was to determine the main communicable diseases that affect the community. Imagine that during your first interview in the village you learned that the main diseases or syndromes were HIV/AIDS, malaria, diarrhea, upper respiratory diseases and epilepsy. Now consider the newest tool in your participatory epidemiology toolkit – transect walks! For each disease, how would a transect walk help you understand the disease determinants and risk factors associated with each disease or syndrome? What other information could this direct observation of the village on a transect walk provide you?

HIV/AIDS:

Malaria:

Diarrhea:

Upper respiratory diseases:

Epilepsy:

Other information:

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Method

- 1. Determine the objective for your transect walk. Was there information in the interview about the environment and village resources that you would like to see first hand? Are there confusing issues that you would like to clarify with community members as you meet them on your transect walk? Do you want to see if there are voices or opinions that were not expressed in your interview? Did the community mention something interesting, like a river where the carcasses of poultry who die suddenly are being tossed?
- 2. Find a community member to accompany you on the transect walk. Make sure this is the right person. For example, if you want to meet women during your walk and your guide is a man, will the women feel comfortable? Explain to your guide the objective of your walk.
- 3. During the transect walk, directly observe and note community life and physical features of the area.
- 4. Informally interview your guide as you walk. Questions can be prompted by what is seen on the way.
- 5. If you come across community members on the way, you can stop and conduct short informal interviews as appropriate.
- 6. From the transect walk notes, you can construct a diagram of the cross-section showing land use, etc., and triangulate this with maps already prepared.

Example

Human-animal interactions in Tanzania

Community members said during the interview that they do not share housing with their animals. However, during a transect walk, no animal enclosures or huts were observed. As the only shelters were for human habitation, it became evident that animals and humans must share the same dwellings at night. This helped the research team understand housing patters, but it also helped them understand that the sharing of housing was a sensitive issue in this community, and the reasons behind both the lack of animal housing and the community sensitivity would need to be understood if behavior change communication about zoonotic diseases would be effective.

Example

Latrine use in refugee camps, eastern Chad

In the early days of a refugee crisis in eastern Chad it was not possible to implement the good standard of sanitation of one latrine for every 20 people, because of the rapid influx of refugees. As the conflict continued, latrine building became a priority until the standard was achieved. However, on a transect walk it was observed that only a small number of latrines were being used while the rest showed little sign of use. Questions to a camp resident clarified that the new latrines were incorrectly placed, causing one's back to face Mecca. As a consequence, everyone avoided those latrines even if it meant sharing the other ones with as many as 50 people!

Tips

• Transect walks may be done at the beginning of an interview to provide a basis for probing responses and inspiration on how to use other participatory epidemiology tools

during the interview. Transect walks may be more useful at the end of an interview, however, so that respondents can demonstrate some of the topics that were raised during the interview.

- There may be situations when a complete transect is not possible, such as inclement weather, or there is too large of an area to be covered. In these scenarios, it may be helpful to conduct purposive walks to key sites recommended by informants. Conducting a 'transect drive' may also be appropriate in these scenarios.
- Explaining the purpose and objective of the transect walk is a very important first step before the activity begins. Informants must clearly understand that everyday sites and activities are of interest, and that main roads are fine but it is also desirable to observe hidden areas of the community that demonstrate daily life.
- Do not follow the main road through a village.
- It is equally important to note that a transect walk provides a snapshot in time. To get a better idea of what goes on in a village, it is best to stay and camp or live in the village for several days. This will provide a more in depth understanding of routine activities, both during the day and night.

Example

Accompanied by a community representative, a transect walk was undertaken through the Itereleng informal settlement. The purpose of the transect walk was to determine the vulnerabilities of the community.

The walk started at the entrance to the informal settlement commencing down the second road until the end of the settlement, then up along the outskirts until the last road was reached. Finally the return walk commenced by going back across through the settlement, detouring among some of the houses and back down to the entrance.

A steady flow of residents walked alongside explaining some of the hardships they encounter, providing an indication of what community life entails.

Certain hardships and health dangers were obvious. These included a lack of working taps, pit latrines rather than proper sanitation and locked cubicles on several of the temporary toilets. The settlement was also built on a steep incline: when flooding occurred, water would surge through the settlement with great force and speed.

The residents communicated that the greatest risk to the community was fire. Large areas of dry grass surrounded the settlement and fire hydrants and hoses were absent. Residents also identified that the roads were in poor condition and rescue vehicles could not access the community easily. In the far south corner of the settlement, the dwellings were not partitioned by roads but were nearly on top of each other. If a fire did break out in this area, it would spread quickly to surrounding dwellings and make escape and rescue difficult.

From Van Staden, D., Rogers, E., Makaudi, I., Winkler, J., White, J., Kangale, M., Rudman, N., Nkosi, S., Dreyer, T.R. and Coetzer, T. 2006. A transect walk undertaken in Itereleng informal settlement to observe community vulnerability. Pretoria: City of Tshwane Metropolitan Municipality Disaster Risk Management Centre. Unpublished report.

Day Four

12. Global Positioning System (GPS) Tutorial Guide

Developed by Research Methods Group (RMG), International Livestock Research Institute (ILRI) Nairobi, Kenya, October 2009

12.1. What is GPS?

The Global Positioning System (GPS) is a location system based on a constellation of about 24 satellites orbiting the earth at altitudes of approximately 11,000 miles. GPS was developed by the United States Department of Defense (DOD), for its tremendous application as a military locating utility. However, over the past several years, GPS has proven to be a useful tool in non-military mapping applications as well.

GPS satellites are orbited high enough to avoid the problems associated with land based systems, yet can provide accurate positioning 24 hours a day, anywhere in the world. Uncorrected positions determined from GPS satellite signals produce accuracies in the range of 2 to 10 meters. When using a technique called differential correction, users can get positions accurate to within millimeters.

As GPS units are becoming smaller and less expensive, there are an expanding number of applications for GPS. In transportation applications, GPS assists pilots and drivers in pinpointing their locations and avoiding collisions. Farmers can use GPS to guide equipment and control accurate distribution of fertilizers and other chemicals.

Recreationally, GPS is used for providing accurate locations and as a navigation tool for hikers, hunters and boaters. Many would argue that GPS has found its greatest utility in the field of Geographic Information Systems (GIS). With some consideration for error, GPS can provide any point on earth with a unique address (its precise location). A GIS is basically a descriptive database of the earth (or a specific part of the earth). GPS tells you that you are at point X,Y,Z while GIS tells you that X,Y,Z is an oak tree, or a spot in a stream with a pH level of 5.4. GPS tells us the "where". GIS tells us the "what". GPS/GIS is therefore reshaping the way we locate, organize, analyze and map our resources.

12.2. How GPS Determines a Location

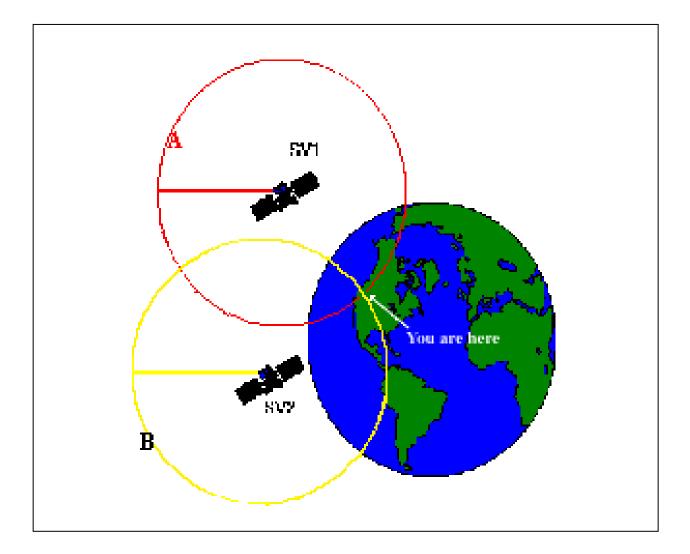
GPS is based on satellite ranging - calculating the distances between the receiver and the position of 3 or more satellites (4 or more if elevation is desired) and then applying some good old mathematics. Assuming the positions of the satellites are known, the location of the receiver can be calculated by determining the distance from each of the satellites to the receiver. GPS takes these 3 or more known references and measured distances and "triangulates" an additional position.

As an example, assume that I have asked you to find me at a stationary position based upon a few clues that I am willing to give you. First, I tell you that I am exactly 10 miles away from your house. You would know I am somewhere on the perimeter of a sphere that has an origin as your house and a radius of 10km. With this information alone, you would have a difficult time to find me since there are an infinite number of locations on the perimeter of that sphere.

Second, I tell you that I am also exactly 12km away from the ABC Grocery Store. Now you can define a second sphere with its origin at the store and a radius of 12km. You know that I am located somewhere in the space where the perimeters of these two spheres intersect - but there are still many possibilities to define my location.

Adding additional spheres will further reduce the number of possible locations. In fact, a third origin and distance (I tell you am 8km away from the City Clock) narrows my position down to just 2 points. By adding one more sphere, you can pinpoint my exact location. Actually, the 4th sphere may not be necessary. One of the possibilities may not make sense, and therefore can be eliminated.

For example, if you know I am above sea level, you can reject a point that has negative elevation. Mathematics and computers allow us to determine the correct point with only 3 satellites.



Based on this example, you can see that you need to know the following information in order to compute your position:

- A) What is the precise location of three or more known points (GPS satellites)?
- B) What is the distance between the known points and the position of the GPS receiver?

12.3. How the Current Locations of GPS Satellites are Determined

GPS satellites are orbiting the Earth at an altitude of 11,000 miles. The DOD can predict the paths of the satellites vs. time with great accuracy. Furthermore, the satellites can be periodically adjusted by huge land-based radar systems. Therefore, the orbits, and thus the locations of the satellites, are known in advance. Today's GPS receivers store this orbit information for all of the GPS satellites in what is known as an **almanac**. Think of the almanac as a "bus schedule" advising you of where each satellite will be at a particular time. Each GPS satellite continually broadcasts the almanac. Your GPS receiver will automatically collect this information and store it for future reference.

The Department of Defense constantly monitors the orbit of the satellites looking for deviations from predicted values. Any deviations (caused by natural atmospheric phenomenon such as gravity), are known as **ephemeris** errors. When ephemeris errors are determined to exist for a satellite, the errors are sent back up to that satellite, which in turn broadcasts the errors as part of the standard message, supplying this information to the GPS receivers.

By using the information from the almanac in conjunction with the ephemeris error data, the position of a GPS satellite can be very precisely determined for a given time.

12.4. Computing the Distance between Your Position and the GPS Satellites

GPS determines distance between a GPS satellite and a GPS receiver by measuring the amount of time it takes a radio signal (the GPS signal) to travel from the satellite to the receiver. Radio waves travel at the speed of light, which is about 186,000 miles per second. So, if the amount of time it takes for the signal to travel from the satellite to the receiver is known, the distance from the satellite to the receiver (distance = speed x time) can be determined. If the exact time when the signal was transmitted and the exact time when it was received are known, the signal's travel time can be determined.

In order to do this, the satellites and the receivers use very accurate clocks that are synchronized so that they generate the same code at exactly the same time. The code received from the satellite can be compared with the code generated by the receiver. By comparing the codes, the time difference between when the satellite generated the code and when the receiver generated the code can be determined. This interval is the travel time of the code. Multiplying this travel time, in seconds, by 186,000 miles per second gives the distance from the receiver position to the satellite in miles.

12.5. Four (4) Satellites to give a 3D position

In the previous example, you saw that it took only 3 measurements to "triangulate" a 3D position. However, GPS needs a 4th satellite to provide a 3D position. Why??

Three measurements can be used to locate a point, assuming the GPS receiver and satellite clocks are precisely and continually synchronized, thereby allowing the distance calculations to be accurately determined. Unfortunately, it is impossible to synchronize these two clocks, since the clocks in GPS receivers are not as accurate as the very precise and expensive atomic clocks in the satellites. The GPS signals travel from the satellite to the receiver very fast, so if the two clocks are off by only a small fraction, the determined position data may be considerably distorted.

The atomic clocks aboard the satellites maintain their time to a very high degree of accuracy. However, there will always be a slight variation in clock rates from satellite to satellite. Close monitoring of the clock of each satellite from the ground permits the control station to insert a message in the signal of each satellite that precisely describes the drift rate of that satellite's clock. The insertion of the drift rate effectively synchronizes all of the GPS satellite clocks.

The same procedure cannot be applied to the clock in a GPS receiver. Therefore, a fourth variable (in addition to x, y and z), time, must be determined in order to calculate a precise location. Mathematically, to solve for four unknowns (x,y,z, and t), there must be four equations. In determining GPS positions, the four equations are represented by signals from four different satellites.

12.6. The GPS Error Budget

The GPS system has been designed to be as nearly accurate as possible. However, there are still errors. Added together, these errors can cause a deviation of +/- 50 meters from the actual GPS receiver position. There are several sources for these errors, the most significant of which are discussed below:

12.6.1. Atmospheric Conditions

The ionosphere and troposphere both refract the GPS signals. This causes the speed of the GPS signal in the ionosphere and troposphere to be different from the speed of the GPS signal in space. Therefore, the distance calculated from "Signal Speed x Time" will be different for the portion of the GPS signal path that passes through the ionosphere and troposphere and for the portion that passes through space.

12.6.2. Ephemeris Errors/Clock Drift/Measurement Noise

As mentioned earlier, GPS signals contain information about ephemeris (orbital position) errors, and about the rate of clock drift for the broadcasting satellite. The data concerning ephemeris errors may not exactly model the true satellite motion or the exact rate of clock drift. Distortion

of the signal by measurement noise can further increase positional error. The disparity in ephemeris data can introduce 1-5 meters of positional error, clock drift disparity can introduce 0-1.5 meters of positional error and measurement noise can introduce 0-10 meters of positional error.

12.6.3. Selective Availability

Ephemeris errors should not be confused with Selective Availability (SA), which is the intentional alteration of the time and epherimis signal by the Department of Defense. SA can introduce 0-70 meters of positional error. Fortunately, positional errors caused by SA can be removed by differential correction.

