

Indian Community Health Profile Project Toolkit



Northwest Tribal Epidemiology Center

Northwest Portland Area Indian Health Board

Acknowledgements

The Indian Community Health Profile was first developed by Dee Robertson, MD, MPH, former Director of the Northwest Tribal Epidemiology Center. From 2000 onwards, Tam Lutz, MPH, MHA, has provided expert direction for the Profile Project. The success of the Profile model and project is due in large part to creative vision, professional expertise, and commitment to tribally-directed health planning.

The initial Profile model was refined by a working group lead by Dr. Robertson and Tony d'Angelo, MS, Director of the Indian Health Service (IHS) Headquarters Program Statistics Team, and composed of the following members: Wara Alderete, DrPH, MPH, of the University of California at Berkeley; Thomas Becker, MD, PhD, of Oregon Health Sciences University; Colleen Cawston, Colville Tribal Council member and former Tribal Health Director; Nathaniel Cobb, MD, IHS Epidemiologist; David Espey, MD, MPH, of the Centers for Disease Control and Prevention (CDC); Howard Goldberg, PhD, of the CDC; Leslie Randall, RN, MPH, Nez Perce tribal member and IHS Epidemiologist; Francine Romero, PhD, MPH, of the Northwest Tribal Epidemiology Center; Paul Stehr-Green, DrPH, Consulting Epidemiologist at the Northwest Tribal Epidemiology Center; and Doni Wilder, MPA, Executive Director of the Northwest Portland Area Indian Health Board.

The Profile was piloted in collaboration with three Northwest Tribes: the Coeur d'Alene Tribe in Idaho, the Fort Peck Tribes in Montana, and the Port Gamble S'Klallam Tribe in Washington. Many talented and committed people contributed to the success of the project at each site. At Port Gamble, this group included (in alphabetical order): Nicole Aikman; Jimmy Bidtiwah; Danette Ives; Kerstin Powell; Lourdes Schmitz, MPH; Julia Smith; Destiny Wellman; Kris Zipperer; and the numerous tribal staff members who volunteered to help pilot test survey instruments. At Fort Peck, those involved with the project included (in alphabetical order): Julie Bemer, MPH, RN; Elaine Boyd; Melissa Buckles, BS; Tatum Even-son; Anthony Headress; Edgar Jones, BS; Margaret Longtree; G. James Melbourne; Rose Neumiller; Linda Pavel; John Pipe; and Verbena Savior. At Coeur d'Alene, project personnel included (in alphabetical order): Dale Bates, MPH; Leta Campbell; Debra Hanks; Mary Riley; and Melody Rhodes. Profile Project staff express their sincere admiration and appreciation for the work of all the individuals mentioned above, as well as any others involved with the project whom we may have inadvertently omitted here.

A draft of the Toolkit manual was developed by Lisa Angus, MPH, and piloted by Spirit Lake Nation in North Dakota and Pascua Yaqui Tribe of Arizona. Staff at Spirit Lake included Cindy Lindquist and Gloria Jetty Lefthand. Christina Oré Girón, MPH, was the site coordinator for the Pascua Yaqui Tribe. Both sites gave valuable feedback for the preparation of the final Toolkit Manual.

Major funding for the project has been provided by the Indian Health Service and the Robert Wood Johnson Foundation. In addition, several agencies and individuals have generously provided supplemental funding or in-kind support. Profile Project staff would like to thank: Drs. Howard Goldberg, Jay Friedman, and Wyndy Amerson of the Centers for Disease Control and Prevention, Julia Dilley, MES, of the Washington State Department of Health, and Drs. Bonnie Bruerd and Kathy Phipps of the Northwest Tribal Dental Support Center.

Since 1999, the staff of the Indian Community Health Profile Project at the Northwest Tribal Epidemiology Center (*The EpiCenter*) have been providing training, technical assistance, and other support to tribal communities implementing the Profile Model. Currently, the Indian Community Health Profile Project is directed by Tam Lutz, MPH, MHA, with support from Paul Stehr-Green, PhD, Lisa Angus, MPH,. Former project staff include: Trula Breuninger, MPH; Julia Putman, BA; Dee Robertson, MD, MPH; James Vinson; and Donald Weeks. Emily Puukka, MS, Manager of the Northwest Tribal Registry, graciously conducted data linkages when needed for the pilot site profiles. *The EpiCenter* Director Joe Finkbonner, R.Ph., MHA, and Epidemiologist Francine Romero, PhD, MPH, have been sources of valuable advice and insight throughout the project.

