

Community Needs Assessment and Data-Supported Decision Making:

Keys to Building Responsive and Effective Health Centers

November 2012



Judith Shea, MHSA

Jennifer Jones Santos, MSHS

Pamela Byrnes, PhD



NATIONAL ASSOCIATION OF
Community Health Centers

7501 Wisconsin Avenue, Suite 1100W

Bethesda, MD 20814

Phone 301.347.0400

Fax 301.347.0459

www.nachc.com

This publication was made possible by grant number U30CS16089 from the Health Resources and Services Administration, Bureau of Primary Health Care. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the HRSA.



The National Association of Community Health Centers provides technical assistance and support in the development of access to quality health care through community health centers. This monograph is intended to assist communities and organizations who are undertaking the development of new community health center clinics.

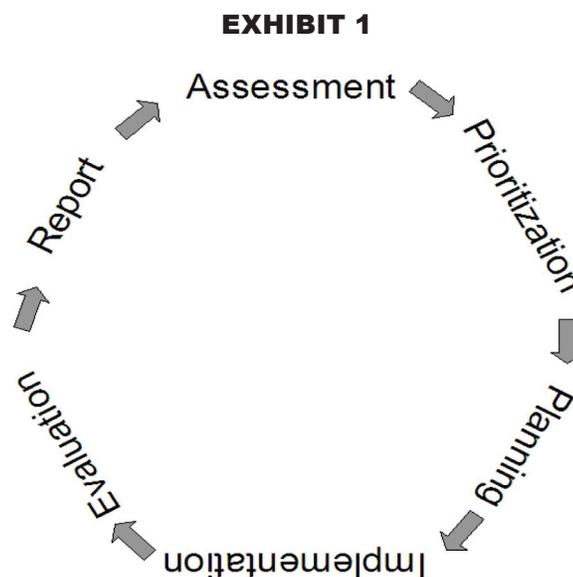
We thank all of the health center staff, board members, community volunteers, Primary Care Associations, staff of the Bureau of Primary Health Care, and everyone else whose daily experiences have contributed to the content of this guide and to building the health center movement.

Preface

An organization does its best work when that work is based on systematic and active planning, accurate assessments of need, and community knowledge. Community development, conscientious data collection, and complex analysis are key processes that contribute to establishing and sustaining Section 330 health centers.¹ These activities are the basis for developing services to meet the ongoing and often changing needs of diverse populations and underserved communities.

The purpose of this guide is to help you gather and analyze information that will allow you to understand the health problems, access issues, and barriers experienced by your community and potential patients, so that you can use that information to develop and implement patient programs.

The National Association of Community Health Centers (NACHC) has created this practical guide, which you can customize to the specific needs of your health center. **Community Needs Assessment and Data-Supported Decision Making: Keys to Building Responsive and Effective Health Centers** compiles information and resources that you can use to establish a data-supported decision-making methodology, which will provide you with the foundation for planning activities, grant submissions, operations management, and performance evaluations.



Data-supported decision-making is a continuous process of assessing, prioritizing, planning, implementing, evaluating, and reporting (Exhibit 1). This process is central to the health of your organization, your patient base, AND your community. Building this process into your health center's administration infrastructure, finances, and service programs will result in value-added benefits for both you the provider and the patients within your community.

¹ The term Health Center includes Community Health Centers, Migrant Health Centers, Health Care for the Homeless Centers, and Public Housing Primary Care Centers.

Table of Contents

Introduction 1

Data-Supported Decisions 5

The Nature and Elements of a Needs Assessment 7

Information Gathering Techniques: Qualitative Methods 13

Information Gathering Techniques: Quantitative Methods 19

Some Useful Data Sources and Other Resources 26

Introduction

This monograph, *Community Needs Assessment and Data-Supported Decision Making: Keys to Building Responsive and Effective Health Centers*, is about making decisions. It focuses on data and answers several questions: What are data? How do you find or collect data? How do you analyze data? How do you understand and apply data? How do you integrate and synthesize data? And how do you make projections and decisions based on data? This resource guide has been developed to help you collect, analyze and use data in more advanced ways beyond what is basically required from funders. The more you know about and understand a community, the greater the opportunity to participate collaboratively as an organization in a leadership position. NACHC hopes that this guide will assist you in becoming a comfortable and competent data user!

Health centers are not just independent healthcare facilities. Health centers are a part of the fabric of the community as employers and economic infrastructures in the neighborhood, vital portions of the local and statewide health care system, health care home, and for some, refuge in times of community or family crises. The awareness of a health center's community position provides opportunities for community organizing where patients and residents not only share what they know, but participate in a community-learning environment. This has implications and applications for patient and community involvement in addressing environmental and other community issues that lie outside of the realm of direct health care. This is the root of community-oriented health care long practiced by health centers.

This guide is specific to health centers, but the data-gathering techniques are universal. The Internet provides access to an abundance of national, state, and local data that have been collected by a myriad of sources. These various data sources allow comparisons across states and smaller areas. For instance, the U.S. Census breaks data down by county, city/town, census tract, and neighborhood. State and local health departments can provide vital statistics, morbidity and mortality rates, rates of infection, and much more. Federal and state agencies that administer the Medicaid and Medicare programs, Women, Infants and Children (WIC), HIV/AIDS programs, mental health services, substance abuse programs, and other social services are all sources of data as well.

What are Data? Data are pieces of factual information. When data are in the form of numbers, they are measurable or countable and therefore are considered to be “quantitative” data. Weight, height, temperature, age, and costs are all examples of quantitative data. When the data are more descriptive, based on observations that cannot be measured, they are considered to be “qualitative” data. Qualitative data are typically obtained by asking about people's experiences, perceptions, and beliefs, or by observing processes occurring at a particular time and place.

There are numerous methods for collecting data. For instance, quantitative data may be collected by administering surveys with closed-ended questions, and tallying up the number of responses in each category. Quantitative data may also be obtained by reviewing patients' medical records and counting the number of instances of specific diagnoses or services. Qualitative data are often collected through focus groups, forums, or interviews.

As you prepare for your needs assessment, you should ask yourself how the information you collect will be used. Qualitative data are excellent for improving the richness, quality, and description of the problem or situation you are analyzing. Quantitative data are often used for numeric demonstrations of problems, needs, or disparities; comparisons across groups, time, and geography; measurement of performance and changes in performance; or evaluation of the impact of an intervention on particular outcomes of interest. Quantitative data also allow outside auditors to objectively verify your performance or the need for funding in your area.

Data can be obtained by either primary or secondary collection techniques. **Primary data** collection is when you collect your own data; for instance, using your own center's patient data to conduct quality assurance analyses is a good use of primary data. **Secondary data** collection is when you use data that others have collected. The numerous databases available on the internet are examples of secondary data because they contain information that someone else has collected and possibly already manipulated or analyzed in some way.

Primary Data

Primary data collection involves going out and collecting data yourself. In this case, you can tailor the information-gathering efforts or survey questions, because you know the purpose of your analysis and the specific information you need. For example, you could develop a survey instrument containing demographic information and specific health-related questions to administer to a group of your patients.