12.6.4. Multi path

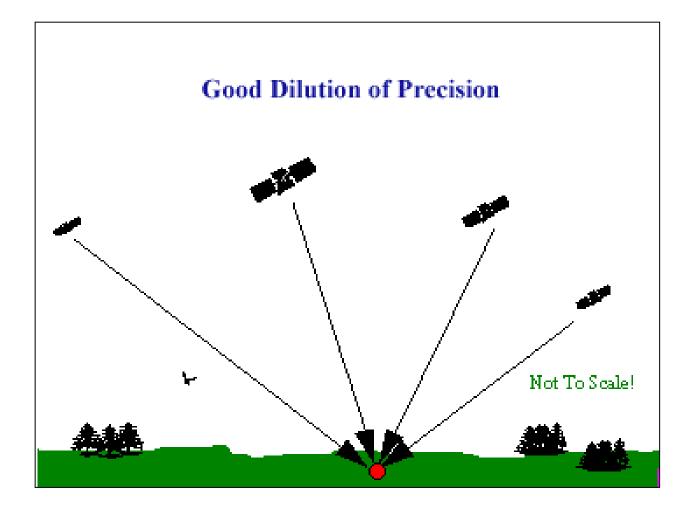
A GPS signal bouncing off a reflective surface prior to reaching the GPS receiver antenna is referred to as multi path. Because it is difficult to completely correct multi path error, even in high precision GPS units, multi path error is a serious concern to the GPS user. The chart below lists the most common sources of error in GPS positions. This chart is commonly known as the GPS Error Budget:

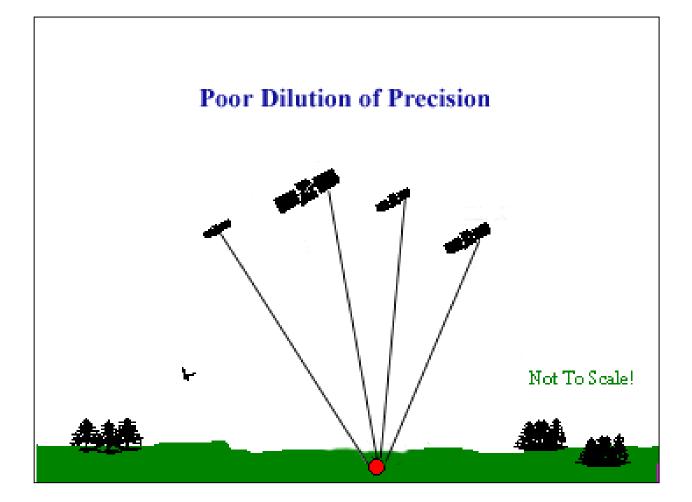
GPS Error Budget

Source	Uncorrected Error Level
Ionosphere	0-30 meters
Troposphere	0-30 meters
Measurement Noise	0-10 meters
Ephemeris Data	1-5 meters
Clock Drift	0-1.5 meters
Multi path	0-1 meter
Selective Availability	0-70 meters

12.7. Measuring GPS Accuracy

As discussed above, there are several external sources that introduce errors into a GPS position. While the errors discussed above always affect accuracy, another major factor in determining positional accuracy is the alignment, or geometry, of the group of satellites (constellation) from which signals are being received. The geometry of the constellation is evaluated for several factors, all of which fall into the category of Dilution of Precision, or DOP.





DOP is an indicator of the quality of the geometry of the satellite constellation. Your computed position can vary depending on which satellites you use for the measurement. Different satellite geometries can magnify or lessen the errors in the error budget described above. A greater angle between the satellites lowers the DOP, and provides a better measurement. A higher DOP indicates poor satellite geometry, and an inferior measurement configuration.

Some GPS receivers can analyze the positions of the satellites available, based upon the almanac, and choose those satellites with the best geometry in order to make the DOP as low as possible. Another important GPS receiver feature is to be able to ignore or eliminate GPS readings with DOP values that exceed user-defined limits. Other GPS receivers may have the ability to use all of the satellites in view, thus minimizing the DOP as much as possible.

12.8. Using Differential GPS to Increase Accuracy

As powerful as GPS is, +/-50 - 100 meters of uncertainty is not acceptable in many applications. How can we obtain higher accuracies?

A technique called **differential correction** is necessary to get accuracies within 1 -5 meters, or even better, with advanced equipment. Differential correction requires a second GPS receiver, a *base station*, collecting data at a stationary position on a precisely known point (typically it is a surveyed benchmark). Because the physical location of the base station is known, a correction factor can be computed by comparing the known location with the GPS location determined by using the satellites.

The differential correction process takes this correction factor and applies it to the GPS data collected by a GPS receiver in the field. Differential correction eliminates most of the errors listed in the GPS Error Budget discussed earlier. After differential correction, the GPS Error Budget changes as follows:

GPS Error Budget

Source	Uncorrected	With Differential
Ionosphere	0-30 meters	Mostly Removed
Troposphere	0-30 meters	All Removed
Signal Noise	0-10 meters	All Removed
Ephemeris Data	1-5 meters	All Removed
Clock Drift	0-1.5 meters	All Removed
Multi path	0-1 meters	Not Removed
SA	0-70 meters	All Removed

By eliminating many of the above errors, differential correction allows GPS positions to be computed at a much higher level of accuracy.

12.9. Levels of GPS Accuracy

There are three types of GPS receivers that are available in today's marketplace. Each of the three types offers different levels of accuracy, and has different requirements to obtain those accuracies. To this point, the discussion in this book has focused on Coarse Acquisition (C/A code) GPS receivers. The two remaining types of GPS receiver are Carrier Phase receivers and Dual Frequency receivers.

12.9.1. C/A Code receivers

C/A Code receivers typically provide 1-5 meter GPS position accuracy with differential correction. C/A Code GPS receivers provide a sufficient degree of accuracy to make them useful in most GIS applications.

C/A Code receivers can provide 1-5 meter GPS position accuracy with an occupation time of 1 second. Longer occupation times (up to 3 minutes) will provide GPS position accuracies consistently within 1-3 meters. Recent advances in GPS receiver design will now allow a C/A Code receiver to provide sub-meter accuracy, down to 30 cm.

12.9.2. Carrier Phase receivers

Carrier Phase receivers typically provide 10-30 cm GPS position accuracy with differential correction. Carrier Phase receivers provide the higher level of accuracy demanded by certain GIS applications.

Carrier Phase receivers measure the distance from the receiver to the satellites by counting the number of waves that carry the C/A Code signal. This method of determining position is much more accurate; however, it does require a substantially higher occupation time to attain 10-30 cm accuracy. Initializing a Carrier Phase GPS job on a known point requires an occupation time of

about 5 minutes. Initializing a Carrier Phase GPS job on an unknown point requires an occupation time of about 30-40 minutes.

Additional requirements, such as maintaining the same satellite constellation throughout the job, performance under canopy and the need to be very close to a base station, limit the applicability of Carrier Phase GPS receivers to many GIS applications.

12.9.3. Dual-Frequency receivers

Dual-Frequency receivers are capable of providing sub-centimeter GPS position accuracy with differential correction. Dual-Frequency receivers provide "survey grade" accuracies not often required for GIS applications.

Dual-Frequency receivers receive signals from the satellites on two frequencies simultaneously. Receiving GPS signals on two frequencies simultaneously allows the receiver to determine very precise positions.

12.10. GPS and Canopy

GPS receivers require a line of sight to the satellites in order to obtain a signal representative of the true distance from the satellite to the receiver. Therefore, any object in the path of the signal has the potential to interfere with the reception of that signal. Objects that can block a GPS signal include tree canopy, buildings and terrain features.

Further, reflective surfaces can cause the GPS signals to bounce before arriving at a receiver, thus causing an error in the distance calculation. This problem, known as multi path, can be caused by a variety of materials including water, glass and metal. The water contained in the leaves of vegetation can produce multi path error. In some instances, operating under heavy, wet forest canopy can degrade the ability of a GPS receiver to track satellites.

There are several data collection techniques that can mitigate the effects of signal blockage by tree canopy or other objects. For example, many GPS receivers can be instructed to track only the highest satellites in the sky, as opposed to those satellites that provide the best DOP. Increasing the elevation of the GPS antenna can also dramatically increase the ability of the receiver to track satellites.

Unfortunately, there will be locations where GPS signals simply are not available due to obstruction. In these cases, there are additional techniques that can help to solve the problem. Some GPS receivers have the ability to collect an offset point, which involves recording a GPS position at a location where GPS signals are available while also recording the distance, bearing and slope from the GPS antenna to the position of interest where the GPS signals are not available. This technique is useful for avoiding a dense timber stand or building.

Further, a traditional traverse program can be used to manually enter a series of bearings and ranges to generate positions until satellite signals can again be received. This position data can then be used to augment position data collected with the GPS receiver.

12.11. GPS for GIS

Up to this point, the discussion has focused on describing how GPS determines a location on the surface of the Earth. Now the discussion can shift to the process of describing what is at the location. The "what" is the object or objects that will be mapped. These objects are referred to as "Features", and are used to build a GIS. It is the power of GPS to precisely locate these Features that adds so much to the utility of the GIS system. On the other hand, without Feature data, a coordinate location is of little value.

12.11.1. Feature Types

There are three types of Feature that can be mapped: Points, Lines and Areas. A Point Feature is a single GPS coordinate position that is identified with a specific Object. A Line Feature is a

collection of GPS positions that are identified with the same Object and linked together to form a line. An Area Feature is very similar to a Line Feature, except that the ends of the line are tied to each other to form a closed area.

12.11.2. Describing Features

As stated above, a Feature is the object that will be mapped by the GPS system. The ability to describe a Feature in terms of a multi-layered database is essential for successful integration with any GIS system. For example, it is possible to map the location of each house on a city block and simply label each coordinate position as a house. However, the addition of information such as color, size, cost, occupants, etc. will provide the ability to sort and classify the houses by these categories.

These categories of descriptions for a Feature are known as Attributes. Attributes can be thought of as questions that are asked about the Feature. Using the example above, the Attributes of the Feature "house" would be "color", "size", "cost" and "occupants".

Logically, each question asked by the Attributes must have an answer. The answers to the questions posed by the Attributes are called Values. In the example above, an appropriate Value (answer) for the Attribute (question) "color" may be "blue".

The following table illustrates the relationship between Features, Attributes and Values: Feature Attribute Value

House	Color	Blue
	Size	3 BDR
	Cost	\$118K
	Occupants	5

By collecting the same type of data for each house that is mapped, a database is created. Tying this database to position information is the core philosophy underlying any GIS system.

12.11.3. Feature Lists

The field data entry process can be streamlined by the use of a Feature List. The Feature List is a database that contains a listing of the Features that will be mapped, as well as the associated Attributes for each Feature. In addition, the Feature List contains a selection of appropriate Values for each Attribute. The Feature List can be created on the CMT hand-held GPS data collector, or on a PC.

When a Feature List is used in the field, the first step is to select the Feature to be mapped. Once a Feature is selected, the Attributes for that Feature are automatically listed. A Value for each Attribute can then be selected from the displayed list of predetermined Values.

The use of a Feature List streamlines the data entry process and also ensures consistent data entry among different users in the same organization.

12.12. Exporting to a GIS System

The final step in incorporating GPS data with a GIS system is to export the GPS and Feature data into the GIS system. During this process, a GIS "layer" is created for each Feature in the GPS job. For example, the process of exporting a GPS job that contains data for House, Road and Lot Features would create a House layer, a Road layer and a Lot layer in the GIS system. These layers can then be incorporated with existing GIS data.

Once the GPS job has been exported, the full power of the GIS system can be used to classify and evaluate the data.

12.13. Practical Exercises

In this section, the participants will be taught how to configure the GPS in order to avoid errors when capturing data in the field. Emphasis will be put on the need to make proper configurations

when changing zones. The second exercise will deal with practical work on the various data capture methods upon proper configuration i.e. data capture from simple points to polygons where terms such as waypoints and tracks will be explained and their relevance to the participants work shown. The third and last section will deal with the process of converting field data into readable GIS maps through export and cleaning to obtain the final products which could be used for decision making processes.

At the end of this training course participants will be expected to participate in any form of mapping in the field from simple data capture e.g. forage, water resources, market places and diseases hotspots to complex real time data capture on animal migration routes etc.

- 1. Configure the provided GPS to the following specifications
 - a. Set the units to decimal degrees
 - b. Datum Arc1960
 - c. Distance units to metric
 - d. Elevation meters
 - e. Depth meters
- 2. Collect 10 waypoints along the track to represent the lamp posts on the road between the dining room and the gate
 - a. Go to main menu and select mark any time you want to collect a new waypoint
- 3. Collect the track between the training room and the main gate using the road where you collect your waypoints
 - a. Go to main menu, select tracks
 - b. Use the joystick to select clear
 - c. Go to the menu bar and select the page button
 - d. Select record method to be time
 - e. Change the interval to 1 minute
 - f. Select the on button to start the tracking (P/s remember to put off the tracking when through with the transect)

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- 4. Download the collected data into the GIS system or manually input the data into a database.
- 5. Clean the data and convert it into a GIS map and view it in ArcView or other software.

13. Tools: Ranking & Scoring 2



By the end of the session, participants will be able to:

- 1. Demonstrate the use of matrix scoring
- 2. Explain why matrix scoring is more valuable than proportional piling in certain situations

13.1. Matrix scoring

Matrix scoring is essentially a series of proportional piling exercises in two dimensions, where a list of items such as diseases is scored against a list of indicators such as clinical signs. This method can be used to better understand the local characterization of diseases, and the meanings of local disease names. This tool can take some time to complete, so make sure you plan your time well.

13.2. Matrix scoring for disease definitions

When interviewing community members, technical terms are rarely used. An important first step in any study is to understand how community members think about and characterize diseases. You may find, for example, that your respondents mention several diseases, each with their own name in the local language, but to you they seem very similar. Matrix scoring can be a very useful tool for understanding the symptoms and epidemiological characteristics of the different diseases respondents mention.

Method

Imagine that you would like to conduct a matrix scoring exercise to understand the clinical signs a community associates with different diseases.