This manual was primarily written by Lisa Angus, MPH. The comments, feedback, suggestions and review of Tam Lutz, MPH, MHA, Sayaka Kanade, BA, Francine Romero, PhD, MPH, Paul Stehr-Green, DrPH, and Emily Puukka, MS, and Nicole Smith, MPH are gratefully acknowledged. Cover art was contributed by Tam Lutz.

Indian Community Health Profile Project

Toolkit

June 2005

Produced by:

Northwest Tribal Epidemiology Center
Northwest Portland Area Indian Health Board

Supported by

Indian Health Service
Robert Wood Johnson Foundation

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Suggested Citation

Angus L, Stehr-Green P, Robertson LD, Lutz T. Indian Community Health Profile Project Toolkit. Portland, OR; Northwest Portland Area Indian Health Board, 2005.

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I. Introduction

"The indicators a society chooses to report to itself about itself are surprisingly powerful. They reflect collective values and inform collective decisions. A nation that keeps a watchful eye on its salmon run or the safety of its streets makes different choices than does a nation that is only paying attention to its GNP [Gross National Product]. The idea of citizens choosing their own indicators is something new under the sun - something intensely democratic."

Donella Meadows, 1941-2001

Community health assessment

All across the country, Indian health programs have the same goal: to elevate the health status of American Indians and Alaska Natives (AI/ANs) to the highest possible level. This is a worthy goal, but one that raises some questions: what is that highest possible level of health? How will we know when we have achieved it? How can we track our progress toward this goal? The Indian Community Health Profile can help individual tribal communities conduct a community health assessment to answer these questions for themselves.

A community health assessment (CHA) is a way of documenting the current status of health of the community in order to make plans for improving it in the future. Community assessments are conducted in fields as different as economics and social work, so the approach tends to differ from one case to another. In the field of public health, however, one philosophy behind CHAs is that both the product *and* the process of the assessment will bring about improved community health.¹ The product—the final report or other document in which comprehensive health status information is

compiled—will give the community an accurate picture upon which to base their future health planning. The process of conducting the CHA will foster the community capacity, accountability, and motivation needed to put future health plans into action.

When properly carried out, CHAs can make an enormous difference in the well-being of a tribe or community. CHAs can help determine whether there is a good fit between community health needs and currently available services. This in turn allows tribes to make well-informed plans for future health services and to write persuasive requests for financial or other support. CHAs can also provide a set of baseline data to which the tribe can refer over time in order to track its progress toward improved health. Perhaps most importantly, conducting a CHA can create the community interest and strategic relationships needed to make any plans for improving tribal health a reality.

What are indicators?

Indicators are small pieces of information that reflect the status of a larger system.

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For example, the gas gauge, the speedometer, and the engine temperature are all indicators of the status of your car. Together, these indicators can give you a general sense of how well the car is running. Indicators are most useful when the system you are interested in would be too difficult or too big to look at directly, as is the case for community health. Indicators cannot tell you everything about the health of your tribal community, but if they are chosen and measured well, they can help you make informed decisions about how to improve health in the future.

Indicators are being used by hundreds of organizations all across the country to set priorities, monitor progress, and as a means of educating people about different issues. For example, the Alexandria Economic Development Partnership in Virginia tracks indicators like unemployment rate and the number of new business licenses to assess the strength of the economy in their area.² In the field of public health, the federal government has established 10 Leading Health Indicators that will be used to measure the nation's health between 2000 and 2010.³

The Indian Community Health Profile

The Indian Community Health Profile (ICHP) is a user-friendly health assessment tool developed specifically for tribal communities of approximately 1000 – 5000 members. Most tribes in the U.S. fall within this range. Currently, much of the available data about Indian health pertains

to whole states or to multi-state regions. These data cannot give smaller tribes the information they need to identify and address the particular health issues that may be of concern to them. In addition, the Indian health data that are currently available consist largely of birth and death rates, which are difficult to use in small communities. The ICHP was designed to address these shortcomings by providing AI/AN communities with a useful, useable, and valid way to measure their overall health status.

Two Northwest tribal health leaders, officials from the Indian Health Service (IHS) and the Centers for Disease Control and Prevention (CDC), epidemiologists from the University of California at Berkeley and the Oregon Health Sciences University, and the Director of the Northwest Tribal Epidemiology Center at the Portland Area Indian Health Board (NPAIHB) all worked together to develop the Indian Community Health Profile. With generous support from both IHS and the Robert Wood Johnson Foundation, the Profile was pilot-tested with three tribes in the Northwest from 1999 to 2002, and was implemented in two additional tribal communities beginning in 2003.