There are several approaches to conducting primary data collection, including face-to-face interviews, telephone surveys, mail-in questionnaires, medical record reviews, and payment claim reviews. In deciding which approach will yield valid and reliable information, you should consider several factors:

- Will the method provide equal opportunity for people to participate? For example, a mail-in questionnaire would not be appropriate when surveying people who are homeless. In addition, telephone surveys may not be appropriate if you have reason to believe that many patients in your target population do not have landlines, which is becoming more and more common as people increasingly rely on cell phones. One final example refers to conducting a door-to-door survey on a weekday morning in a neighborhood where most people between the ages of 18 and 65 work during the daytime.
- Does the method introduce systematic bias for or against certain populations? This question is similar to the first question but focuses more on the content or other possible issues that may arise from the survey tool itself. For instance, respondents may be more willing to provide highly personal information through mail-in or phone surveys than through face-to-face interviews, particularly when the topic of inquiry is a sensitive matter (e.g., substance use, mental health).
- Does the data collection itself introduce bias into the data? You should ensure that the people collecting the data on your behalf are doing it in a consistent manner. For example, are those people asking the survey questions in the same order or using the same language every time? In the case of qualitative methods such as focus groups or key informant interviews, are the facilitators using the same methods to encourage probing and discussion? Particularly if you are surveying populations with different cultural or educational backgrounds or language proficiencies, you should pay special attention to question wording, literacy levels, translation quality, and so on. Regardless of the data collection method you choose, you should make sure to train all data collectors appropriately, and conduct intermittent quality checks to assure consistency and reliability.
- Does the method of recording the data introduce "bias" into the results? This means that the way the data are collected or recorded change they are interpreted. When people are involved in reading and counting survey answers, or manually inputting results into a database, there is a risk of introducing mistakes into the dataset due to human error, inconsistent interpretation of responses, or any number of other problems. There is less opportunity for inconsistent or incorrect data if surveys are completed on a computerized form which automatically populates a dataset. It is important to train the data entry staff or raters on these procedures, and to perform quality checks of their work on a regular basis.

Secondary Data

Secondary data collection involves obtaining data that have already been collected, and often manipulated, by other people. This is by far the most common approach used by health centers in developing need assessments, as primary data collection is often lengthy and costly. The U.S. Census, state vital statistics records, county primary care needs surveys, Primary Care Association needs assessments, and the Kids Count dataset are all examples of secondary data sources. While these sources are readily available and cover a vast number of topics, there are important cautionary notes and issues to understand before using them:

- **Definitions:** How are the traits that are measured being defined? For example, is inadequate prenatal care defined as not entering care in the first trimester? The first and second trimester? What is the threshold blood-glucose level used for diabetes?
- **Changes in definitions:** If you are doing trend analysis or looking at the same factor at different points in time, are the definitions the same over time even in the same dataset? For example, International Classification of Diseases codes are modified every few years. In addition, the U.S. Census changed the borders of some census tracts from 1990 to 2000.
- **Data collection and analysis:** Could bias have been introduced in the sampling or the manipulation of the data? Is the population studied similar to yours?
- **Data presentation:** Are data provided as crude rates, adjusted rates, age-specific, ratios, prevalence rates, or incidence rates (more on these terms later on)? In order to understand the data, you must be clear on how they are being manipulated..
- **Data interpretation:** Could the findings from the data be inaccurate or inappropriate for some reason? Do the data directly or indirectly measure the characteristic of interest? For example, if you were to use participation in the Free and Reduced School Lunch Program as a substitute measure for poverty, and tracked participation trends from kindergarten through high school it would seem that children become less poor as they age. However, this is not true, and is simply a reflection that children become more embarrassed about their status as they get older and therefore do not participate in the program as much.

Custom-Generated Data: In some cases, other people have collected primary data that are not available to the general public, so you cannot access the data yourself to conduct your own secondary data analyses. For example, the Connecticut Tumor Registry is a primary data source made up of information about the incidence and prevalence of cancer in the state. Because the records contain personally identifying information, it is not a public access dataset. However, you may be able to work with the organization which originally collected the data and request that they conduct some data analyses on your behalf. In these situations, you can ask them to create indicators that are tailored to your specific population. In the case of the Connecticut Tumor Registry, the Registry staff will produce customized reports that can provide very specific rates based on geography, gender, age, race/ethnicity, tumor type, and staging. If you attempt to obtain custom-generated data, keep in mind the following considerations:

- Be sure the person generating your data understands what you are asking for
- Be sure the person generating your data understands your goals and intended use for the data
- Be sure the person generating your data knows how to perform the analyses you are asking for
- Understand the assumptions underlying the data you obtain

It helps to have a discussion with your point of contact prior to asking them for the data. This way, you can ensure that both of you understand each other and that you are comfortable with the process.

Funding

Regardless of whether the data are quantitative or qualitative, all data collection efforts cost money to conduct. Staff hours, facilitators, planning time, refreshments, incentives, and administrative costs add up. If you have designated funding and a solid budget for your needs assessment activities, you are in a good position. If you do not have available funds, you can still have a strong needs assessment plan in place that can serve as the pathway to future funding. A good plan can bring together community residents and stakeholders with the objective of addressing the issues for which your community seeks relief.

Data-Supported Decisions

How valuable are data? Exhibit 2 shows the many potential uses of your data collection efforts in establishing an effective and efficient patient-centered, community-oriented health center. You can customize this figure to focus on the data applications that will be used by your health center.

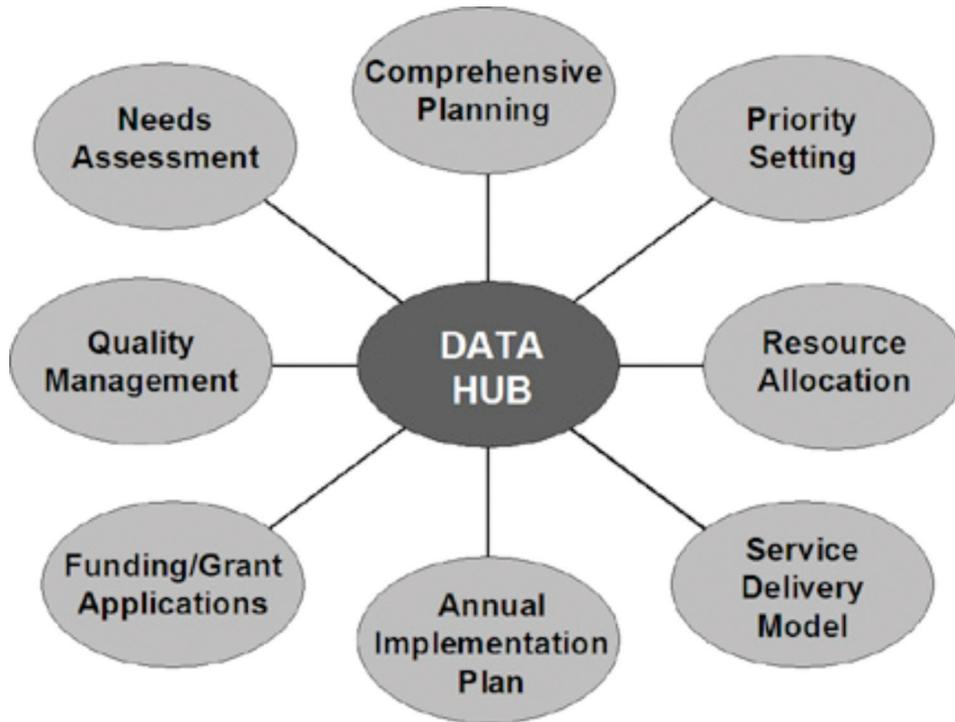
Data-based decisions use quantitative and/or qualitative data to inform decisions, while presuming that the underlying ethics have been properly considered. **Data-supported decisions** use the same data but they also take into account people, issues, ethics, and broader system effects. An excessive “data driven” emphasis can contribute to ethical blind spots, altering logic, ethics, and systems outcomes. It is important to note that not all aspects of a system can be measured and captured by data, and that the situational context must be considered when using data to inform decisions. Some aspects can only be experienced. You can measure ethnicity and language, but these do not represent a person’s context and understanding of health and healthcare.

Comprehensive data collection and analysis are the foundation of data-supported decisions. For instance, data can be used for:

- Priority setting
- Strategic development
- Comprehensive planning
- Performance evaluation
- Service delivery modeling and strategy
- Resource allocation
- Statements of need
- Funding applications
- Quality management
- Leveraging resources
- Advocacy
- Identifying collaborative partners and allies
- Mapping the locus of local power and identification of power brokers
- Improving community responsiveness to health care needs across the community

If you adopt a data-supported decision-making strategy for your health center, you will likely also discover your own applications for your data.

EXHIBIT 2
Data Supported Decision-Making Applications



Data Challenges

There are several challenges involved in data collection, analysis, and interpretation. For health centers, the most difficult challenge may be obtaining comprehensive data on your target patient population, including your current patient base as well as community members who are not currently patients. Comprehensive data about this latter group are the most difficult to find, and in many cases you may only be able to obtain general population data.