- Use the diseases mentioned by your respondents. When your respondents tell you the name for a disease in their language, use that name during the interview rather than an English or scientific name. That way everybody, respondents and research team alike, are on the same page.
- 2. For each disease obtain a list of clinical signs and epidemiological features.
- 3. Draw a matrix on the ground or on flip chart paper. Make sure it is big so that everyone can see it. Put enough columns for each of the diseases. Use pictures, objects or cards to represent the diseases and place these across the top of the matrix. Be sure to mention what disease each card represents, using the local language name, as you place it on the ground. This way those that cannot read or understand the picture can memorize the cards as they appear.
- 4. You will use all the indicators (clinical signs) mentioned by the respondents for the various diseases. Write the first indicator on a card, or use a picture or object to represent it. Place this to one side of the first row of the matrix. Be sure to repeat it aloud so all the participants know what it is.
- 5. Place a pile of 30 counters next to the indicator and ask the participants to use them to show how strongly the indicator correlates with each disease. Summarize and crosscheck for agreement between the respondents. Leave the counters where they are.
- Repeat the exercise for each indicator one by one, gradually building up the matrix.
 Leave the matrix in place so that everyone can view the results and discuss as a group.
- 7. During the exercise and after the matrix is complete, it is essential that the investigator carefully probe the informants as to why they are scoring the way they are. After the matrix is complete, summarize the results and give the informants the opportunity to make changes if they wish. Ask your respondents what new learning or insights they have gained from the exercise.
- 8. Record the results in a matrix in your notebook.

Example

Matrix scoring for disease definitions of four common causes of childhood mortality in sub-Saharan Africa

	Menakido	Malaria	Uulete	Kojuke
>3 liquid stools/day			26	4
Fever	8	10	6	6
Cough	17	8		5
Failure to eat/drink	10	10	5	5
Vomiting		10	20	
Convulsions		30		
Bluish discoloration/cyanosis	30			
Rapid breathing	18	8		4
Head nodding	30			
Lethargic	9	9	7	5
Blood in stool			30	
Runny eyes & nose	5			25
Rash				30

The research team diagnosed these diseases as:

Menakido = pneumonia

Malaria = malaria

Unlete = diarrheal diseases

Kojuke = measles

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Example

Matrix ranking of causes and impacts of eye problems in rural India

		Cataract	Blurred	Watering
			vision	eyes
Causes:	Injury	30		
	Old age	10	20	
	Fever with rash	30		
	Poor nutrition	5	25	
	Smoke (cooking)			30
	Body heat			30
	Eye strain			30
Impacts:	Worrying	30		
	Feeling sad	30		
	Feeling a burden	30		
	Facing teasing	30		
	Work	30		
	Social activity	30		
	Minimal impact		15	15
Source of	Hospitals	10	10	10
treatment:				
Barriers:	Money	20	5	5
	Family	20	5	5
	circumstances/responsibilities			
	Fear of treatment	30		
	Distance to service	10	10	10

Adapted from: Fletcher AE, Donoghue M, Devavaram J, Thulasiraj D, Scott S, Abdalla M, Shanmugham, Murugan PB. 1999. Archives of Ophthalmology, 117:1393-1399.

Tips

- Matrix scoring on diseases and clinical signs is most useful with individuals who have a lot of knowledge and experience, and can show the subtle differences between different diseases or syndromes.
- Use the names of diseases or syndromes as given by the community members.
- Be patient. Do not interfere with the discussion or try to hurry the informants.
- Avoid 'correcting' the results. It is a common mistake for investigators to give their opinions and 'correct' the participants. Sometimes this develops into the investigator lecturing the informants about the right answer. Do not offer your views, but instead use probing questions to reveal reasoning behind scores that seem strange to you.
- Too many items to score with a long list of indicators will cause the participants to get bored and lose interest. If the informants make a long list of items or indicators, use simple ranking to determine which are the most important.
- Be aware of literacy. Just as with proportional piling, it is better to use pictures or everyday items to represent items and indicators. Carefully explain the meaning of the symbols and repeat throughout the exercise to remind the informants of the meanings.
- Do not make the mistake of totaling the columns. Indicators will often have different levels of importance or 'weights' and summating the scores for each item has limited value.
- Let the matrix grow and leave it. Do not clear the matrix until after you have interviewed the participants about the results. This will reveal more about the scores and open further areas for discussion. Visualizing the matrix allows the informants to better understand the differences between the diseases as well.
- Be clear about the question. Often investigators will ask the participants to pile the counters based on the 'importance' of an indicator to the diseases listed in the matrix. It is important to define 'important' as meaning that the indicator is either always associated with the disease or linked to the severity of the disease. If you are going to compare matrix results from different interviews, the criteria used must be the same between interviews.

• Leave copies of the matrix for the informants. This will allow them to discuss the results and learn from one another after the interview has come to an end.

When conducting research using participatory epidemiology, it may be desirable to have a uniform matrix to be used across space and time to improve comparison of the results. In this case, run a few open matrices in selected areas to determine the key diseases of interest and the most important indicators. After the results of a few matrices are analyzed, select the common diseases and indicators and introduce them to the informants during the interview (in other words, the investigator sets up the matrix but the informants distribute the counters).

Matrix scoring can be used in many ways to help investigators understand local situations and priorities. Examples include livelihood activities and the household members who conduct them, behaviors that promote or prevent diseases, etc. The list goes on! Please take a few minutes to brainstorm different ways that you can use matrix scoring in your own work.

Exercise

Please think about the different ways you might use matrix scoring in your own work. Decide on an example you would like to try, and set up a matrix by developing the categories and indicators. What probing questions might you ask as respondents work on your matrix?

Example: I am a public health nutritionist. I'd like to try matrix scoring to understand what types of food different categories of residents in my work area consume. The categories (columns) will be different members of society: herders, farmers, workers (teachers, etc.). The indicators (rows) will be food types: milk, chicken, meat, eggs, maize, sorghum, cassava, vegetables, fruit, beans, peanuts, candies and chips, bread. By probing I can learn why different people in the community consume different foods, and why certain people face difficulty in obtaining certain foods.

	Categories ->			
•				

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14. Tools: Visualization 3

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Demonstrate the use of seasonal calendars
- 2. Demonstrate the use of timelines
- 3. Demonstrate the use of Venn diagrams

14.1. Seasonal calendars

Many human and animal health problems show seasonal variation. A seasonal calendar can be used to visualize and analyze local perceptions about the seasonality of disease incidence, vector populations, risk factors, farming practices, etc. The seasonal occurrence of diseases is interesting to understand in relation to the seasonality of factors that affect their occurrence, such as climate, management practices, vectors, etc. New or unusual factors may emerge that are important in a particular area. The information can be useful for improving disease mitigation strategies, such as timing of vaccination or prophylaxis.

In order to construct a seasonal calendar it is first necessary to be familiar with local terminology, descriptions of seasons and how these relate to the months of the year. This information can be gathered from key informants. The seasonality of different events or activities of interest is then demonstrated by indicating timing of occurrence or scoring occurrence in relation to the seasons.

Seasons are defined by different characteristics in different regions. Understanding the characteristics that are used to define the seasons in the area under investigation is the first step

in creating a seasonal calendar. Then other seasonal events (indicators) can be investigated. Human activities, namely political, religious and cultural events such as festivals, holidays and times when cash is needed can affect movements and disease spread. Other seasonal factors such as availability of water or presence of vectors may be of interest, depending on the disease of interest. Management and marketing practices for livestock may be seasonal due to movements, calving, housing and buying stock or off-take, and may be significant in terms of zoonoses risk. School calendars may be important, as schools are important sources of exposure for children, as is travel during holidays. Other important uses of seasonal calendars include vulnerable periods for child-care and exposure to infectious agents.

Having developed a seasonal calendar, the results are discussed and probed with respondents to find out why things happen at certain times and how they may or may not be related to other factors.

Method

The interviewer should be familiar with local customs and practices, common disease problems and factors that may affect disease occurrence. This information can be gathered during the interview, or from other sources. From this information a list of indicators is developed, and the following method used to explore seasonality.

- 1. Draw a line on the ground or at the top of a piece of flip chart paper and indicate that this represents one year.
- Ask the informants to describe the seasons that they experience during the year. Record the local names for these seasons. Ask the participants to divide the line into seasons based on their occurrence and length during the year.
- Label the seasons either by writing them on cards or representing them with local objects or pictures. If the months of the year are commonly used, then write these along the line above or below the relevant seasons.
- 4. Ask the informants about key indicators that define each season (rainfall, temperature, length of day, etc.). For each indicator give them a pile of 20 counters, and ask them to divide the counters between the seasons to show the relative association of the indicator with the seasons. All the counters for an indicator should be used. After each indicator is

completed draw a line beneath it and go on to the next indicator. Record the results but do not remove the counters.

- 5. Repeat this with other types indicators (health event or disease), so that gradually a matrix is built up. The name of the indicator may be written on the flip chart or on a card and placed at the side of the matrix. For illiterate participants, a picture or object may represent the indicator.
- 6. Once the calendar has been completed, the results should be discussed with the informants using open and probing questions. For example, you could ask, 'Why is this disease more common in this season? Do you know what causes this disease? So this disease seems to occur when there is a lot of rain, why is that?'

Example

Seasons of the year and common illnesses experienced by nomadic Somali communities in Mbalambla, Kenya

Season	Short & hot	Long rainy	Long dry with cold	Short rainy
	dry (Jilaal)	(Gu'u)	nights (Xagaa)	(Deyr)
Months	Dec-March	April-June	July-Sept	Oct-Dec
Rainfall	*	******	*	******
Measles	*****	**	*	****
Whooping cough	****	**	*	*
Malaria	****	*****	***	****
Pneumonia	***	****	****	*
Diarrhea/vomiting	**	****	*	****
Asthma	-	-	***	-
Malnutrition	-	-	****	*
Anemia	-	-	***	*
Conjunctivitis	-	-	-	****

From Maalim AD. 2006. Participatory rural appraisal techniques in disenfranchised communities: a Kenyan case study. International Nursing Review, 53(3): 178-188.

Alternative method: Timing of occurrence

This method simply indicates the presence or absence of an indicator by season rather than scoring, and therefore gives useful but less detailed information.

- 1. Draw a line on the ground or at the top of a piece of flip chart paper and indicate that this represents one year.
- 2. Ask the informants to describe the seasons that they experience during the year. Record the local names for these seasons.

- 3. Write the seasons along the line in the order in which they occur, crosschecking with the participants. The names can either be written on cards or represented with local objects or pictures.
- 4. If the months of the year are commonly used, then write these along the line next to the relevant seasons.
- 5. Ask the participants to think about rainfall and how it varies with the seasons. Ask them to mark on the matrix when rainfall occurs; draw on ground with a stick or on flip chart paper with a marker pen.
- 6. Repeat this with each indicator (activity, event, disease). The name of the indicator may be written on a card or on the flip chart and placed at the side of the matrix. For illiterate participants, a picture or object may represent the indicator. The indicators used will be linked to the species or disease(s) of interest. They may be determined before the participatory epidemiology interview, but are likely to be added to or modified as a result of discussions during the interview.
- 7. Once the calendar has been completed, the results should be discussed with the participants using open and probing questions, for example, 'Why is this disease more common in this season?' 'Do you know what causes this disease?' 'So this disease seems to occur when there is a lot of rain, why is that?'
- 8. Ask the respondents if they have any new ideas after having done the exercise.
- 9. Record the calendar in your notebook.

Tips

- A seasonal calendar shows the seasonal patterns of diseases, events and activities over a normal year. Later we will learn about timelines, which show what happened during a given period of time a few weeks, months, years or decades depending on the issue of interest.
- Use the local names for seasons and months. Try to obtain this information beforehand so you just need to crosscheck during the interview.
- Not all cultures use the Gregorian calendar based on 12 months in a year (January December). This is why it is important to start by asking informants to describe the seasons before correlating them to months. While they are describing the seasons, ask

how long the seasons last and when they begin and end. Some examples of alternative calendars include:

- Lunar calendar: a calendar based on the phases of the moon. This calendar is widely used in Muslim cultures.
- Julian calendar: a precursor to the Gregorian calendar. Still in use by the Berber people in North Africa and some Orthodox Christian sects.
- During calendar construction, participants will often mention key risk factors such as humidity, vector populations, water scarcity, etc. Thus, not only do calendars provide information on seasonality, they are also useful tools for identifying predisposing factors.
- As with all participatory epidemiology tools, it is important to have a clear question in mind when conducting the activity, and to write the question down in your notebook. Sometimes you may be interested in the quantity of an indicator or the incidence of disease while other times you make ask the informants to pile counters based on the importance of an indicator.
- Seasonal calendars may be best used at a late stage in a study or interview after other methods have been used to determine meanings of local terminology for diseases. This will allow for more in depth probing of disease occurrence and help prevent misunderstandings when interpreting a seasonal calendar during follow-up data analysis.
- When discussing risk factors such as vectors, it may be helpful to carry preserved specimens in clear bottles, or ask informants to collect specimens during the study. This will create interest and enthusiasm on the part of the community members.
- Notes taken during the probing phase of the seasonal calendar activity should be written up as part of the results, as these are important for understanding why the informants piled the counters the way they did.
- It is nice to leave behind a copy of the calendar for the informants to discuss with other members of the community. This helps prevent the problems associated with extractive research techniques in which communities are not provided with feedback or results after a study is conducted.

14.2. Timelines

Many diseases of interest occur as epidemics at finite time points, or as flare-ups of endemic disease. The interviewer may note the years of major epidemics for various diseases on a timeline. Timelines are a useful tool for exploring the frequency of key disease events and patterns over time. Information on major events, such as droughts and famines or political events may also be included to assist informants in remembering the timing of key disease events. These events may also have an impact on disease occurrence because of the changing movements and habits of animals and people. Their inclusion may allow for triangulation of reported risk factors for disease occurrence. Local names for events should be used as much as possible.

Besides providing information in itself, the timeline will provide a useful reference for triangulating the reports made by the community with information in the official government surveillance system.

Timelines are useful for:

- Helping to clarify the details of disease events mentioned by respondents, because it prompts them to remember things that happened before or during the disease event
- Prompting participants to remember additional information, such as other disease outbreaks not already mentioned
- Estimating the duration of events like outbreaks, and how frequently they occur
- Showing the cause and effect relationship between events, such as the timing of heavy rainfall and occurrence of Rift Valley fever in cattle and humans
- Enabling the surveillance team to involve the communities in evaluating targets, e.g. how soon after a disease report did implementation of disease control interventions start

The timescale can vary depending on the disease of interest. For example, it could be five years to capture information for diseases that occur fairly frequently such as measles and meningitis. It could be 50 years of more for diseases with long epidemic cycles such as Rift Valley fever. It is

also interesting to create a timeline if you are exploring events around a specific disease outbreak. For example, the days, weeks or months over which a new disease was introduced into an area and the time it took for authorities to respond.

Timelines have many uses, including understanding trends in disease incidence, epidemics, women and child-care patterns, nutrition and feeding related practices, and traditional and conventional health care practices.

Method

- 1. Decide on the timescale to be used, based on the issues of interest.
- To set the scene, ask the participants to indicate key events during the timeframe events affecting the community, political, social or cultural events, major harvest or climatic events. This will help everyone, researchers and respondents alike, to have a common frame of reference.
- 3. Add indicators of interest related to the disease of interest, such as start, ending, peaks in the number of affected, when different locations became affected, responses, disease control interventions, appearance of new symptoms, etc. As each new indicator is added, listen to the discussion and probe the results. For example, "Did the vaccination program start on the same day in all the affected areas?" "Were there some areas that weren't affected, and what are their relation to those you have put on the timeline?" "Did you notice anything else unusual at that time, besides the arrival of the new type of mosquito?"
- 4. Probe the completed timeline. For instance, you could ask, "Did the disease ever occur in this area before that year?" "Did anything different or significant happen in the few months before the outbreak?"
- 5. Ask the respondents if they have any new ideas after having done the exercise.
- 6. Record the timeline in your notebook.

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Example

Timeline for the period 1999-2008 of key events and major outbreaks in Uganda

Year	Key Events	Major Outbreaks
1999	Kabaka's wedding	
	Congo war	
2000	Kanungu massacres	Ebola outbreak begins
	Kisangani I and II	
	Besigye declares political intentions	
2001	Presidential elections	Ebola outbreak in North Uganda
	Signing of EA pact	
2002	Bill Clinton visits Uganda	
	Congo war ends	
2003	Death of Amin (ex-president)	
2004	Uganda withdraws from Congo	
	Constitutional amendments	
2005	Death of Obote (ex-president)	
	Discovery of oil in Uganda	
	Amendment of constitution	
2006	Presidential elections under multi-party	
	system	
	Floods in East and North Uganda	
2007	Uganda hosts CHOGM (Queen)	Ebola in Bundibugyo
	Floods in Teso region	Marburg outbreak in Western Uganda
	Peace in Northern Uganda	
	Balaio saga	
2008	Budo inferno	Hepatitis outbreak in Northern
	Obama elected US president	Uganda
	Minister of State MAAIF Sebunya dies	Plague outbreak in West Nile
	Kyabazinga dies	

From: http://www.mapreport.com/countries/uganda.html Accessed 20091217.

Exercise

Construct a timeline for a disease outbreak that you recently worked on. Begin by deciding on a timescale that will capture all of the events during the outbreak, as well as events before and after that had a bearing on the outbreak. Then list key events to provide references that you and others can identify with. Finally, list all of the outbreak evens that can be referred to in time. When you have all your indicators, prepare your timeline with them.

Timescale (example, July 2006 – June 2007):

Key events (example, early warning released):

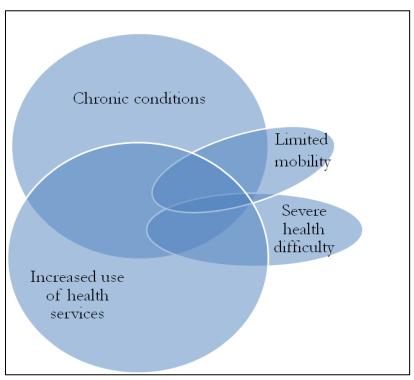
Outbreak events (example, start of rains):

Timeline:

14.3. Venn diagrams

Venn diagrams show logical relationships between sets or groups of items or characteristics. They are comprised of various sized circles based on the importance of the item or characteristic. The degree of overlap (or non-overlap) indicates the inter-relatedness of the items.

An example of a simple Venn diagram used for participatory epidemiology would be to make various sized circles based on the indicators of child ill health. Four indicators are selected to demonstrate the relative number of children demonstrating each of these indicators. The circles



are overlapped to show how children with several indicators of ill health are handled.

The example demonstrates that chronic conditions and increased use of health services are the most important indicators of child health, followed by severe health difficulty and limited mobility. There is a great degree of overlap between chronic conditions and increased use of

health services, and less overlap with limited mobility and severe health difficulty. Some children suffer from all four indicators but their numbers are small.⁶

Venn diagrams can provide useful information on relationships that are difficult to describe orally. The ways in which informants organize the diagram can provide insight into their thinking about management practices, health policies and other topics of interest, etc.

⁶ From: Kohen DE, Brehaut JC, Garner RE, Miller AR, Lach LM, Klassen AF, Rosenbaum PL. 2007. Conceptualizing childhood health problems using survey data: a comparison of key indicators, <u>BMC Pediatr.5</u>(7):40.

Method, an example for village health resources in the Democratic Republic of the Congo

- It would be good to have a mental checklist of items or resources that you want to cover, or a list in your notebook. For example, you may include: clinics, health personnel, traditional healers, NGOs, district offices, hospitals, pharmacies, forests for traditional plants, midwifes, village leaders, etc. But keep in mind that there will likely be resources that you had not been able to anticipate.
- Begin the discussion with an open question like, "Tell me about your local health resources. Where do you go or who can you ask for help when someone in your family gets sick?"
- 3. When an item is mentioned, draw a circle in the middle of a piece of flip chart paper, or on the ground, and label it. You can write the name of the category, such as 'village health center', in the circle, or you can use an object or picture. You can also do this exercise by cutting a circle out of colored paper and asking your respondents to place it on the ground for everyone to see the item.
- 4. When each subsequent item is named, you need to ask clarifying questions. For instance, when one respondent in your group said, "Village health center," that might prompt another respondent to say, "Community health worker". You need to find out how the second item is related to the first, if at all, and the degree of overlap. You can ask, "Does the community health worker work out of the village health center?" "Does she visit your homes, or does she work in an office at the center?" "Does she work in other villages too?" "Is she independent, or does she work for an organization like an NGO?"
- 5. As the group gets an idea about the relationship between the newly introduced category and the categories already shown, you can draw a circle for the new category that overlaps the other categories. Or you can cut out a new circle and ask your respondents to place it in the diagram.
- 6. The degree of overlap of the circles shows the level of interaction whereas the size of the circle shows the size of the group considered.
- Allow your respondents to continue to discuss their health resources, asking clarifying questions or prompting new ideas as the group goes along.

- 8. When the diagram is finished ask your respondents to consider the final product, and help you correct any inaccuracies.
- 9. Ask your respondents if they have any insights or new ideas after having done the exercise.
- 10. Relationships among different groups can change and therefore it is important to indicate the date when the diagram was made.

Exercise

Please think about the agencies and institutions involved in public health surveillance in your country, and brainstorm a list of them. Now review your list and think about how these categories of actors are related, and what their roles in surveillance are. Now you are ready to show these roles and relations in a Venn diagram. Draw your diagram below. The sizes of the circles should show the size of the actor, and the amount of overlap between the circles should indicate the level of interaction between actors.

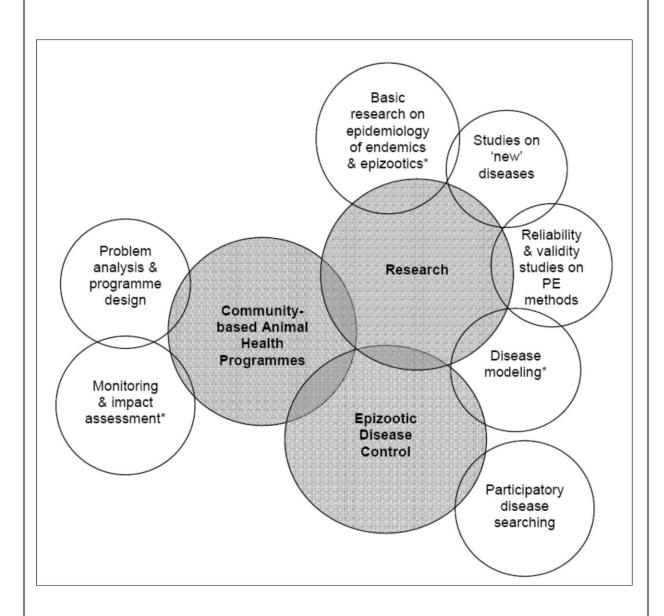
Public health actors (example, Ministry of Health, AFENET):

Venn diagram:

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Example

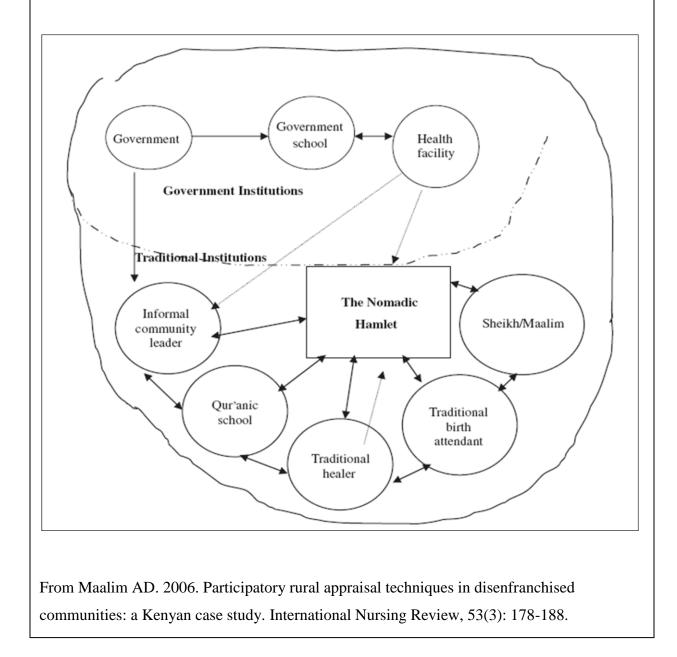
Venn diagram showing current uses of participatory epidemiology in pastoral areas of the Horn of Africa



From Catley A. and Admassu B. (2003) Using Participatory Epidemiology to Assess the Impact of Livestock Diseases. FAO-OIE-AU/IBAR-IAEA Consultative Group Meeting on Contagious Bovine Pleuropneumonia in Africa. 12-14 November 2003, FAO Headquarters, Rome, Italy. <u>http://www.participatoryepidemiology.info/userfiles/FAO-PE-Impact-Assessment.pdf</u>. Accessed 25 August 2009.

Example

Venn diagram showing a nomadic Somali hamlet's linkage and relationship with traditional institutions



15. Non-communicable Chronic Diseases of Adults

Session Learning Objective

By the end of the session, participants will be able to:

1. Discuss and advise others on common and important non-communicable diseases of adults

It is important that you have a reasonable understanding of non-communicable diseases, and are conversant to the degree that you can comfortably and accurately address the concerns of stakeholders when they arise during your work. If you are a physician, this may not be challenging. But if you are veterinarian or wildlife ecologist, it may be very intimidating indeed!

Please take a minute to think about the non-communicable diseases that people suffer from in the area where you work. Can you list them, their disease determinants, and prevention and control measures? They most likely include some or all of the following: hypertension, diabetes mellitus, congestive heart failure, musculoskeletal disorders, arthritis, chronic obstructive pulmonary disease, ulcers, cancers, mental illnesses, allergies, road traffic accidents, malnutrition, obesity, alcoholism, hernias, occupational diseases, etc.

Please make a note to familiarize yourself with government policies regarding specific diseases, such as cancer screening or peri-natal screening for women. Also familiarize yourself with the public and non-governmental initiatives for disease prevention and control that are being implemented in the area where you work. Questions regarding resources and policy often come up during interviews in communities that have public health problems. Make sure to discuss your work with public health resource persons in your area, and have their contact information on file, so that if you cannot address the questions of community members or you can put them

in contact with resource persons. Colleagues in your training program will likely be able to point you in the right direction, or even be the resource people you need!

Exercise

Please think about the four or five common non-communicable diseases that people suffer from in the area where you work. In the table below list them across the top. Then write into each cell what you know about the different determinants for each disease. Are you missing information? Where can you go to learn more? What organization is working on that disease problem in the community?

	Example:	Disease	Disease	Disease	Disease
	Malnutrition	1:	2:	3:	4:
Clinical signs	Stunting, underweight, etc.				
Differentials	GI disease, etc.				
Risk factors	Poverty, etc.				
Prevention					
Importance					
Treatment					
Epidemiology					
Morbidity					
Mortality					
Ages affected					
Gender affected					
Information sources					
Helpful organizations					

Day Five

16. Field Practice 2

Time again to get out into the field and practiced what you have learned! The objective of this practice study is to determine the main non-communicable diseases that affect a community. Please make a point to practice each of the tools used in participatory epidemiology that you have learned. Follow the same three phases to organizing your fieldwork: preparation, field and review, including preparation of a report to be presented for feedback.

17. Study Design, Analysis and Reporting

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Explain when and how to use triangulation, and to obtain a reliable level of consistency in their results through the use of triangulation
- 2. Calculate descriptive statistics for results from their studies, and determine which methods are best to use for their data
- Describe different approaches to designing epidemiological studies, and how causal diagrams can assist in design

Analysis is a continuous process that happens throughout an interview, throughout a study and after the study. Continuous crosschecking should be carried out. If necessary, the hypothesis, the checklist and tools used can be updated based on information gathered during earlier interviews, so that new leads can be followed and new information verified. The analysis can be summarized during the interview and discussed with the community. A report can be submitted to the appropriate authorities.

17.1. Triangulation

Triangulation should be performed:

- Between questions and tools used with the same informants
- Between questions and tools repeated with different informants
- Between information collected from interviews and laboratory results

• Between information from interviews and laboratories, and secondary sources of information

Information should be examined for levels of agreement or disagreement. As a good rule of thumb, information from one interview should be confirmed in at least two other interviews before being considered a finding.

17.2. Quantitative approaches

Descriptive analysis describes the basic features of the data in a study. The three main types of results generated through descriptive statistical analysis are:

- Distribution of the data
- Central tendency
- Dispersion

Distribution is the basic pattern of the data. To determine the distribution of data you obtained for a variable, list the observations in sequential order. For example, in 20 different villages you did a ranking exercise on the importance of five different species of livestock in terms of how much they contribute to a family's livelihood. The observations for the variable chickens, listed in sequential order, are as follows:

Second, second, third, third, third, fourth, fourth, fourth, fourth, fourth, fourth, fourth, fourth, fourth, fifth, fifth, fifth

For the variable, you can now see the proportion of observations that has each value obtained:

First = 0Second = 2 Third = 4 Fourth = 10 Fifth = 4

We can make a simple graph, called a histogram, to better visualize the results:

Ra	nking	of chickens	in terms of th	eir contribu	tion to livelih	oods in 20
			vil	lages		
ng	10					
ınki	9					
ch ra	8					
e ea	7					
gav	6					
who	5					
ages	4					
vill	3					
er of	2					
Number of villages who gave each ranking	1					
Nu		First	Second	Third	Fourth	Fifth
				Ranking		

Now we can see that the majority of the villages ranked chickens fourth in terms of how much they contribute to livelihoods. We can use different methods to graphically display the distribution of data:

- Bar and line graphs (more suited for discrete data)
- Pie charts (more suited for displaying proportions)
- Histogram (more suited to continuous data)

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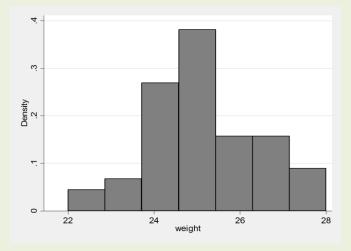
Exercise

The weights of 52 children aged seven years were taken during a routine malnutrition survey. The data and its frequency distribution are shown below.