The strategic use of data for analysis requires high-quality, comprehensive datasets. Traditional datasets from federal and state agencies are consistent and comprehensive, and they allow you to draw comparisons across several population groups and/or time periods. However, you should be alert to data limitations. For example, race/ethnicity data may be less reliable if an outside researcher or evaluator assigns race or ethnicity to the patient of interest (rather than the patient self-reporting their own racial and ethnic background). When this is the best information available to you, you should note its limitations when you use the data.

Another challenge relates to the interpretation and presentation of data. There are numerous options for graphically displaying your data (e.g., bar graphs, pie charts, maps). Graphics can be helpful if they are able to synthesize a lot of information to communicate a simple message. However, they can also be misleading if they do not accurately tell the story that the underlying data represent. Statistics and graphics can easily be manipulated to present the conclusion you are hoping for; you must ensure that you are presenting the data accurately and honestly.

The final challenge in engaging in data-supported decision making is the need for additional resources, especially staff support and time. You will need to ensure that you allot sufficient time for the project team to engage in strategic thinking and to perform the data collection and analysis techniques described in this guidebook.

The Nature And Elements of a Needs Assessment

A Needs Assessment is a research and planning tool that includes collecting, analyzing, synthesizing, and evaluating data for use in decision making.

A needs assessment can be both a process and a method. As a process, it can build leadership, group unity, and a sense of local involvement in the community. Some needs assessment techniques, including surveys and focus groups, provide participants an opportunity to express their opinions on community issues. As a method, a needs assessment is a tool that helps to move the mission of the organization through decision making and implementing strategies. To be successful, needs assessments must be comprehensive. They require active planning and involvement from key players in the targeted community. They also require ongoing and extensive review of epidemiological health indicators and demographic data sources. Needs assessments must also consider a community's social or political context, which can determine the acceptance and integration of a health center into the community at large.

Needs Assessment Process

Needs assessments include community involvement through techniques such as focus groups, asset mapping, forums, and surveys. Involving people from your community allows residents to know that their voices are being heard, gives health and social services providers an opportunity to be more responsive and effective in addressing community concerns, provides community leaders with up-to-date knowledge about how to better serve their community, and supplies the health center project planning team with the necessary data to guide its decision-making process.

This is an opportunity to secure and/or expand your organizational value in the community, as well as to develop data that will inform strategic planning and program development. It is a time for identifying uncovered assets, developing relationships that may lead to buy-in and collaboration, and strengthening existing working relationships, both within your health center and across your community.

There are four key phases in a needs assessment. As you move through the planning stages of your needs assessment project, remember that a plan is only a starting point. You will be most effective in the implementation process if you plan, evaluate, and make course corrections as you go along.

Phase 1 – Brainstorm

The project team usually arrives at this stage as a result of a commitment to addressing the health care needs of a community. As you prepare for the needs assessment, the following questions can assist in the early stage of the process. A brainstorming session is a great way to consider these questions, especially when you bring people with diverse interests to the table. Some of the participants should be potential consumers, others should be skeptics, and most should be committed people like you.

The Questions

1. Who is the assessment attempting to inform? Influence? Persuade?
2. Whose needs are to be assessed?

3. What questions do we need to answer?
4. How will the information be used?
5. Which issues and questions are of particular interest to our organizational development?
6. What resources are available to do needs assessments?

You can ask many versions of these questions. Allot a limited time for the exercise, organize the responses, and prioritize the answers. Additional questions may also come up in discussions with colleagues, professionals, consumers, and others.

Phase 2 – Finalize the questions you will ask in your needs assessment

In this phase, the objective is to arrive at the core questions you will seek to answer in your community research. Questions must be clear and free of jargon. Some of the questions may be provocative, and that is fine. Always consider your audience and ask questions in ways that engage rather than exclude. It is useful to send your draft questions to influential community members and refine your questions based on their suggestions. Review the questions one final time and proceed to the next phase.

Phase 3 – Identify the information sources

Who has the answers to your questions? Identifying your sources of information should, by now, have been partly addressed by your work to date. You will likely need to turn to diverse sources in your community. Start with the patient base you currently serve or are planning to serve. Other potential sources of information may include small and large businesses, politicians and officials, social service agencies, healthcare providers, faith-based and community-based organizations, and educators. You may wish to construct a matrix identifying the relevant stakeholders in your community and their relationship (actual or potential) to your health center.

Phase 4 – Select the information-gathering techniques

The quality of information you gather about a community is only as good as the techniques used to collect it. A single technique may be too narrow, while combining several techniques may be too time consuming and costly. Different needs will require different techniques. The following sections of this guide will provide detailed information about various information-gathering techniques for collecting both qualitative and quantitative data. We encourage starting with Community Assets and Capacity Mapping (see below). The information gathered in the first portion of the asset map will provide the basis for selecting your sources for other data collection techniques.

As you familiarize yourself with the various methods, weigh the pros and cons of the techniques, consider your health center's specific situation, and recall the most significant questions you wish to answer. The most appropriate technique(s) will be the one, or the combination, that will draw out the most informed responses from the participants. Remember that certain methods may be better suited to certain situations, and that different questions may require different methods in order to obtain answers. In short, you should make sure to (1) identify your sources of information, (2) tailor your information-gathering technique(s) for those sources, and (3) tailor your information-gathering technique(s) to your objectives and questions.

Community Assets and Capacity Mapping

Traditionally, when people hear the term “needs assessment” they think of quantitative data gathering, with a focus on community gaps and deficiencies resulting in a negative characterization of the community. About 30 years ago, John McKnight of Northwestern University began his research on social services delivery systems. He hypothesized that a deficiency-oriented community needs assessment would lead to a community that perceives itself as having special needs that can only be met by outsiders. In deficiency-oriented needs assessment approaches, people become consumers of services with no incentive to be producers. This traditional problem-oriented, deficit-based approach focuses on negative questions and responses:

- How do we fix this problem?
- It's too big. I'm only one individual.
- Other people need to fix this.
- It's always been like this. Nothing ever changes.

In contrast, McKnight's work on community assets² provides a framework in which individuals and organizations represent resources upon which to build. This results in more positive attitudes:

- How can we create more health services?
- We are all in this together!
- I am working with others in a common context.
- I can help change the status quo.

For an in-depth understanding of the community assets approach, refer to *Mapping Community Capacity* by McKnight and Kretzmann (1996).³ The document contains inventories, resource lists and maps, and other suggestions for the application of the model.

Application of the Community Assets and Capacity Mapping Model

Strength-based community assets and capacity mapping can be used as a precursor to data-based decision making, to build a community infrastructure with committed stakeholders and funders that can successfully bring health care services to underserved and underrepresented community residents.

The goal of this approach is to assemble a broad representation of individuals and organizations so that you can clearly assess the needs of the community, as well as the opportunities and the challenges. A good analysis will produce a social “map” of the community. The process begins by identifying different sectors of the community, including business, government, religious, voluntary and civic organizations, and labor. You will also want an analysis of stakeholders and their capacity to influence the success of your organization.

There are two separate yet related approaches to looking at your community as you begin the community asset and capacity mapping. The knowledge resulting from these two activities will enhance your capacity to mobilize a strong base to support your health center.

2 *Building Communities from the Inside Out: A Path Toward Finding and Mobilizing a Community's Assets*. J. Kretzmann, J.L. McKnight. Evanston, IL: Institute for Policy Research, Northwestern University, 1993.

3 *Mapping Community Capacity*. John L. McKnight and John P. Kretzmann. Evanston, IL: The Asset-Based Community Development Institute, Institute for Policy Research, Northwestern University, Revised 1996.

The first approach is a **power analysis**. It describes the local and state power structure, and is built on knowledge of voting records, funding histories of federal/state agencies and foundations, and political constituencies, as well as previously successful/unsuccessful endeavors within your community that have engaged these stakeholders, and individuals or organizations that have served as champions for your patient base.