Weights of 52 children aged 7 years

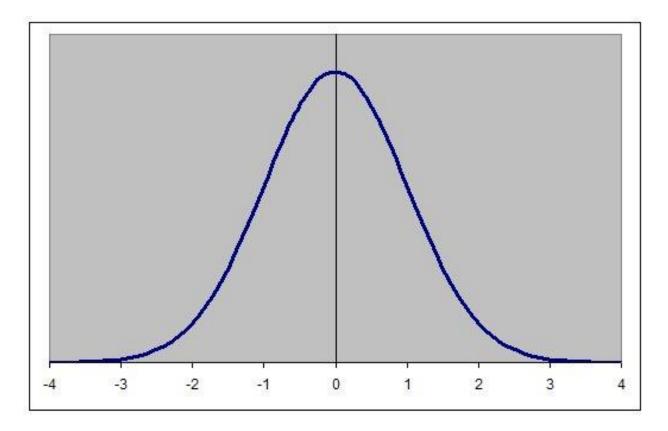
24	25	27	26	22	23	24	25	24	25	24	23	26
28	24	25	23	24	25	25	24	25	25	22	27	28
27	26	25	24	25	28	26	25	27	25	24	27	24
25	25	24	25	24	26	27	25	27	26	25	28	26

Histogram showing frequency distribution of weights of 52 children aged 7 years



How much do the majority of the children weigh? Determine the mean (average) weight for the children. How do these two numbers compare?

Often we will find that data we generate will have a *normal distribution*. If we were to create a histogram of our data, we will find that it fits into a bell-shaped curve, like this:



From: Economics.help, <u>http://www.economicshelp.org/dictionary/b/bell-curve.html</u>, download 28 June 2011

However, we may find that our data has a *Poisson distribution* or a *geometric distribution*, where the slope on one side of the bell is steeper than the slope on the other. This means we have more observations to one side of the mean than the other side. If our set of observations for a variable is small, there is a greater risk that our data will not have a normal distribution.

Central tendency is an estimate of the center of a distribution of values.

- The *mean* or average of a set of numbers (*n*) is the sum of the numbers divided by n.
 - The mean of 15, 20, 21, 20, 36, 15, 25 is 21.7
 - Mean = (15+20+21+20+36+15+25)/7 = 152/7 = 21.7

- The *median* of *n* numbers is the middle number when the numbers are written in order (ascending or descending order). If *n* is even, the median is the average of the two middle numbers.
 - The median of 15, 20, 21, 20, 36, 15, 25 is 20
 - o The median of 12, 13, 14, 16, 16, 18, 20, 24, 24, 24, 26, 27 is 19
 - Median = (18+20)/2 = 38/2 = 19
- The *mode* of *n* numbers is the number that occurs most frequently. If two numbers tie for most frequent occurrence, the data has two modes, i.e. bi-modal. Sometimes it can be multi-modal.
 - The modes of 15, 20, 21, 20, 36, 15, 25 are 15 and 20
 - o The mode of 12, 13, 14, 16, 16, 18, 20, 24, 24, 24, 26, 27 is 24

If the distribution of your data is not normal, or you suspect it is not normal because the sample size is small, then you should use median, or perhaps mode, to describe the central tendency of your data, not the mean.

Exercise

Participatory epidemiology was used to assess the impact of drought emergency interventions for pastoralists in central Turkana, Kenya. The team used proportional piling to rank livestock species by importance to livelihoods. Below are the scores by species from 16 *adakars* (settlements). Please estimate the mean, median and mode, and interpret your findings. Discuss the best descriptive statistics to provide for this study.

	Puch	Lochorekuyen	Lokiriama	Lochorealomala	Lorengippi	Turkwell	Kalemnyang	Kalemnyang	Lomil	Napeililim	Naipa	Lokamichura	Lorengelup	Lomuria	Nakurio	Kangirisae
Goats	48	44	34	32	45	36	32	35	43	42	30	31	35	20	28	25
Camels	8	24	18	29	20	19	11	20	20	20	12	18	21	12	27	19
Cattle	15	0	20	15	6	12	11	14	0	0	23	18	12	17	0	5
Donkeys	8	10	6	14	9	10	8	6	12	12	21	10	6	11	9	20
Sheep	21	22	22	10	20	17	18	19	25	26	15	20	22	30	25	15
Chicken	0	0	0	0	0	0	19	5	0	0	0	0	4	6	7	4
Dogs	0	0	0	0	0	0	0	0	0	0	0	0	0	4	2	12

Mean:

Median:

Mode:

Discussion:

Exercise

Participatory epidemiology was used to study the 2006/7 outbreak of RVF in Kenya. This figure shows timelines prepared with herders in 11 locations in Northeast Province, with the type and timing of control responses implemented.

Village	A	ugust		Sep	temb	er	Oc	tober		Nov	embe	er	Dec	ember		Janua	ry		Feb	oruary		Ma	rch	
	E	М	L	Е	Μ	L	E	М	L	Е	Μ	L	Е	М	L	Е	М	L	E	Μ	L	Е	Μ	L
Sangailo							*				÷													
Lione					<u> </u>		*				-U-			•										
Ijara	_ ₽-									- -				*										
Kotile					-		I -	*													-			-
Fafi							∙		*	÷					-		*		<u> </u>					
ran								+	- 4				+			+								
Saka							-	*	_	_				•										
	_														*									
Alango-arba										*				+	•								*	
Mansabubu													*											
													-\$-·			• °	*			I				
Saretho											*	-												
							<u> </u>		*	•				¢		*								
Hara								۰.	~					÷										
Dalolowan									*															
Shanta-Abak														*										
	Durat	ion of e	xcepti	onally	y high	rains																		
*	Mo	osquito j	popula	ation i	ncreas	ed																		
	Clini	ical case	es of F	RVF ii	n lives	tock																		
?	Η	uman c	ases w	ere ol	bserve	d																		
•		Interver	ntion b	by the	MoH																			
?		Interv	ention	n by D	OVS																			
0	I	interven	tion b	y the	NGOs																			

Exercise (continued)

This table gives the estimated time intervals (in days) between each event identified in the timelines of the 2006/7 outbreak of RVF in Kenya.

Timeline	Sangailu	Ijara	Kotile	Fafi	Saka	Alango- Arba	Mansabu bu	Sareto	Hara	Dalolow an	Shantaba k	Weza	Diizo	Median
Rain – Mosquito	20	60	20	20	20	20	30	20	20	20	50	60	70	
Mosquito- Animal	0	20	10	0	30	20	0	20	50	50	20	20	10	
Animal – Human	40	10	10	0	-	20	0	10	10	-	-	50	60	
Animal – Intervention	-	60	80	80	30	130	50	30	-	-	-	80	80	
Human - Intervention	20	40	70	50	-	10	40	20	-	-	-	40	30	

Determine the median and range for each event. Describe the patterns manifested in the RVF timeline and compare this with the expected sequence of events based on conventional epidemiological knowledge. List the observations that can be drawn from the timeline.

From: Jost, C.C., Nzietchueng, S., Kihu, S., Bett, B., Njogu, G., Swai, E., Mariner, J.C. 2010. Participatory Epidemiological Assessment of the Rift Valley Fever Outbreak in Kenya and Tanzania in 2006 and 2007. American Journal of Tropical Medicine, 83(Suppl 2), 2010, pp. 65–72.

Dispersion refers to the spread of the values around the central tendency.

- The *deviation* is how far a particular observation deviates from the mean.
 - Deviation can be expressed mathematically as $x_i \overline{x}$, where the first variable represents the mean, and the second variable represents the observation of interest.
 - The deviation of 15 from the set of observations 15, 15, 15, 20, 20, 21, 25, 36 is
 5.9
 - Deviation = $x_i \overline{x}$; deviation of 15 = 20.9 15 = 5.9
- The *range* is the highest value minus the lowest value, and gives an idea of how far the observations spread out from the central tendency.
 - The range of 15, 15, 15, 20, 20, 21, 25, 36 is 21
 - Range = 36-15 = 21
- The *variance* is how much all the observations vary from the observed mean.
 - Variance can be expressed mathematically as $\sum_{i=1}^{n} (x_i x_i)^2 / n 1$, or the sum of
 - $x_i \overline{x}$ squared, and then divided by the total number of observations (*n*) minus 1.
 - The variance of 15, 15, 15, 20, 20, 21, 25, 36 is 50.1
 - This table shows the variance formula broken down to its component parts and used to calculate the variance of 15, 15, 15, 20, 20, 21, 25, 36

Observation value	Mean	Deviation $x_i - \overline{x}$	Squared deviation $(x_i - \overline{x})^2$	Observations minus one (n – 1)	$(x-\overline{x})^2/n-1$
15	20.9	5.9	34.8	7	5.0
15	20.9	5.9	34.8	7	5.0
15	20.9	5.9	34.8	7	5.0
20	20.9	0.9	0.8	7	0.1
20	20.9	0.9	0.8	7	0.1
21	20.9	-0.1	0.0	7	0.0
25	20.9	-4.1	16.8	7	2.4
36	20.9	-15.1	228.0	7	32.6

- So, variance = $\sum (x_i x)^2 / n 1$ = 5.0+5.0+0.1+0.1+0.0+2.4+32.6 = 50.1
- The *standard deviation* (σ): is the square root of variance and gives the spread around the mean. That is how far away numbers on the list are from their average.
 - o The standard deviation of 15, 15, 15, 20, 20, 21, 25, 36 is 7.1

•
$$\sigma = \sqrt{\mathring{a}(x_i - \overline{x})^2 / n - 1} = \sqrt{50.1} = 7.1$$

- The *lower quartile* is the median of the numbers that occur before the median of a set of observations, and the *upper quartile* is the median of numbers that occur the median of a set of observations.
 - The lower and upper quartiles of 15, 15, 15, 20, 20, 21, 25, 36 are 15 and 25, respectively.
 - Lower quartile = median of 15, 15, 15, 20 = 15
 - Upper quartile = median of 20, 21, 25, 26 = (21+25)/2 = 23
- The *upper and lower percentiles* are value below and above which a certain percent of observations fall. The 25th percentile equals lower quartile, 50th percentile equals the median and 75th percentile equals the upper quartile. Often we report the 10th and 90th percentile of our set of observations for a variable:
 - The 10th percentile of 15, 15, 15, 20, 20, 21, 25, 36 is 15.0
 - The 90th percentile of 15, 15, 15, 20, 20, 21, 25, 36 is 28.3
- The *coefficient of variation* s is the ratio of standard deviation to the mean. It is useful for comparing multiple series of data with different units or means.
 - Coefficient of variation can be expressed mathematically as $c_v = S / M$, where σ is the standard deviation and *m* is the mean.
 - o The coefficient of variation of 15, 15, 15, 20, 20, 21, 25, 36 is 0.3

• $c_v = S / M = 7.1/20.9 = 0.3$

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Example

Analysis of simple ranking data

Five interviews were conducted with different groups of community members. In each interview the respondents were asked to rank childhood health conditions by the greatest risk they pose in terms of mortality. The results, analyzed to derive final rankings, are shown below:

	Group1	Group2	Group3	Group4	Group5	Total	Rank
Pneumonia	1	1	2	1	1	6	1
Measles	2	2	1	2	2	9	2
HIV/AIDS	3	3	3	4	3	16	3
Malnutrition	4	5	4	5	4	22	4
Diarrheal diseases	5	4	5	3	5	22	4

Based on the results from the five groups, pneumonia causes the greatest amount of childhood mortality, malnutrition and diarrheal diseases the least. However, a sixth group was interviewed, and added the following information:

	Group1	Group2	Group3	Group4	Group5	Group6
Pneumonia	1	1	2	1	1	1
Measles	2	2	1	2	2	2
HIV/AIDS	3	3	3	4	3	3
Malnutrition	4	5	4	5	4	
Diarrheal diseases	5	4	5	3	5	4
Injuries/accidents						5

The respondents in the sixth group did not mention malnutrition, but added another health condition – injuries and accidents.

Example (continued)

With the information from the new group, you may want to analyze the data like this:

	Group1	Group2	Group3	Group4	Group5	Group6	Total	Rank
Pneumonia	1	1	2	1	1	1	7	2
Measles	2	2	1	2	2	2	11	3
HIV/AIDS	3	3	3	4	3	3	19	4
Malnutrition	4	5	4	5	4		22	5
Diarrheal diseases	5	4	5	3	5	4	26	6
Injuries/ accidents						5	5	1

However the above is incorrect, because there are groups who did not score every condition. Convert the original ranks to scores. Because the number of health conditions is six, the lowest score would be 1 and highest 6. For each group the health condition ranked 1 is given a score of 6, the condition ranked 2 is given a score of 5, etc. Our results are:

	Group1	Group2	Group3	Group4	Group5	Group6	Total	Rank
Pneumonia	6	6	5	6	6	6	35	1
Measles	5	5	6	5	5	5	31	2
HIV/AIDS	4	4	4	3	4	4	23	3
Malnutrition	3	2	3	2	3	-	13	4
Diarrheal diseases	2	3	2	4	2	4	16	5
Injuries/ accidents	-	-	-	-	-	2	2	6

Now we can see that pneumonia causes the greatest amount of childhood mortality, injuries and accidents the least.

However, before analyzing data derived from ranking exercises, it is good to assess the data to make sure that the rankings provided by the different groups are substantially in agreement with one another. In other words, we estimate rank correlation coefficients. Only after ascertaining that the observers are in agreement should we derive and report a composite rank.

The method for computing rank correlation coefficient depends on the number of rankings (*m*). If we only have two rankings (m = 2), *Spearman's rank correlation coefficient* is computed. This is denoted by r_s , and is derived as:

$$r_s = 1 - 6 \sum_{i=1}^n d_i^2 / (n^3 - n)$$

where d_i equals the difference between the two ranks assigned to the *i*th individual, and n is the number of objects. (range from -1 to +1)

If we have more than two rankings (m > 2), a measure known as *coefficient of concordance* is computed. This is denoted by *W*, and is derived as:

$$W = 12 \cdot S / m^2 (n^3 - n)$$

where *S* equals the sum of squares of the deviations of the total of the ranks assigned to each individual from m(n+1)/2. The quantity m(n+1)/2 is the average value of the totals of the ranks, and hence the *S* is the usual sum of squares of the deviations from the mean. *W* ranges from 0 to 1, 0 denoting no agreement and 1 complete agreement.

Exercise

Spearman's rank correlation

Two groups of women were interviewed. They mentioned six reproductive outcomes that they feared could cause death. Then they ranked those outcomes, with number one being the outcome they feared the most and six being the outcome they feared the least. The results are presented below.

	Group 1	Group 2	Difference in ranks $= d$	d^2	$\frac{d^2}{n^3 - n}$			
Severe bleeding	4	4						
Infections	1	2						
Unsafe abortions	6	5						
Ecampsia	5	6						
Obstructed labour	3	1						
Other indirect causes	2	3						
Total								

Ranking of fear of reproductive outcomes affecting maternal mortality (n = 6)

Please calculate the Spearman's rank correlation coefficient by first completing the table. Then calculate:

 $n^{3} - n =$

 $r_s = 1 - (6*) =$

Should we derive a composite rank from these two groups?

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Exercise

Coefficient of concordance

Three groups of women were interviewed. They mentioned six diseases that were common in children in their area. Then the ranked the diseases, with number one being the most prevalent disease and six being the least prevalent. The results are presented below.

	Group 1	Group 2	Group 3	Sum of ranks	Deviation from m(n+1)	Squared deviations
Accidents/injuries	5	2	4			
Malnutrition	4	3	1			
Diarrhea	1	1	6			
Measles	6	5	3			
Malaria	3	6	2		I	
Pneumonia	2	4	5			

Ranking of childhood diseases by prevalence

Please calculate the coefficient of concordance (*W*) by first completing the table. Then calculate:

 $n^{3} - n =$

m(n+1)/2 =

Should we derive a composite rank from these three groups? W > 0.26 = weak; 0.26 - 0.38 = moderate; >0.38 = good

17.3. Study design with analysis in mind

Inferential analysis allows one to evaluate association between variables, usually an *exposure of interest* and *outcome of interest*. This is important for assessing the impact of interventions, such as an intervention to control a disease. Three conventional study designs are most often used to assess impact, or the association between an exposure and an outcome:

- *Cross-sectional:* A sample of subjects is identified, and information on the exposure and outcome of interest is collected at a specific point in time. This type of study is often used to assess prevalence.
- *Cohort (longitudinal):* Like in a cross-sectional study, a sample of subjects is identified. The subjects are then followed over time to see who develops the outcome of interest and who does not. The histories of the subjects can then be analysed to identify exposures, usually called risk factors, positively associated with the individuals who develop the outcome of interest, but not associated with those who don't. This type of study is often used to assess incidence.
- *Case-control:* A sample of subjects with the outcome of interest, which serves as the 'cases', is paired with a sample of similar subjects that do not have the outcome of interest, who serve as the 'controls'. Data is collected from both groups to find the exposure(s) positively associated with the cases, but negatively associated with the controls.

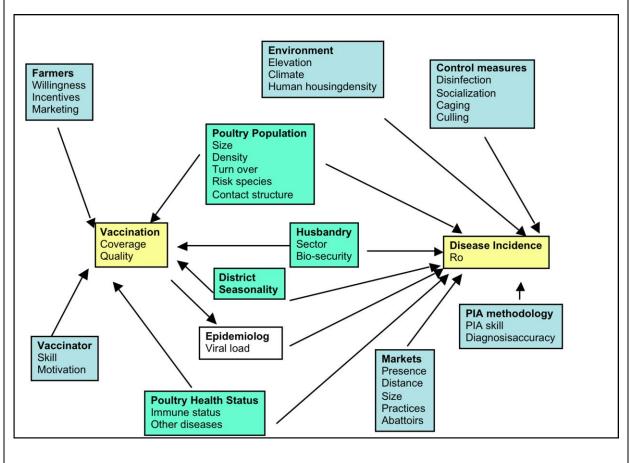
With all of three of these study designs, the investigator should have some idea about the exposure of interest, and the variables related to them, so that they can be measured during the study. Most epidemiologists develop a *causal web diagram* to help them think about all the variables involved, and which ones they should measure:

- The exposure and outcome variables
- Variables that have direct influence on either the exposure or the outcome
- Potential confounding factors that influence exposure-outcome relationship
- Intervening variables for the exposure outcome relationship

As a general rule of thumb, we don't need to measure intervening variables, although we may want to as a surrogate in cases where we cannot measure the actual exposure or outcome.

Example

A causal-web diagram was drawn by investigators designing a longitudinal study to measure the impact vaccination against H5N1 in backyard and small-scale commercial poultry would have on the incidence of the disease in West and Central Java, Indonesia. The exposure and outcome variables are in the yellow boxes, variables that directly influence the exposure or outcome in blue, potential confounding variables that may influence both the exposure and outcome in green, and variables that intervene between the exposure and outcome in white.



From ILRI. 2011. Operational Research in Indonesia for More Effective Control of Highly Pathogenic Avian Influenza final report. Submitted to the United States Agency for International Development under cooperative agreement No. 497-A-00-07-00021-00.

17.4. Designing a participatory epidemiology study

Participatory epidemiology is about problem solving with PRA tools. When designing a study, it is a good idea to focus on areas where the strength of participatory epidemiology, namely its qualitative nature, can produce reliable evidence alone or compliment more conventional approaches. Participatory epidemiology can be used in various ways, including:

- As a study's exclusive method
- To gather qualitative information prior to designing a larger conventional study so as to inform study design
- In conjunction with a conventional study so as to provide context and depth of information to quantitative results
- After a conventional study to probe results and conclusions

Examples of potential applications of participatory epidemiology to the study of real world situations are:

- Identifying the initial source of Ebola hemorrhagic fever outbreaks in remote areas
- Studying transmission dynamics of meningitis in traditional communities
- Identifying the source and transmission dynamics of repeated cholera outbreaks
- Any disease where the actual situation (incidence, prevalence, treatment stocks, etc.) is different from what is expected, or is unknown

When designing a participatory epidemiology study, the objective should be achievable and focused, not too broad and of finite scope. An example could be to determine the relative prevalence and importance of meningitis in a district.

A *hypothesis* is a question you want to answer in a way that scientists raise questions. The goal is to determine whether the hypothesis is true or not. In participatory epidemiology, you can refine your hypothesis as you carry out the study. This added flexibility allows us to discover new and unanticipated information that would not be evident were we to stick to a rigid study

plan guided by a hypothesis that could not evolve. The questions you ask get more specific as you refine your hypothesis.

As with any other research project, a participatory epidemiology study should include the following elements:

- Study goal
- Study objective(s) or specific aim(s)
- Initial hypothesis
- Study area
- Study population
- Sampling methodology
- Participatory epidemiology methods
 - Key informants list
 - Secondary sources of information
 - Checklist
 - Case definitions
- Conventional methods
- Biological testing methods
- Data recording and analysis plan
- Reporting and dissemination plan
- Confidentiality protection
- Other ethical issues and concerns
- References

Tips for participatory epidemiology studies

- The best information generally comes in the first hour: keep interviews as close to one hour as possible.
- Checklists may be too long for an hour. Do not feel that you must cover an entire checklist in a single interview. As your study moves along continuously analyze your

results to see where a certain subject has not been researched in enough depth, so that you can make a point of addressing that subject first in your next interview.

- The checklist should be designed to meet the study's objectives, not to exhaust all possible information related to a disease or issue. A frequent beginners mistake is to develop a checklist that is too ambitious to be achievable.
- If relative incidence and importance to the community is essential, a scoring exercise such as proportional piling is required.
- Get out of town as soon as possible. Rural areas tend to be less complicated working environments. A common problem is that it may be difficult to determine the best location for the first visit based on information gathered in town.
- The only truly valid way to determine prevalence is by conducting random sampling. Participatory epidemiology may be best used to provide an overview from which a quantitative survey can make better use of resources.
- Selecting appropriate key informants and secondary sources of information is critical. Don't shortchange your study by limiting the amount of this type of information you gather.
- Crosscheck everything you hear from various sources, including health centers and key informants. Remember, a good rule of thumb is confirmation of information by at least three sources makes it a finding.
- Begin your study in a place thought to be most affected by the disease you are investigating. Take a risk-based approach to identifying the place. This will help you become quickly familiar with the disease as it occurs in your study area.
- Random sampling vs. risk-based sampling Traditional studies rely on random sampling, but when time and resources are limited risk-based sampling provides quick and inexpensive information. As an example, if you are expected to go to battle tomorrow and you want to know about your enemy's resources and attack strategy, would you prefer to design a questionnaire or capture a few captains to serve as informants? Surveys conducted by random sampling are good but require a much longer time frame and resources.

Day Six

18. Field Practice 3

The objective of this field practice is to facilitate a community discussion on behavior change communication with regards to safe water treatment. You are encouraged to explore facilitators, barriers and other determinants of behavior, identify doers and non-doers, and discuss possible solutions. The discussion should focus on previous messages and interventions in the community, and reasons why they do or do not treat their drinking water. Most importantly, the community should be asked to identify solutions so that they no longer face behavioral barriers to treating drinking water all the time. You should discuss beforehand what barriers and facilitators you expect to find, and how you intend to assist the community in resolving them. You will be expected to suggest behavior change communication approaches for the community that you visit.

Please make a point to practice the tools used in participatory epidemiology that you have learned. Follow the same three phases to organizing your fieldwork: preparation, field and review, including preparation of a report to be presented for feedback.

When you are reporting back during the feedback sessions, you should now add how you chose to analyze your data, and the results you obtained. Based on the results of your analysis, have you proved or disproved your hypothesis? What conclusions can you draw from your study? What questions remain, and what are your suggested approaches for answering those questions? If you propose a follow-on study, how would you design that study?

In preparation for your fieldwork, consider and discuss with your team the following questions:

- Why do some individuals not treat their drinking water?
- Why do some communities not treat their drinking water?
- What are some solutions at the individual level to overcome not treating drinking water?

• What are some solutions at the community level to overcome not treating drinking water?

Based on the insights you gain, generate a checklist for your discussions with the community. Items that you may want to consider including are:

- Introduction/community rapport
- Background
- H2O sources
- H2O uses
- Methods of treating H2O (if at all)
- Vessels to transport H2O
- Health problems associated with H2O (susceptibility)
- Feelings re: H2O treatment
- Benefits of H2O treatment
- Reasons for not treating H2O (barrier analysis): Assess the degree of each reason as barriers
- Identify doers & non-doers
- Those affected mostly by water-borne diseases (susceptibility, severity)
- H2O storage
- Previous messages/interventions
- Possible messages/interventions what would work in this community?
- How to measure behavior change
- Advocacy issues
- Questions/Answers
- Thank you

This list of potential items, though it can be expanded, contains far too many items for one team to cover. You and your team may want to communicate with the other teams in your training to add items to the list. Then you can split up the list between the different teams, so that each team has a reasonable number of topics to cover.

19. Childhood Morbidity and Mortality

Session Learning Objective

By the end of the session, participants will be able to:

1. Discuss and advise others on common and important diseases that affect children under five

It is important that you have a reasonable understanding of common and important health problems affecting children, and are conversant to the degree that you can comfortably and accurately address the concerns of stakeholders when they arise during your work. If you are a physician, this may not be challenging. But if you are veterinarian or wildlife ecologist, it may be very intimidating indeed!

Please take a minute to think about the diseases that children suffer from in the area where you work. Can you list them, their disease determinants, and prevention and control measures? They most likely include some or all of the following: diarrheal diseases, pneumonia, malaria, malnutrition, measles, congenital disorders, accidents/injuries, epilepsy, skin infections, etc.

Please make a note to familiarize yourself with standard advice for various conditions, such as government policies on access to treatment for malaria or epilepsy, and recipes for oral rehydration solutions. Also familiarize yourself with the public and non-governmental initiatives for disease prevention and control that are being implemented in the area where you work. Questions regarding resources and policies often come up during interviews in communities that have public health problems. Make sure to discuss your work with public health resource persons in your area and have their contact information on file, so that if you cannot address the questions of community members you can put them in contact with resource persons who can.

Colleagues in your training program will likely be able to point you in the right direction, or even be the resource people you need!

Oral Rehydration Therapies				
SSS (Sugar & Salt Solution)	ORS (Oral Rehydration Salts)	ORS + Zinc		
1 teaspoon salt	1 packet	1 packet		
8 teaspoons sugar 1 liter water	1 liter water	1 liter water		

Exercise

Please think about the four or five most important diseases that young children suffer from in the area where you work. In the table below list them across the top. Then write into each cell what you know about the different determinants for each disease. Are you missing information? Where can you go to learn more? What organization is working on that disease problem in the community?

	Example:	Disease 1:	Disease 2:	Disease 3:	Disease 4:
	diarrheal				
	diseases				
Pathogen	Rotavirus, etc.				
Transmission					
Clinical signs					
Differentials					
Treatment					
Control					
Prevention					
Risk factors					
Morbidity					
Mortality					
Ages affected					
Gender affected					
Information sources					
Helpful organizations					

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Day Seven

20. Tools: Ranking & Scoring 3

Session Learning Objectives

By the end of the session, participants will be able to:

1. Demonstrate the use of proportional piling for morbidity and mortality, and analyze data generated using this tool

Proportional piling for morbidity and mortality is a specific application of the proportional piling technique to determine the relative morbidity, mortality and case fatality of different diseases. The advantages of this method are: 1) it does not require the actual number of individuals in the group to be known, and 2) it compares the morbidity and mortality of different diseases. This can reduce bias towards an individual disease problem.

Method

- 1. Use a pile of 100 counters to represent all of the individuals in the population under consideration.
- 2. Ask the participants to divide the counters to show what proportion of the population was healthy and what proportion became sick in the last year.
- 3. Using the list of diseases already given during the interview, put the disease names on cards, or use pictures to represent the diseases. In general it is best to use no more than 4-5 diseases, otherwise the division of the counters will get difficult near the end of the exercise. You can put all other mentioned diseases under a category "other diseases".
- Using the counters representing all those who became sick in the last year, ask the members to divide the counters to show the proportion that suffered from each of the diseases on the cards.