Table 1 presents an example of a modified power analysis. This type of analysis is an opportunity to assess the positions of power brokers and stakeholders on a given issue. The result is a gauge of levels of support or opposition. Though this is a point-in-time assessment, it will show you where energy can be invested to support your health center, where potential opposition may come from, and how to strategically involve various stakeholders to either assure their buy-in or to neutralize their opposition.

TABLE 1
Power Analysis

Who? (Individual, Organization)	What Kind of Asset?	What Kind of Power Base?	Potential Ally or Foe?	Potential Impact (For/Against)
District State Legislator XYZ	Former Hospital Administrator	Responds to State-wide Hospital Association	Unclear, with the rising cost of care in hospital clinics; may try to persuade hospitals to apply as look-alikes	Depends on location of hospitals or their clinics within shortage areas
Local Health Department Director	15 years in DPH MPH	Has the ear of the Mayor; well respected by the State DPH	Ally	Can provide support and non-\$\$ resources for development

The second approach is an examination of **community assets**. This is an in-depth depiction of community sectors, sector components, and probable areas of influence. The information compiled using this approach will include details about individuals, agencies, and organizations that will serve as a foundation for outreach and resources strategies.

The first step in outlining your community’s assets is to list the many active sectors of your community. Next, you should brainstorm about specific sector components: lists of people, groups, and organizations that comprise each sector. Remember to include diverse components, including independent small businesses, stores, merchant associations, cultural organizations, school-based health initiatives, social service agencies, community action agencies, agricultural agencies, migrant workers and farm owners, religious groups, and so on. Finally, you should take into account the influences and impact of each sector within your community.

Table 2 presents an example of a community assets outline. It describes community sectors and components within each sector, and also summarizes where each component has specific influence. As you can see, the distinction between Tables 1 and 2 is the stakeholder versus sector breakdown. The questions are intentionally different. A more complete representation of the community assets outline can be found in the NACHC publication, *So You Want to Start a Health Center*.⁴

⁴ *So You Want to Start a Health Center*. (2011). P. Byrnes, J. Hirschfeld. Available at: http://iweb.nachc.com/Purchase/ProductDetail.aspx?Product_code=11_START_CHC

TABLE 2
Community Assets

Sector	Components	Influences
Business/ commercial organizations	<ul style="list-style-type: none"> ■ Major and minor employers; estimate number of employees, average wage and health insurance coverage ■ Chamber of Commerce, state business census, business leaders, minority business groups 	<ul style="list-style-type: none"> ■ Key business leaders or particularly influential employers ■ Businesses with health care relationships
Government	<ul style="list-style-type: none"> ■ Executive branch (mayors, county executives) ■ Local legislative branch (city and county councils, boards of health) ■ State and federal elected representatives 	<ul style="list-style-type: none"> ■ Key political figures, staffers ■ Political climate ■ Recent regulations or laws affecting health care
Labor organizations	<ul style="list-style-type: none"> ■ Unions ■ Cooperatives 	<ul style="list-style-type: none"> ■ Labor leaders and cooperative board members ■ History and current labor relations climate
Health care (medical, dental, behavioral health)	<ul style="list-style-type: none"> ■ Hospital(s) ■ County medical society ■ Regional dental association ■ Etc. 	<ul style="list-style-type: none"> ■ Public and private health care providers ■ Health insurers/HMOs ■ Associations/societies for health care professionals, including minority organizations ■ Continuing education programs for professionals ■ Health boards/departments (state and local) ■ List full range of health care facilities
[Others]		

A good community assets and capacity mapping process takes into account the individuals within a community as well as the specific assets each offers. Consideration of individuals is a means to identify the formal as well as informal—and often hidden strengths—of any community. Formal influence can come from an official role within the community (e.g., elected official, business owner, social service agency, religious body). Informal influence comes from a variety of unofficial sources (e.g., ancestry, community participation, social connections, wealth, activism).

As you proceed through your own community assets and capacity mapping activities, you may want to consider the following questions:

- Which issues, questions, and behaviors are of particular interest to our organization, and why?
- What questions do we need to have answered?
- What outside resources can we access to help us understand the issues?
- What do we already know about available resources and the needs of the community?
- Have other asset analyses been done in our community? How do they apply to our objectives?
- Where is the experience and up-to-date expertise in our community?

The group or coalition that you form to conduct your health center's needs assessment will be able to outline an initial community assets map. After that, you will be able to engage community leadership and talk to people within the community to add detail to the map. This will be the first opportunity to invite and involve more people in your efforts, and may lead to the mobilization of individuals and organizations to make connections, build capacity, and establish a sustainable base of community commitment and support for the health center.

Information-Gathering Techniques: Qualitative Methods

This section focuses on qualitative methods for gathering information, including key informant interviews, focus groups, and listening sessions/community forums. The techniques described below are in no particular order and may be used multiple times for different purposes. In addition, multiple techniques can be used together to obtain richer data. Your objective is to get the best and deepest answers, and you may decide that more than one technique is needed to get the answers you are looking for.

Key Informant Interviews

A key informant is a person with community ties through professional affiliations with agencies or local government, civic or religious membership, or other links to important constituencies. These individuals are connected across the spectrum of the community and possess in-depth knowledge or experience about your particular issue of interest, the history of the community, and/or current activities and relationships. Key informants often serve as conduits to other useful contacts or information.

The key informant interview typically lasts about one hour, and consists of a one-on-one interview. A skilled interviewer uses extensive probing and open-ended questions to obtain information from the informant about your community's needs. This format allows respondents to express their opinions and understanding in their own terms. It is an easy and inexpensive method for obtaining information and perspectives about community needs. The key informant interview is a means to gather input from many individuals—a window to insiders' viewpoints and perceptions—and it also establishes rapport and helps you determine which key informants will be of future value to your project.

To conduct key informant interviews, you should begin by compiling a list of possible key informants by name. Your community assets map will be an important source for identifying key informants. The list must represent the community across race, ethnicity, age, sex, years of residency, or any other characteristics you deem important. Informants should also be chosen based upon the longevity and/or the nature of their involvement with the community; your goal is to speak to various informants who will represent the full range of community opinion. Be certain that your key informants are clear about the purpose of the interview and that they are interested in participating.

During the interviews, questions should be uniformly asked of all informants. You may tailor specific questions to each key informant, related to his/her area of interest and/or expertise. Interview questions may touch on attitudes about the community as a whole; focus on specific areas such as economics, education, health, or leadership; explore what is being done to address certain concerns; and/or solicit the informant's ideas about what should be done. Other steps to consider when conducting key informant interviews are as follows:

- 1) Construct a brief interview guide of open-ended questions.
- 2) Select and train interviewers with probing, reflective techniques, such as “Could you say more about that?” or “Would you share an example?” Be certain the interviewer knows how to follow an unexpected “lead” while keeping the interview on track. It is the job of the interviewer to develop rapport with the informant and to make him/her feel comfortable.
- 3) Conduct the interview, using the question guide you created. Always conclude the interview with the question “Is there anything you'd like to add?”

- 4) Organize the responses from the various key informants. For example, if you have ten questions, compile all Question 1 responses together, all Question 2 responses together, and so on.
- 5) Interpret the data and write up a report synthesizing the key findings. Key informant interviews will elicit a range of views, comments and possible biases. Since this interview information represents community perspectives from potential patients to bankers to policy makers, the report of the findings must be carefully crafted to represent the whole. Key findings will be a synthesis of the findings from each interview, covering the scope of comments and approaches. Though the report will have a primary author, a sub-set of development team members who participated in the structure and design of key informant questions and/or surveys should be designated readers of the interviews and the team that comments on and edits report drafts.
- 6) Report the findings back to the key informants. This is the best time to ask additional questions prompted from the findings. It also keeps the lines of communication open with the community.

You should keep in mind that certain factors may not be conducive to a productive interview. For instance, you may learn that one or more key informants is more adversarial toward your project than you imagined. When this occurs, listen attentively. You may still gain valuable information. Do not enter into any arguments with an informant. Some informants may not speak easily. When this occurs, invite them to take some time to consider the question. Also be aware that the interviewer may permit his or her own preconceived biases or perceptions to get in the way of hearing negative information from the informant. You may also find that individuals provide you with information that represents a bias of the organization or agency that employs those people. In addition, some community members may harbor resentment toward the leadership of the new project if they are not consulted in this round of information collection. The project team must be cognizant of maintaining a balance between the attitudes and views of key informants and the larger voice of the community, as well as keeping its own biases in check.

Focus Groups

A focus group is a small, selected discussion group, typically of about 8 to 10 individuals from similar backgrounds, guided by a trained facilitator or moderator. It is used to learn more about views on a designated topic, to guide future action. The groups usually meet for 1.5 to 2 hours. Keep in mind that focus group participants are not necessarily a random sampling of the population and that it is not appropriate to use these groups as arbiters of any final decisions that are the responsibility of the planning group.

Focus groups provide a unique set of information that differs from other qualitative techniques of information collection. Some of the key features of focus groups are as follows:

- a. Focus group responses are typically spoken, open-ended, relatively broad, and qualitative. They have depth, nuance, and variety. Nonverbal communications and group interactions can also be observed. Focus groups can therefore get closer to what people are really thinking and feeling, even though their responses may be more difficult — or impossible — to score on a scale.
- b. The group is structured and focused. Participants directly involved with or impacted by the topic form one or more small discussion groups. Examples of focus group discussions include: asking a group of parents to discuss local child care needs and what can be done to improve services already available; and convening small groups to help a start-up health center identify gaps along the healthcare continuum.
- c. The group is led by a trained facilitator with excellent listening and observation skills. The facilitator's job is to keep the discussion on course and refine what s/he hears.
- d. The group composition and discussion are carefully planned to create a non-threatening environment in which people are free to talk openly.

The structure, focus, and open-ended characteristics of this technique are unique. Group size is a significant element that permits the facilitator to pursue a question or response in depth, in a contained environment. This rarely happens in other information-gathering techniques, such as listening sessions or community forums. Moreover, participants usually build on each other's comments, unlike an open forum, where many people have specific agendas.

There are several steps involved in conducting a focus group:

- 1) **Find a good group leader/facilitator.** This is an important step! Your leader will determine the success of your focus group. What kind of leader do you want? Consider these characteristics:
 - Experience with facilitating groups
 - Knows something about the topic
 - Does not enter a discussion with preconceived notions of what the participants will say or what the outcome should be
 - Relates well to the focus group participants
 - Does not steer the focus group in a particular direction, allows participants to share their thoughts freely

This can be a delicate decision for your team. We often have people in our organizations with skills and temperament of a good facilitator. We also have people who believe they have the skills and temperament! Be careful. This selection will determine the success of your focus groups. You might consider looking for someone outside your organization, someone that specializes in facilitating these kinds of groups. In addition, it is always wise to have a second set of eyes watching the body language of the group and observing non-verbal cues, to augment the facilitator's observations.

- 2) **Find a good recorder.** Your recorder is as critical as your facilitator! The position of recorder will be someone from your team who is fully knowledgeable about the project. Generally, focus groups do not record comments on newsprint/flipchart. It is the recorder's job to listen carefully to the language and tone of what is being said and to record the comments of focus group members as accurately as possible, without qualification or censorship. Notes will then be compared with the recording, if taped, and annotated as reasonable to ensure the responses of the focus group are accurately expressed. At no point in this process, should the comments and opinions expressed by the focus group be massaged, manipulated or spun to reflect opinions of the leadership.

This is a position that is often hard to fill. It takes both a good ear and the ability to rephrase. This position should be filled in advance, and should also be given much thought. You may choose to tape record the session. If so, you must get permission of the participants and ensure that participant names are not revealed. It is important to factor in time and money for transcription and any necessary translation.

- 3) **Confirm the focus group logistics.** Confirm the day, time, place, length, and number of focus groups. These specifics must be decided before the recruitment process and must be sensitive to the community's needs. Participants will feel well cared for by your organization if you anticipate their needs. Go to them, rather than having them come to you. Provide an information packet or letter that includes clear directions to the site of the focus group, information on the facilities at the location, and necessary contact information.

- 4) **Create an invitation list.** The list should be representative of those whose opinions you are concerned about. You should consider the constituency of your health center. Does it include tenants, farm workers, people living in the inner city or frontier settings, local practitioners serving your population, shopkeepers, or small businesses? If you have time, you should run several different groups, to include more people and more diverse interests. You will get your best results when you conduct more than one focus group. Remember to offer invitations to a cross section of the community, and not just the most vocal, most supportive, or most difficult people!

You should also consider whether you will be able to bring one or more focus groups together without offering any participant incentives. Some people may be willing to volunteer their time because they support your health center, are committed to the issue at hand, are strong community advocates, or any other number of reasons. However, you may also find that it is helpful to offer a small incentive or token of appreciation to encourage participation in the focus groups. Possible incentives include transportation, childcare, food and drink, money, and gift certificates. Your selection of an incentive may depend on the focus group composition. Keep in mind that the incentive must not be too big or valuable, otherwise it may be perceived by outsiders as a bribe to encourage participant involvement, and may bring into question the validity of the responses you obtain.

- 5) **Recruit participants for the focus groups.** Recruitment may be harder than it sounds. People have many reasons not to participate. When possible, engage local leaders—formal or informal—such as a minister or head of the tenants’ association to issue the invitations. Using these intermediaries may reduce hidden barriers to participation. In health center communities, people are often accustomed to feeling invisible and not having a voice, and it may take some coaxing to encourage participation. Participant incentives can certainly help. You should use the most appropriate means for contacting potential participants. This may involve contacting people in person, by phone, or some other means that may be necessary depending on the specific context. Once someone agrees to participate in the focus group, you may wish to send them a confirmation postcard (if you have a verified address) and to place a reminder phone call the day before the focus group.
- 6) **Write your list of focus group questions.** Thoroughly discuss the questions more than once. Remember that a focus group is structured and focused, so this is not the time to improvise as you go along. However, this does not mean that you must use a script from which you cannot deviate, because a focus group is also intended to be open-ended and flexible. A skilled facilitator will use the questions and topics as a guide for the discussion. The facilitator will be responsible for making decisions about the question phrasing, ordering, follow-ups, and timing; some of these decisions will be made on the spot. An experienced facilitator will be able to do this. This is why you have spent time looking for one!
- 7) **Conduct a thorough review of all the elements of the meeting.** Make sure that you have confirmed the participant incentives, building access, room arrangements, sign-up sheets, information materials, and all other details that are necessary to complete the focus groups.
- 8) **Conduct the focus group(s).** The facilitator/moderator will set the stage and state the purpose of the focus group. S/he will provide a description of the flow of the meeting, ground rules, and ways for participants to contribute. The facilitator will also encourage open participation from everyone in the focus group. Make sure that participants know that they will receive information resulting from the focus group session. Once all questions have been asked, the facilitator will ask about any additional comments or areas not previously touched on. Participants will be thanked and the meeting concluded. Remember that you must obtain permission from the participants if you tape record the session.
- 9) **Write up the focus group results.** After the focus groups are conducted, you will have observation notes as well as an audio recording that needs transcription. Transcription may be provided by the facilitator or by an outside transcription company. Once the written transcription is available, the document should be reviewed and analyzed to reveal common themes, emerging patterns, and new questions to be considered. It is wise to have multiple people participate in this phase, to ensure that the results of the session are being interpreted

and synthesized appropriately. Next, you should write up a report describing the results of your analysis. The report can be used internally to evaluate your results against your initial hypotheses about what you expected to find, as well as prioritize and apply what you have learned from the focus groups to determine next steps.

- 10) **Once the report is written, share the results with the focus group participants.** Perhaps members have now become more interested in the issue, and would like to get more involved. Consider offering them an opportunity to do so. A focus group can also be a recruiting tool.

Why: The structure, focus and open-ended characteristics of this technique are unique. Group size is a significant element that permits the facilitator to pursue a question or response in depth, in a contained environment. This rarely happens in a listening session or community forum. Moreover, participants usually build on each other's comments, unlike an open forum, where many people have specific agendas.