- 5. Taking one disease at a time, ask the group to use the counters allocated to that disease to show what proportion died and what proportion recovered.
- 6. Count the counters at the end, when the group has finished scoring every condition.
- 7. Summarize and crosscheck the results with the participants.

Note: The exercise can be repeated for different age groups and genders within a community. For example, the exercise could be conducted with older women and then repeated for younger women and girls to determine if different morbidity, mortality or case fatality rates are seen for unsafe abortions.

Tips

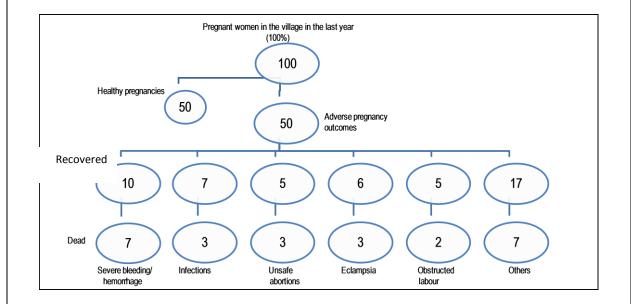
- The method works well with either individuals or groups of informants. If working with a group of informants, it is important that they are able to reach a consensus. Listen carefully to the discussion while they are debating the proportion of counters to place with each category. This debate can provide important information for probing and triangulation.
- Having the criteria for the exercise in mind before beginning to avoid confusion.
- Movements of individuals into and out of the community can be very complex. In some cases, it makes sense to define 'community' as the group of individuals living in a defined area over a particular time period, or to ask the informants to classify all of the individuals present in their village.
- This method looks at the relative proportion of diseases observed during a given time period, rather than diseases affecting individuals. So if a given individual suffers from two or more diseases during the period in question, it doesn't matter, as the purpose is to avoid categorizing individuals.
- The strength of this exercise is that we do not need to know the number of people in the community. The method gives us proportions, not absolute numbers.

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Example

Perinatal morbidity and mortality

Women in a village said the major conditions affecting pregnant women in their area were: severe bleeding/hemorrhage, infections, unsafe abortions, eclampsia and obstructed labor. They said a few other diseases occurred infrequently. Completing a proportional piling exercise for morbidity and mortality with the women, the research team found the following:



Results:

Overall Maternal morbidity (all causes) = 50/100 = 50%

Overall Maternal mortality (all causes) = (7+3+3+3+2+7)/100 = 25/100 = 25%

Overall Maternal case fatality is (7+3+3+3+2+7)/50 = 25/50 = 50%

Severe bleeding/hemorrhage morbidity = 10/100 = 10%, mortality = 7/100 = 7%, case fatality = 7/10 = 70%Infections morbidity = 7/100 = 7%, mortality = 3/100 = 3%, case fatality = 3/7 = 43%Unsafe abortions morbidity = 5/100 = 5%, mortality = 3/100 = 3%, case fatality = 3/5 = 60%Eclampsia morbidity = 6/100 = 6%, mortality = 3/100 = 3%, case fatality = 3/6 = 50%Obstructed labor morbidity = 5/100 = 5%, mortality = 2/100 = 2%, case fatality = 2/5 = 40%Other causes morbidity = 10/100 = 17%, mortality = 7/100 = 7%, case fatality =7/17 = 41%

21. Field Practice 4

The objective of this field practice is to investigate the main childhood diseases that affect a community, including those that are reportable.

Please make a point to practice the tools used in participatory epidemiology that you have learned. Follow the same three phases to organizing your fieldwork: preparation, field and review, including preparation of a report to be presented for feedback.

When you are reporting back during the feedback sessions, you should now add how you chose to analyze your data, and the results you obtained. Based on the results of your analysis, have you proved or disproved your hypothesis? What conclusions can you draw from your study? What questions remain, and what are your suggested approaches for answering those questions? If propose a follow-on study, how would you design that study?

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Day Eight

22. Participatory Disease Surveillance

Session Learning Objectives

By the end of the session, participants will be able to:

- 1. Define surveillance and describe different approaches to gathering surveillance information
- 2. Discuss the strengths and weaknesses of different approaches to surveillance
- 3. Design a PDS activity

22.1. Principles of surveillance

Surveillance is the collection of action-oriented information and intelligence within a realistic timeframe. Surveillance is information for action! When designing a surveillance system, it is very important to have the objectives of the system clearly defined. When the objectives are well defined, and the amount of available resources known, choosing the different components of a surveillance system is easy. Examples of surveillance system objectives include:

- Prevention and control of diseases
- Gather information for further planning
- Detect new outbreaks
- Follow up on a disease situation
- Assessment of the health status of a population
- Evaluation of control programs

The approaches most commonly used in national surveillance systems include:

- **Passive surveillance** involves the collection of disease reports, often from facilities that are designated reporting centers or through designated reporting channels. In national animal health surveillance systems, reports may be received from animal owners, veterinarians and other animal health care professionals, field-based and other public veterinary staff, laboratories, etc. A public health surveillance system may capture information from animal health surveillance, as well as physicians, hospitals, field-based and other public health staff, laboratories, members of the public, etc. Passive surveillance usually involves standardized reporting forms that flow through linear systems from the field to the national level. Large amounts of data can be easily collected, collated, stored and analyzed in this fashion. However, we must remember that case reporting is not a passive activity for the reporter. Therefore, limitations include non-reporting or under-reporting so that the information generated does not reflect the real situation, the perception on the part of the health care provider that a suspicion should not be reported unless a definitive diagnosis can be made, the perception on the part of the health care provider that nothing will be done if a report is made, lack of interest or compliance with the system, etc.
- Active surveillance involves outreach to detect specific diseases of interest, or for early detection of emerging or re-emerging diseases. In animal and human surveillance systems, outreach may involve visits to communities to learn from people if there are any disease problems, biological sampling of subjects, etc. Active surveillance is often guided by an understanding of risk, rather than randomized, so that the likelihood that the outreach will find a disease problem, if it exists, is enhanced. It usually involves personnel who have been trained in the active surveillance technique being used. Limitations may include scale, as active surveillance activities are best targeted rather than implemented on a large scale, variable results depending on the capacity of those carrying out the activity including the potential for misleading laboratory results, potential to miss cases if subjects mistrust the team or activity and hide cases from investigators, etc.

- Sentinel surveillance involves collecting case data from part of the total population to learn something about the larger population. The advantages of sentinel surveillance data are that they can be less expensive than those gained through active surveillance of the total population, and the data can be of higher quality than data collected through passive systems. Sentinels may be members of the normal population, or placed in the population for surveillance purposes. For example, a few unvaccinated individuals placed in populations of vaccinated chickens so as to detect a disease that would otherwise be subclinical in the population. Limitations include representativeness of the sample, scale, and human capacity to regularly sample the sentinel population.
- Special approaches are occasionally implemented to generate surveillance information that is not possible to acquire using other approaches. Special systems include *targeted studies* to better understand an epidemiological issue for inclusion in surveillance, and *targeted surveillance* in which high risk individuals, communities or areas are targeted to increase the likelihood of finding the disease. Participatory disease surveillance is a form of targeted active surveillance.

A well-designed surveillance system often includes elements of all four types of surveillance. By combining approaches, decision-makers are able to gather a variety of information to help them meet their surveillance objectives. The exact design of a system is often a reflection of objectives and available human and financial resources. Surveillance personnel need to have the capacity and time to effectively and accurately carry out the intended surveillance activities, and the necessary resources to conduct the activities on a meaningful scale. The cost of surveillance is more of a reflection of design than type of surveillance. For example, biological sampling is an effective way to find pathogens. However, when it used in isolation it must be carried out on a large and costly scale, usually randomized, to be effective in detecting diseases of concern. On the other hand, when less costly methods such as participatory disease surveillance or risk mapping are used to identify high risk areas, and then samples are taken from subjects in those areas, the scale and therefore the cost of the biological sampling activity is greatly reduced. The seven attributes of effective surveillance systems are⁷:

- *Simplicity:* The structure and ease of operation of a surveillance system. Surveillance systems should be as simple as possible while still meeting their objectives.
- *Flexibility:* The ability to adapt to changing information needs or operating conditions with little additional cost in time, personnel, or allocated funds. Flexible systems can accommodate new diseases and health conditions, changes in case definitions and variations in reporting sources.
- *Acceptability:* The willingness of individuals and organizations to participate in the surveillance system
- *Timeliness:* The speed or delay between steps in a surveillance system
- *Sensitivity:* The proportion of cases of a disease or health condition detected by the surveillance system as well as the ability to detect epidemics
- *Predictive value positive*: The proportion of persons identified as having cases who actually do have the condition under surveillance
- *Representativeness:* The ability of a surveillance system to accurately describe the occurrence of a health event over time, and the distribution in the population by place and person. Quality of data is an important part of representativeness.

Participatory disease surveillance as a component of a surveillance system helps the system to be sensitive, timely, representative and acceptable. Why do surveillance systems fail?

- Lack of defined objectives
- Lack of feedback to participants
- Lack of action

⁷ Adapted from Thacker S.B., Parrish R.G. & Trowbridge F.L. (1988). – A method for evaluating systems of epidemiological surveillance. World Hlth Stat. Q., 41 (1), 11-18. Erratum: 42 (2).

22.2. Participatory disease surveillance

Participatory Disease Surveillance (PDS) is the application of participatory epidemiology approaches to disease surveillance. It is a method of surveillance where participatory rural appraisal approaches are used to establish the presence or absence of a specific disease in a particular area. It is the collection of action-oriented information and intelligence within a realistic timeframe (information for action). It is commonly used for active surveillance, and is supported by laboratory diagnostics.

In PDS, the investigator uses outbreak reports and risk factors to determine the target areas to search for a disease of interest, and areas most likely to harbor the disease are chosen for investigation. As a PDS investigation is carried out and information is gathered, the investigator will follow the evolving information to continuously narrow down on the location of the disease. The investigator makes contact with informants who are likely to know about the local disease situation. Community members' knowledge and experience (existing knowledge) forms the bulk of the information gathered, as community members are the ones with first-hand experience with the disease. A range of tools and methods are used that are open-ended and flexible, and can be used to crosscheck information gathered.

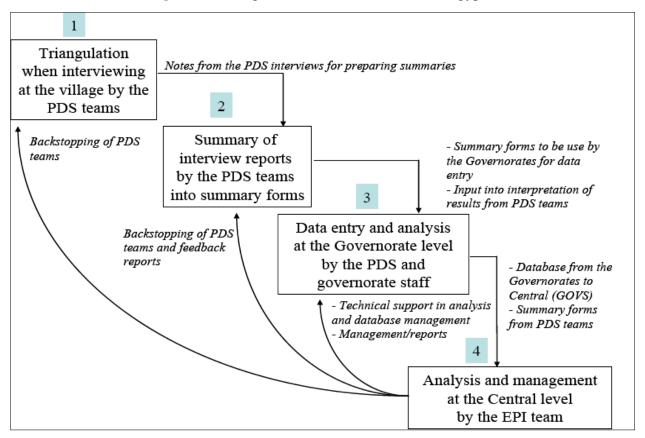


Figure: PDS algorithm for avian influenza in Egypt⁸

The strength of PDS is that it is sensitive, timely, and cost-effective compared to conventional methods involving random sampling and laboratory testing, because the method of sampling is purposive or risk-based rather than random. Surveillance using conventional methods tends to be costly, logistically complicated and slow; the result may also be difficult to interpret in the absence of qualitative intelligence. The objectivity and specificity of the quantitative data collected using these methods is necessary for declaring disease freedom to international standards. A surveillance system is most powerful when a combination of both qualitative and conventional methods are applied. PDS should be linked to a field or laboratory diagnostic test to maximize the accuracy of the case finding methodology. Laboratory-based tests for definitive diagnosis are critical in disease-free situations.

⁸ From Jones, B. and ElMasry, E. (2009) Participatory Disease Surveillance Training Course, Fayoum, 28th June – 8th July 2009. Report from ILRI for FAO ECTAD, Egypt. Pages 57

23. Field Practice 5

With the information you have gathered from your field practices to date, you will need to decide on a childhood health topic that you will study in your final two field practices. Please use the Proposal Format for a Participatory Epidemiology Study in the appendixes to organize your planning.

First you will need to decide on an objective for your study. Choose an objective related to child health. With your training colleagues, you may decide that all the practice groups will work on the same objective, or that each group will work on its own objective. Example objectives are:

- Determine if childhood diarrhea is a problem in the target area and its significance
- Compare surveillance statistics for measles to community experiences in the last year
- Determine vaccination coverage for children under five years of age in the target area
- Identify the common practices for prevention of childhood disease in the target area
- Explore the community's behavior regarding treatment of drinking water for children
- Determine the impact of the last major outbreak of childhood disease on the community

Now create a checklist for your study. If all the practice groups will be working on the same objective, you may decide to produce a single checklist to be used by all the groups, or different checklists for each group. For each item on the checklist, decide on participatory epidemiology tools that you will use to explore that topic. If all the groups are using the same checklist, then you will likely want to group all the data together in the end for analysis. So be sure that everyone in the training is very clear on the criteria to be used for each topic. For example, will you be determining the importance of childhood diarrhea in terms of prevalence or its impact of on kid's livelihoods, or both?

It is important to remember to crosscheck information. Comparing information from the other teams is a valuable method. Recall the importance of probing, triangulation, weighing of evidence, identifying conflicts of interest, and obtaining laboratory diagnostics.

Most likely, community members will ask you for advice on the topics that are discussed. Brainstorm important advice that you would like to relay. This should include government policies and initiatives, as well as generic advice about childhood diseases. It should also include the actions to be taken for a suspected case of an important childhood disease. Depending on the objective of your study, and therefore the topics you will be discussing with community members, examples of important information that you could share include:

- Importance of disease reporting, especially incidents of high morbidity or mortality
- Early health seeking behaviors and contact with health workers
- Immediate consultation with health care facility for child for clinical examination
- Obtaining appropriate diagnostics, sample collection & laboratory testing
- Measures to combat malnutrition and ensure a healthy diet
- Importance of complete immunization for all children
- Healthy living conditions
- Encourage consultation of public health facilities rather than traditional healers
- Recipe for ORS
- Stocking ORS packets for when needed
- Free or subsidized malaria treatment for children under five
- Free or subsidized insecticide treated bed nets for new mothers
- Personal hygiene
- Proper sanitation and latrine location

Please make a point to practice the tools used in participatory epidemiology that you have learned. Follow the same three phases to organizing your fieldwork: preparation, field and review, including preparation of a report to be presented for feedback. When you are reporting back during the feedback sessions, you should now add how you chose to analyze your data, and the results you obtained. Based on the results of your analysis, have you proved or disproved your hypothesis? What conclusions can you draw from your study? What questions remain, and what are your suggested approaches for answering those questions? If propose a follow-on study, how would you design that study?