Listening Sessions / Community Forums

A listening session is a form of community "give and take." It can also provide great data for asset mapping and power analysis. Listening sessions or community forums resemble focus groups, but with critical points of difference. The purpose of a community forum is to identify or solve a problem with diverse community representation, to provide a basis for subsequent planning.

Listening sessions and community forums are important because they can offer valuable insights into community dynamics. They also offer opportunities for linkages for people who are willing and able to help. The forums can raise the credibility of the needs assessment process by enhancing openness and inclusion, and can raise the level of awareness and understanding about your issue and the community planning initiative.

There are several steps involved in conducting a listening session or community forum:

How:

- 1) First, decide what your objectives are for the forum. Do you want to identify issues and concerns, community strengths and challenges, perceived barriers, available and needed resources for change, possible solutions, or ways to move forward?
- 2) Publicize the meeting locally through announcements posted wherever residents gather, such as places of worship, grocery stores, coffee shops, newsstands, libraries, health centers, and anywhere else you think you will reach the breadth of audience you seek.
- 3) Decide on and announce ground rules prior to the meeting. This includes rules about how speakers will be identified, time allotted for speakers, and the format for questions and answers. Rules should be provided in writing, available for all participants (including latecomers), and adhered to by the moderator.
- 4) Consider meeting logistics. Important details include location, date, and time. Should you have only one forum or is there value in moving around your community to draw a more diverse audience? Similarly, should you conduct several forums at different time points? Is there an optimum time or should you stagger the meeting times? Beware of getting participation from only a slice of the community because of the time, day, or place you choose. Participant incentives are another important consideration. Transportation may be necessary for some, childcare for others, and refreshments are always a crowd pleaser!
- 5) Confirm your staffing for the meeting. This must include a skilled facilitator and at least one recorder. One recorder can be responsible for providing flipchart notations for the group, and s/he may be supplemented by one or two back-up recorders taking comprehensive written notes.

- 6) Prepare for the meeting and draft questions. There may be several categories of questions for which you seek answers. For instance, if you ask a group about certain problems and the consequences of those problems, you may want to follow-up with a question about solutions and barriers to those solutions.
- 7) Conduct the listening session. Choices may range from a “Post-it” note process that results in a community dialogue to a simple open-mike process. The facilitator you choose to work with will recommend what he/she considers the most successful way to elicit participant responses based on his/her experience, what you already know about forum types used by your community, the amount of time available, and the types of information you are requesting. The critical thing to remember is that this is a *listening* session, so other than keeping the conversation on topic, your job is to allow the group to express themselves.
- 8) Review meeting results and write a report. After the meeting, you will have detailed notes and possibly an audio recording that needs transcription. Review the notes, transcription, and any observation notes about the listening session participants, and write a document summarizing any common themes, patterns, and new questions.

Assess Your Process

By now, you have made several decisions about the techniques you will use for qualitative data collection. This is the time to consider the entire package with a critical eye. You’ve identified your questions and your potential sources of information. Step back. Allow the team to look at the methods with fresh eyes to see if you can identify any weaknesses or limitations; if so, fix them to the extent possible.

Community Tool Boxes

Many universities and state health departments make comprehensive materials available to assist you in qualitative information gathering. Below are a few sites to help you in your efforts.

University of Kansas <http://ctb.ku.edu/en/tablecontents/index.aspx>

Iowa State University <http://www.extension.iastate.edu/>

Minnesota Department of Health <http://www.health.state.mn.us/communityeng/>

Summary

Now that you have an understanding of how to approach qualitative data collection within your community, please remember that needs assessments should not focus on deficits or negative characterizations. This is an opportunity to secure and/or expand your organizational value in the community. It is a time for uncovering assets, developing relationships that may lead to collaboration, and for nurturing solid working relationships, both within your health center and across your community.

Information-Gathering Techniques: Quantitative Methods

If you can use a calculator, you can do quantitative data analysis. With some basic math skills and a little bit of logic, you can use quantitative data to accurately represent the health conditions, health care needs, and disparities affecting your patient population.

Primer on Basic Quantitative Methods

Before discussing analytical methods and formulas, it is important to understand the basic concepts used in quantitative analysis. The first concept focuses on the **group of interest**. Health centers are generally interested in data on four types of population groups:

- Patients
- Target Population –the group of people you are designing your health center or services for
- Population of the service area – all of the people living in the geographic service area
- Local, state, or national benchmarks (used for comparisons)

Your current patient population may or may not be representative of your target population or service area population. In fact, patients often differ from others in the population just by the fact that they come to your clinic. The more disenfranchised people are the ones least likely to be your patients, but may be the very ones you are most concerned about. Therefore, to sufficiently understand the health needs of your target population of interest, you must use data that represent the entire target population and not just the patients visiting your health center. Patient data can only be used to analyze trends among people who receive services from your health center. However, you also need data from larger population groups to compare your patient data with other groups' data. These comparisons are used for documenting numeric differences between the populations.

Comparisons are often made across age groups, race and ethnicity, income, geographic areas, and time. As a health center, you should consider presenting data on your patient population or target population in addition to some other comparison group, in order to provide a reference point. For instance, if you are trying to document a health disparity that affects your patients, presenting national, state, or local data help to demonstrate that your population of interest is faring worse than the population at large. Alternatively, if you are trying to document that your health center's efforts are having a positive impact on diabetic patients, you should present comparisons of your patients' data over the period of time in which your intervention(s) took place.

The key to making valid comparisons across different groups or time periods is to make sure you are comparing the same types of data. You must make sure that the different types of data you are analyzing use the same definition for your measure of interest. In other words, you must compare apples and apples, not apples and pomegranates. Apples and pomegranates may look alike to the untrained eye, but once you take a bite, you quickly realize that they are very different.

For instance, several years ago when using a state database to compare the state's rates of late entry into prenatal care against the national level, the state's rates appeared to be much better than the national rates. This result did not match the qualitative reports from the communities, and after a little digging it was discovered that there was a problem with the definitions used to measure late entry into prenatal care. The state data had defined late entry as not receiving care in the first two trimesters. The national level data, however, defined late entry into prenatal care

as not receiving care in the first trimester. Discovering this discrepancy allowed the health centers in that state to revise their analyses and ultimately to *correctly* document that there was indeed a health disparity in prenatal care that needed to be addressed in their health care plans.

Types of Quantitative Analyses

A **cross-sectional** or “snapshot” comparison looks at the difference between two or more groups on a certain factor at a single point in time. For example, you might want to identify a health disparity between the state and your target population by comparing the infant mortality rates for the year 2010 in each group. The steps for doing so would include:

- Define what you want to analyze
- Collect the data
- Analyze the difference between the groups of interest

A second type of comparison is called a **time-series** or “trend” analysis. In this instance, you are interested in whether the event or characteristic being measured has changed over time. This approach is often used when one wants to understand the behavior of a certain disease, social factor, or other characteristic, in order to develop a longer-term picture of the population and to plan services appropriately. Instead of comparing two or more groups, you are comparing the same group on the same indicator over different points in time. For example, you might want to know how the rate of deaths from cardiovascular disease has changed from 1980 to 2010 in your target population. In this case the steps are:

- Define what you want to analyze
- Collect the data at Time 1 and Time 2 (ensuring that the definitions at the two time points are the same)
- Analyze the difference between the two time points

A third type of comparison is a **longitudinal** analysis. This approach helps you understand if any change has taken place over time, usually due to some intervention. For example, you may want to determine whether the new immunization clinic you started in the local daycare center is having an impact on immunization rates. There are a few more steps involved in baseline comparisons. You must:

- Define what you want to analyze
- Collect the data before the start of your intervention (called the “baseline”)
- Implement your intervention
- Wait for some period of time to pass (the amount of time should be reasonable enough to allow for changes to occur in the condition/trait being analyzed)
- Collect the data again from the same population you collected your baseline data from
- Compare the results of the first collection against the results of the second collection

A longitudinal analysis differs from a trend analysis because it measures change in the same population due to some kind of intervention. A trend analysis may or may not look at the same population. In the above example regarding deaths from cardiovascular disease, the population measured in 1980 was most likely not made up of the same people that were measured in 2000. By contrast, in longitudinal analysis you are actually following the same group of people and measuring change in that group.