Day Nine

24. Planning a Participatory Epidemiology Study or PDS Activity

After this training, you will conduct a participatory epidemiology study, or PDS activity, for 15 days. This will provide you an opportunity to practice and master your new participatory epidemiology tools. We suggest you carry out your study in a team of 2 - 3 people. Your team members can be colleagues from your training, or other participatory epidemiology practitioners.

Exercise

Post-Module Project

Following your training, you will conduct a 15-20 day participatory epidemiology study or PDS activity. The purpose of the study is for you to practice your new skills in participatory epidemiology by investigating a disease condition, learn about community perceptions, conducting surveillance, etc. It is best for you to conduct this activity in a team of 2-3 people. With your teammates please choose a disease condition and develop a plan for your activity. Please design your activity so that you can practice as many of your new participatory epidemiology tools as possible. Here is a reminder of your toolbox:

Informal interviewing	Ranking & Scoring	Visualization
Semi-structured interview and	Simple ranking	Mapping
checklist		
	Pair-wise ranking	Venn diagrams
	Proportional piling	Transect walks
	Proportional piling for morbidity &	Seasonal
	mortality	calendar
	Matrix scoring	Timeline
	Disease impact matrix scoring	

Please use the Proposal Format for a Participatory Epidemiology Study in the appendixes to organize your planning. Design your activity with your teammates, and share it with a participatory epidemiology trainer for feedback and suggestions. Keep the contact information for your trainer handy while you carry out your activity, so that you can ask him or her any questions as your activity progresses. After your activity, organize and analyze your data with your teammates and prepare a report on your findings. Send your report to your trainer for feedback and suggestions. Once you and your teammates have addressed this feedback, you can submit it to your supervisor and the community you worked in. Always remember to include a feedback plan, where you return your findings to the community verbally or in writing.

25. Field Practice 6

This is your final day of field practice! What tools do you still feel weak in? Please make a point of practicing them today. Have you tried disease impact matrix scoring? Instructions for this tool are available in the appendixes. Follow the same three phases to organizing your fieldwork: preparation, field and review.

When you are reporting back during the feedback session, present your findings from this last day of practice. As well, you should synthesize your findings from all six practice days!

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Day Ten

26. Review of all field practice exercises

To reinforce *data for action*, you should keep a log of significant issues from each of the communities visited, in order for your experiences to become valuable advocacy tools. Priority health concerns should be identified (e.g. rank of most important communicable diseases, lack of water supply, no access to health care within 10km, etc.). Health recommendations for each community should be clearly identified (e.g. subsidized insecticide treated mosquito nets or water treatments, a borehole, nutrition education, education on stigma reduction of epileptics/the disabled/people with AIDS, etc.). You can include observations not discussed with the community as well, if appropriate (e.g. school aged children not in school). A table is provided for you in the appendixes for recording these observations.

The purpose of this session is to identify common themes, priority health issues and recommendations, and to summarize the findings into a presentable format (e.g. 1 or 2 page report or a short Power Point presentation). You should also identify key stakeholders and responsible individuals or agencies who are in positions to respond effectively to your recommendations, and who can act on the lessons learnt. You may also wish to share the report with contributing communities as well.

With your training colleagues, you should decide on a suitable strategy to finalize and communicate your findings, and be prepared to act accordingly.

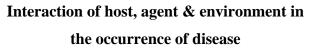
Appendixes

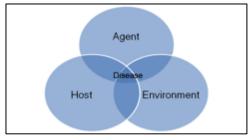
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Handout 1: Basic Epidemiological Principles

Epidemiology: the study of the distribution and determinants of disease in specified populations, and the application of this study to the control of health problems.

The Epidemiologic Triad: In infectious disease epidemiology, disease occurs due to the interactions among the **host** (person/animal), the **agent** (e.g. viruses, bacteria) and the **environment** in which the host and the agent are present. The factors influencing the occurrence of disease are called **determinants**.





Stress	Social context
Genotype	

Examples of disease determinants related to

Agent- associated determinant s	Host- associated determinant s	Environment -associated determinants
Virulence	Age & Sex	Location
Pathogenicity	Immune	Climate
	status	Husbandry

Case Definition: In order to count cases, the epidemiologist first defines what constitutes a case. A case definition is a set of standard criteria for classifying whether an individual has a particular disease, syndrome, or health issue.

Descriptive Epidemiology: Identifies patterns among cases by describing "who, what, where, and when." The information is used to develop hypotheses about causes, risk factors and modes of transmission.

Analytical Epidemiology: Allows for testing hypotheses about the causes, risk factors, or modes of transmission of disease developed using descriptive epidemiology by using a comparison group with different exposures or disease outcomes. Analytical epidemiology quantifies the association between exposures and outcomes.

Types of Data:

- Quantitative data is a measure of "how much" of something and is expressed as a specific quantity with a unit. For example, a distance of 10 km is a quantitative measure.
- Qualitative data is descriptive and considered more subjective than quantitative data. Instead of a specific quantity and unit of measure, in qualitative terms, a distance might be described as "farther" than another.
- Semi-quantitative data has been assigned a numeric quantity but the unit of measure may be irregular. Semi-quantitative data is often created from qualitative data by using systems of ranking or prioritization.

Measures of Central Tendency: Quantitative and semi-quantitative data can be summarized by a central value that best represents the distribution of data.

- Mean: (average) the most common measure of central tendency, calculated by adding all the values in a group of measurements and dividing by the number of values in the group;
- Median: the measure of central location that divides a set of data into two equal parts, above and below which lays an equal number of values. It is the middle value of a set of data in rank order, and

• **Mode:** the most frequently occurring value in a set of observations. It is determined by tallying the number of times each value occurs.

Measures of Frequency: Frequency measures compare one part of the distribution to another part of the distribution, or to the entire distribution. They can be used to compare health status of one population with another or the health status of a sub-population with the entire population. Common frequency measures are **ratios**, **proportions**, and **rates**.

- **Incidence** is the **proportion** of new cases of disease or injury in a population over a specified period of time;
- **Prevalence** is the **proportion** of individuals in a population who have a particular disease or attribute at a specified point in time or over a specified period of time. Prevalence differs from incidence in that it refers to all cases of disease during a period of time rather than only new cases, and
- **Case Fatality Rate** is a proportion, not a rate. It is the **proportion** of individuals with a particular disease that die from that disease. It is calculated by dividing the number of dead individuals from a given disease by the number of individuals sick with that disease within a population.

Handout 2: Summary guidelines for Semi-structured Interviews

- Prepare yourself: Define the topic you want to investigate, write an interview guide/checklist, and determine who it is you would like to interview. Discuss the purpose of your visit with the local authorities. If possible, bring an assistant along as a note-taker and a translator, if necessary.
- 2. Choose a convenient time and a comfortable setting: Interviews should be held in a quiet and comfortable location at a convenient time for the participants. Traditional community meeting sites make good group interview sites. Official offices should be avoided.
- 3. **Introduce yourself, your team and the purpose of the meeting:** Your informants will want to know why you have come and why you have an interest in the selected topic. Be careful not to raise expectations regarding follow-up.
- 4. Watch your body language throughout: Be friendly, informal, and respectful.
- 5. **Start with general questions/comments:** This will put people at ease. Ask only one question at a time.
- 6. **Mix questions with general discussion:** By introducing variety, you will keep up the interest of your informants. Casual dialogue will ensure good communication.
- 7. Use diagrams, symbols and other drawings: These will help in keeping people interested and ensuring everybody participates and understands.

- 8. Use simple language: Avoid 'scientific' words. Avoid leading questions, long or complicated questions, or questions that can be answered with simple, 'yes' or 'no'.
- 9. **Probe:** If an interesting point comes up, try and discover more. Six small words (why, how, who, what, when, where?) will help you to probe: keep them in mind throughout.
- 10. Observe: To make sure that everybody participates (especially women) and the conversation is not dominated by a few individuals. Also make sure that people are not getting restless (a sign they are getting tired). Normally 90 minutes is a maximum for group interviews and 60 minutes is ideal.
- 11. **When the interview is over:** Thank your informants and give them an opportunity to ask their own questions. This is polite and also will give you valuable information.
- 12. **Make full notes after the interview:** (unless you have a note taker) by just writing down the main points you will not slow down or interrupt the conversation.

Handout 3: Disease Impact Matrix Scoring

Disease impact matrix scoring is the same as simple matrix scoring except that the indicators (the impacts the different diseases have on livelihoods) are weighted before they are compared the categories (diseases). In effect, a proportional piling exercise is conducted with the indicators before the counters are distributed across the categories to create a matrix.

Method

The step-by-step example below shows how disease impact matrix scoring is done:

- Use the diseases mentioned by your respondents. When your respondents tell you the name for a disease in their language, use that name during the interview rather than an English or scientific name. That way everybody, respondents and research team alike, are on the same page. It is important that all of the diseases on your list pertain to the same category. For example, diseases of adults, diseases of children, or diseases of livestock.
- 2. Also develop a list of the benefits that the family receives from the category of individual being discussed. For example, if the category is adults, they may bring in an income, produce food on the farm, care for the children, provide shelter and teach the children about family traditions. If the category is chickens, they may provide food for the family, income from sales of eggs and hens, manure for the garden, feathers for pillows and animals for traditional sacrifices.
- 3. Use pictures, objects or cards to represent the benefits and place them on the ground. It will help you construct your matrix later if you place them vertically rather than horizontally (place them in a column rather than a row). Give your respondents 100 counters, and ask them to divide them to show the relative importance of the different benefits to the family's livelihood.
- 4. Record the results in your notebook. Each benefit will now serve as a row.

- 5. Now create the start or a matrix by placing the diseases mentioned by your respondents across the top of the matrix.
- 6. For the first benefit, ask your informants to use the counters they gave to that benefit to show how strongly each disease impacts a family's ability to have the benefit. For example, your respondents might show that HIV/AIDS has the greatest impact on a family's ability to bring in an income, flus the least. For chickens, your respondents might show that Newcastle disease has the greatest impact on their ability to earn an income from their chickens, coccidiosis the least.
- 7. Summarize and crosscheck for agreement on how they have scored.
- 8. Repeat for each benefit, gradually building up the matrix. Leave the matrix in place so that everyone can view the results and discuss as a group.
- 9. During the exercise and after the matrix is complete, it is essential that the investigator carefully probe the informants as to why they are scoring the way they are. After the matrix is complete, summarize the results and give the informants the opportunity to make changes if they wish. Ask your respondents what new learning or insights they have gained from the exercise.
- 10. Record the results in a matrix in your notebook. By adding up the columns you will derive the total score for each disease, showing which disease has the greatest negative impact on a family's livelihood.

Example

Here is an example of a disease impact matrix being built in Indonesia. The two diseases being scored, under the female interviewer's hand, are HPAI and Newcastle disease. The benefits that poultry bring to a family are in front of the male respondent. First the respondent completed a proportional piling exercise with 100 beans to show the relative importance of each of the benefits to his family's livelihood. Now his is showing the impact that the two diseases have on his family's ability to have each benefit. He has completed the first three, and now he is working on the fourth. Because she is unsure if the respondent can read, the interviewer is repeating the diseases and benefit with each piling. She is saying to the respondent, "Thank you, I can see that both diseases impact your family's ability to have poultry manure for your garden, but the impact of this disease called 'tetelo baru' is greater than this disease called 'tetelo'. Now, can you show me the impact these diseases have on your family's ability to eat eggs and chicken meat?"



Example

Disease impact matrix scoring in a study of the benefits of keeping poultry in Nigeria: Participants were about the benefits of keeping poultry. They listed the following benefits of keeping poultry: Hobby, source of income, food for the household, social status, gifts, ceremonies. With symbols for the benefits, the participants use proportional piling with 100 counters to show the relative importance of each benefit to a family's livelihood.

Benefit of poultry keeping	Score
Hobby	6
Source of income	48
Food for the household	17
Social status	5
Gifts	4
Ceremonies	20
Total	100

The participants were then asked to generate a list of common poultry diseases. They provided the following list: Fowlpox, NewCastle Disease (ND), Gumboro, coccidiosis, worms. A matrix was created with the diseases across the top, the benefits and their relative scores down the side. Participants used the counters from the first benefit to show the relative impact of the diseases on a family's ability to have that benefit. They repeated this exercise for all the benefits. The following results were obtained:

Benefit	Relative importance	Fowlpox	ND	Gumboro	Coccidiosis	Worms
Hobby	6	6	-	-	-	-
Income	48	-	40	3	5	-
Food	17	3	10	2	2	-
Social status	5	-	2	2	1	-
Gifts	4	4	0	0	-	6
Ceremonies	20	11	4	2	2	1
Total Impact		24	56	9	10	7

From Pissang, C., Okike I., and Hendrickx S. (2009) Participatory Epidemiology Refresher Training Report. Ibadan, Nigeria, 29 June - 04 July 2009, Pages 24

Handout 4: Proposal Format for a Participatory Epidemiology Study or PDS Activity

Note: This page is a guide that can be used to develop basic research protocols to ensure information for all required elements are included for review and approval.

PROJECT TITLE:

- 1. Principal Investigator(s):
- 2. Other participants in research:
- 3. Project Goals:
- 4. Project Objectives:
- 5. Program needs to be addressed:
- 6. Populations to be studied:
- 7. Methods:
- 8. Sampling Methodology:
- 9. Plans for data collection and analysis:
- 10. Confidentiality protections:

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- 11. Other ethical concerns/issues:
- 12. Projected time frame for the project:
- 13. Plans for publication and dissemination of the project findings:
- 14. Appendices, including informed consent forms:
- 15. References:

Handout 5: Local Language Lexicon Table

Local term (disease, clinical sign, treatment, etc.)	Language	Literal meaning	English term

Handout 6: Table for Recording Recommendations from Field Practice Days

Village Name, Location	Team Members	Priority Health Concerns	Recommendations & Suggested Interventions