This type of analysis is good for documenting change over a period of time. Consider this example to illustrate the importance documenting change over time: Let’s say that your health center wants to implement a change

in diabetes treatment, such as posting a sign in exam rooms as a reminder to patients and providers that patients should take off their shoes at each visit so that the doctor can do a quick foot exam. To demonstrate the impact of this change, you can start by collecting some baseline data on the number of foot exams currently being conducted among diabetic patients seen by your health center. Then you can post the signs, and collect follow-up data again after one month and after three months, to determine whether this small procedural change had an impact on patient care. If your hypothesis is correct, you will find that the percentage of diabetic patients receiving regular foot exams has increased.

A more complicated version of a longitudinal analysis could also include a comparison, or reference, group in addition to your intervention group. This design includes a group that does not get the intervention, allowing you to compare the longitudinal changes in each set of groups to make sure that any changes you find in your intervention group are actually due to the intervention and not just due to some other natural changes over time that would have occurred even without your intervention.

Sampling Methods

You may wonder how you are supposed to review every single medical record of every diabetic patient in your center in order to get these data. Very simply, you don't have to.

Sampling is the process of selecting a smaller group of patients/participants, so that you do not have to collect information from every single individual, medical chart, family, and so on. The basic premise is that if you sample the smaller group properly, the information you obtain from those individuals will be representative of the information you would have obtained if you had actually collected data from everyone in the population. There are several ways to generate a sample, including:

- Simple random sampling
- Systematic sampling
- Cluster sampling
- Stratified random sampling

Simple random sampling means that subjects (e.g., patients, participants, medical records) are selected in a completely random or unpredictable way, and that every subject in the pool of available subjects has an equal chance of being selected. Random samples may be selected with the help of random number tables. Random numbers lists can be found online, and help guide the selection process so there is no guesswork or individual decision involved. It is important that random samples are selected using some documented, objective methodology.

Systematic sampling means selecting every n^{th} person to be a part of your sample. For example, this could be every 10th chart in a paper filing system or every 20th name on the printout from your electronic medical records system. Every person in the system has an equal probability of being selected, as long as the starting point is randomly selected.

Cluster sampling requires selecting all individuals from certain randomly selected groups, areas, or time periods. In other words, instead of randomly selecting patients from your health center, you are randomly selecting certain groups, areas, or time periods. For instance, rather than randomly selecting a sample of diabetic patients from all the diabetic patients your health center saw during the year, you would organize all the patients according to the 52 weeks of the year that they were seen, then randomly select certain weeks and select all the diabetic patients seen during those weeks (e.g., third week of July, first week of October). It is important to be sure that you do not introduce bias into the sample when you select the cluster. For example, if you select patients according to random clusters of clinic hours (e.g., all patients seen between 9am and 11am on Tuesdays and Fridays), you want to ensure that your selected time periods do not exclude certain patient groups (e.g., senior bus program does not run

during the time period so the sample does not include patients ages 65 or older). Consider how excluding certain groups would affect the representation of your clinic’s patient population.

Stratified sampling involves first dividing the larger population into a number of independent subpopulations (or “strata”), and then randomly sampling individuals from each of those strata. For instance, you could stratify your service area into separate zip codes or neighborhoods, and then randomly sample residents within each of those neighborhoods. This ensures that individuals from each of the neighborhoods in your service area will be selected.

Whichever sampling method you use, it is important that you carefully document your approach so that it can be verified by any interested outside party to confirm that your selected group of patients is indeed random.

Analysis Tools

Once you have obtained your data, whether primary or secondary, you can begin to manipulate and analyze it. You should be familiar with these basic concepts because: 1) it is important to understand what the data mean, and 2) you may need to calculate your own health statistics if existing sources do not provide the data you are looking for. For instance, if your target population is primarily Asian American and the local health department lumps Asian American in with “other” racial/ethnic groups, you may need to do some of your own calculations to produce statistics that are more representative of your target population.

Ratio. A ratio tells the relationship between two numbers. A ratio can be written as x:y, or, for example, 1 out of every 8 women develop breast cancer over the course of their lives.

Proportion. A proportion expresses a ratio as a percentage. For instance, 13% of all women develop breast cancer over the course of their lives.

Rate. A rate is a proportion that includes a reference to a specific span of time, usually one year. Rates can take many different forms, including being written as a percentage (i.e., per 100) or per 1,000, or per 100,000. For example, some numbers are expressed per 100,000 to avoid fractions because it is easier to interpret 6 per 100,000 than .06 per 1,000.

Statistical Formulas

The term “morbidity” refers to the occurrence of a given illness or abnormal condition, while the term “mortality” refers to the occurrence of death. Statistics on morbidity and mortality tell us how many people are ill, the *risk* of getting ill, the frequency of death, and so on. Following are several common statistical formulas which are used to depict the burden of disease in populations:

Incidence Rate. An incidence rate is defined as the number of new cases of a disease in a population over a given time period. Incidence rates are used to study the risk of populations getting a disease or other condition. Incidence rates can be used to measure both acute and chronic diseases.

$$\text{Incidence Rate} = \frac{\text{Number of } \textit{new cases} \text{ (persons contracting a particular disease) in the population during a specified period of time (e.g., 1 year)}}{\text{Number of } \textit{persons exposed} \text{ to risk of developing the disease during that same period of time}} \times 1,000 \text{ or } 100,000$$

Prevalence Rate. The prevalence rate measures the number of people in a population who have a disease at a given time. This number provides a sense of the *burden* of disease in your patient population or target population, so it is important for forming your health center’s health care plan, fundraising for clinic services, and monitoring the long-term effectiveness of chronic disease management programs.

$$\text{Prevalence Rate} = \frac{\text{Number of persons in a population having a particular disease at a specified period of time}^*}{\text{Number of persons at risk of having the disease at that specified time}} \times 1,000 \text{ or } 100,000$$

**For the numerator (i.e., number on top of the fraction), set up your equation to take into account total existing cases, deaths, and new cases.*

$$\text{Numerator} = (\text{Total Cases}) - (\text{Deaths}) + (\text{New Cases})$$

It is important to realize that high prevalence does not necessarily signify high risk of disease. High prevalence could be an indication that an intervention is working. It may well be that although people continue to get a certain disease, a new treatment is keeping people alive longer.

Crude Rate. Crude rates describe the overall experience of a population. For example, the crude death rate (CDR) is the total number of deaths in a population during a specified time period, usually one year, divided by the average total population.

$$\text{CDR} = \frac{\text{Total deaths in year}}{\text{Average total population in that year}^*} \times 1,000$$

**The denominator (i.e., number on the bottom of the fraction) is usually defined as the number of persons in the population at the midpoint of the time period (usually 12 months). So the midpoint of a calendar year from January 1 through December 31 would be June 30. The rate is multiplied by 1,000 or 100,000 for ease of interpretation.*

Crude rates do not take into account differences in age and sex. However, they are frequently used because they only require two pieces of information that can often be estimated with reasonable accuracy. The limitation with the CDR (and other crude rates) is that differences between communities could be due to differences in the distribution of the populations by age, or other important factors. Thus, if one population has a higher proportion of elderly persons, its CDR will be higher than that of a community with a higher proportion of young persons.

Adjusted Rate. Adjusted rates take into consideration factors that impact the trait being studied. In the example of mortality given above, age plays a significant role in the risk of dying. In order to understand the true risk of dying in a group, and to compare across populations, it is critical that the difference in age structures is removed. We do this by statistically “standardizing” the two populations. Generally you do not have to do this yourself, but you should be aware that it was done so that you can determine if numbers are indeed comparable.

Specific Rate. Specific rates are similar to adjusted rates in that they allow for comparisons across populations. They also define a group’s risk of getting a disease by focusing on each population separately. For example, the crude breast cancer rate would have the entire population in the denominator and all persons with breast cancer in the numerator. However, whereas men make up half of the population, they only account for a small percentage of breast cancers. To understand the real experience of breast cancer for women you should only include them in the formula.

$$\text{Sex-Specific Breast Cancer Prevalence Rate} = \frac{\text{Total number of female breast cancers in a given year}}{\text{Total female population in that year}} \times 1,000$$

This is where comparing apples and apples is very important. If you are using data that are “age-adjusted”, do not compare them with crude rates since this is not an “apples to apples” comparison.

Projections

Sometimes, the data you obtain may not be in the exact format that you would like because the raw data are not available for your specific target population. This is often the case with health centers targeting portions of an urban area or health centers targeting specific socioeconomic groups within a geographic area. In this case, projections can provide approximations for the target population.

Projections, also called extrapolations, are another method of estimating health statistics for your target population. A basic projection is achieved by simple multiplication and addition, and is called **indirect standardization**. We use this method when the data for our target population do not exist, and available data (perhaps at the county or state level) do not accurately describe the target population.

In the example below, we want to answer two questions: 1) What is the prevalence rate of Type II diabetes in our target population? and 2) Does this represent a health disparity? The issue is that the only available data are at the state level and our target population is made up of a different racial/ethnic mix than the statewide population.

Step 1: Identify the denominator – the target population – by race/ethnicity. In our case we are interested in three groupings: African American, Latino, and Caucasian. Next, we download the race/ethnicity table from the U.S. Census (<http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml>) for our service area and group them as follows:

A. TARGET POPULATION BY RACE/ETHNICITY	B. TOTAL NUMBER IN TARGET POPULATION	C. PERCENT OF TARGET POPULATION (IN DECIMAL) B/TOTAL
African American	6,500	0.520
Latino	3,500	0.280
Caucasian	2,500	0.200
TOTAL	12,500	1.000

Note: You can use any population data from any reliable source for the denominator as long as you use numerator data for the same year.

Step 2: Identify numerator data. In this example we are looking for a dataset that provides prevalence of Type II diabetes by race/ethnicity and in the same year as the denominator data. The data we are using for this example come from the Behavioral Risk Factor Surveillance System (BRFSS) at the state level. Download the data into your table:

RACE/ETHNICITY	TARGET POPULATION BY NUMBERS	TARGET POPULATION BY PERCENT	STATEWIDE DIABETES PREVALENCE
African American	6,500	0.520	0.112
Latino	3,500	0.280	0.096
Caucasian	2,500	0.200	0.071
TOTAL	12,500	1.000	.0840

Step 3: Calculate the projected prevalence rate for Type II diabetes for the target population. Here, we multiply the percent of each group in the target population by the diabetes prevalence rate for that group at the state level. After adding these up, we compare the total diabetes prevalence rate for our target population to the state rate and determine if there is a disparity:

RACE/ ETHNICITY	TARGET POPULATION BY NUMBERS	A. TARGET POPULATION BY PERCENT	B. STATE DIABETES PREVALENCE	PROJECTED TARGET POPULATION DIABETES PREVALENCE A * B
African American	6,500	0.520	0.112	0.058
Latino	3,500	0.280	0.096	0.027
Caucasian	2,500	0.200	0.071	0.014
TOTAL	12,500	1.000	0.084	0.099

Multiply the totals by 100 to turn them into percentages and compare the state rate to the target population rate:

STATE	8.4%
TARGET POPULATION	9.9%

Since the state rate is lower, we conclude that our target population experiences a health disparity for Type II diabetes compared to the state overall. Keep in mind that you must document the sources of your data, including where you got them from and the years they represent.

Interpretation

After you have finished collecting and analyzing your data, you should aim to make the most effective comparisons and interpretations to demonstrate the health disparities being experienced by your target population. For instance, if your entire state has poor vaccination rates, then it may be more effective to compare the vaccination rate within your target population to the national rate in order to demonstrate a disparity.

Some Useful Data Sources and Other Resources

Data Sources

There are various sources of quantitative data available to you that have already been collected by others, including the U.S. Census and various registries, surveys, and surveillance programs. You may wish to consult some of these sources to obtain data on issues that disproportionately affect your target population and/or your patient population.

Below is a list of potential data sources that may be useful to you in conducting quantitative analyses. This is not meant to be a complete or exhaustive list, but it provides a good starting point:

U.S. Census. <http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml> Collected every 10 years, the Census has a variety of information broken down by ethnic and racial groups as well as by geography. The American Community Survey is a part of the Census that is updated every year for larger, metropolitan areas.

FastStats. <http://www.cdc.gov/nchs/fastats/> The National Center for Health Statistics is the central repository for public health-related data. It is organized alphabetically and extremely easy to use. This is an excellent overall resource for benchmark data if you need to compare your target or patient population with some larger group. FastStats also provides links to state health department websites.

Behavioral Risk Factor Surveillance System (BRFSS). <http://www.cdc.gov/brfss/> This is an annual survey on health status and health-related behaviors, conducted by all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. In general, all states ask the same set of questions, but individual states will often include additional questions. In addition, the BRFSS breaks out data by income, racial, and ethnic groups so it is possible to do projections to produce data that are more representative of your patient or target population. The BRFSS also provides some mapping and trend analysis tools.

Youth Risk Behavior Surveillance System (YRBSS). <http://www.cdc.gov/HealthyYouth/yrbs/index.htm> This dataset contains similar data to the BRFSS, but does not provide the same level of flexibility for data searches that the BRFSS provides. However, the data files are downloadable for independent analysis, if you feel ambitious!

March of Dimes Peristats. <http://www.marchofdimes.com/peristats/> This site provides excellent data based on vital statistics from all states. Peristats is user friendly because it breaks the data out into more detailed formats and allows easy comparison between the national level and other states.

National Health Interview Survey (NHIS). <http://www.cdc.gov/nchs/nhis.htm> The NHIS is an annual survey of the U.S. population. It provides information similar to the BRFSS, but also provides data on hard-to-find health issues such as mental health, substance abuse, and disability.

National Immunization Survey (NIS). <http://www.cdc.gov/nis/> This is an annual survey of immunization rates across the states. The data files are also downloadable.

Migrant and Seasonal Farmworker Enumeration Studies. <http://www.ncfh.org/?pid=23> This site provides population estimates for states that historically have had significant populations of migrant and seasonal farmworkers.

Other Resources

State and Local Health Departments. If you are unable find the data you need online, you may want to try making some specific data requests. Health departments will often respond to specific data requests. Make data requests based on zip codes or counties representing your target area.

Mobilizing for Action through Planning and Partnerships (MAPP). <http://www.naccho.org/topics/infrastructure/mapp/framework/index.cfm> MAPP is a community-driven strategic planning process for improving community health. The website allows users to browse, adopt, and tailor tools and resources developed by both MAPP users and staff from the National Association of County & City Health Officials (NACCHO). The MAPP toolbox includes resources for marketing, communication, performance improvement, and evaluation.

UDS Mapper Tool. <http://www.udsmapper.org/about.cfm> The UDS Mapper provides access to preliminary information on existing safety-net providers in a community. This tool includes information on health center service area by ZIP code tabulation area (ZCTA), patients served as reported by Uniform Data System (UDS) data, locations of health center service sites, and locations of federally linked providers (e.g., Rural Health Clinics and National Health Service Corps (NHSC) provider sites).

ArcGIS Resource Center. <http://resources.esri.com/arcgisexplorer/index.cfm?fa=home> This website, hosted by ESRI, has a link to download ArcGIS software as well as a content page with some basic downloads of maps and streets to get you started. A transportation “layer” is also included to help you document potential transportation barriers. If you click on “First Glance”, you will find detailed instructions on how to upload data and create basic maps.

National Center for Health Statistics. <http://www.cdc.gov/nchs/> Besides housing a wealth of statistical information, this site also has a dedicated page to GIS resources. Clicking on “G” on the alphabet bar on the home page will bring up a host of helpful sites.

United State Geological Service. <http://www.usgs.gov/> This site has information on environmental health hazards and emphasizes geographic information systems (GIS).