The Profile consists of a set of fifteen health status indicators (see “What Are Indicators?”, page 1, and “The 15 Recommended Indicators”, page 6) that can be used to provide a broad picture of community health.

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It differs from other health status reports, such as the IHS publication Trends in Indian Health,⁴ in several ways:

- It was specifically designed to assess overall community health.
- It covers multiple domains of health: physical, mental, environmental, and social.
- It is not designed to generate standardized data for large area analysis; instead, it can be customized to meet the needs of individual tribal communities.
- Rather than trying to measure every aspect of health, the Profile contains only 15 indicators, which are benchmarks of health status in five different domains.

The Profile indicators are models; we recommend that you use all fifteen to get a comprehensive view of community health, but you may add to, delete from, or modify the indicators to reflect the needs, priorities, and values of the community.

There are a number of other models that you may want to consider if you are planning a community health assessment project (see Additional Resources at the end of this chapter). Some of these models feature more qualitative methods for an in-depth look at certain health topics; others more closely resemble the ICHP because they use indicators or other numeric measures to get a broad picture of community-level health. However, the ICHP is the only health assessment model that was designed specifically for use in tribal communities. Three tribes have pilot tested the model and their

experiences have been incorporated into this manual in order to give you the best possible tool for using indicators to assess the health of your community.

Is this the right tool for my tribe?

The ICHP and this manual were developed with a particular audience in mind. While the model can be adjusted, it is not the right tool for every community. To help determine whether the ICHP is appropriate for your tribe, take a few minutes to consider the following points about the structure and purpose of the project:

- The ICHP was designed for use in tribes of approximately 1000—5000 members. If your tribe is significantly larger than this (e.g. 10,000+), you might already have the capacity to conduct tribal health assessments and you may prefer to use traditional health status measures and research techniques that require a large population.
- The ICHP provides tribal communities with a broad picture of their overall health. If your tribe is interested in more detailed analyses of a particular topic (e.g. substance abuse) or a particular segment of the population (e.g. youth), this may not be an appropriate tool for you.
- The idea behind the ICHP is that tribes will develop a community-specific health profile process that can be re-

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peated every 3-5 years or so. The first implementation will provide a set of standard procedures and baseline measurements. On following occasions, the updated results can be compared to the baseline measurements in order to monitor changes in the health status of the community. If you do not foresee using your Profile as both a baseline *and* a monitoring tool (i.e., evaluating more than once), you may not want to invest the time and effort that are required for the project.

- Because it would be impossible to anticipate every technical assistance need that a tribe may have, this manual was designed to be used by interested tribes *in partnership with* a local or regional tribal epidemiology center, Indian organization, university, local health department, or other agency with public health research experience and statistical expertise. If such an agency or department already exists within your tribe, then this point does not apply to you. If not, ask yourself whether it will be possible to establish a partnership with an organization that can provide the tribe with the level of detailed technical support needed to supplement the material in this manual. We have provided some suggestions of potential partner organizations in the Additional Resources section of this chapter, but if you have doubts about whether such a partnership would be feasible, we would advise you

against starting the project at this time. For the community assessment process to be effective in helping the tribe meet its health goals, the ICHP tools should only be used under the conditions for which they were designed. We urge you to think carefully about whether the project as described above is a good match for your tribe. Chapter II, Project Planning, also addresses the topic of community readiness for participation in the Indian Community Health Profile Project.

Using this manual

This manual is organized into the following chapters, which reflect the progression of steps involved in implementing the ICHP:

- I. Introduction
- II. Project Planning
- III. Creating a Working Group
- IV. Developing an Indicator List
- V. Collecting & Analyzing Data
- VI. Reporting & Using the Profile Results

These chapters will guide you through each stage of the ICHP and will discuss how to adapt the Profile for your tribal community. Each chapter (apart from the Introduction) contains the following items:

- Working examples or case studies, adapted from the experiences of the three tribal communities in which the Profile Project was piloted.
- A Tools section, with templates or examples of forms and documents that you may find useful for implementing the

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ICHP in your community. The tools are also included on an accompanying compact disc (the Tools CD). For the most part, the tools are designed to be used by the people responsible for the day-to-day work of your community health profile.

- A collection of Additional Resources related to the topic(s) covered in the chapter. This can be found at the end of each chapter.

The bulk of the material in this manual is directed toward the people who will be most directly involved in the details of implementing the ICHP in your tribe. This includes the project working group (see Chapter III) and the organization or department with which the tribe will form a partnership for technical and data assistance. It is our expectation that these people will read the manual thoroughly. We recognize, however, that several steps must be taken before a working group or partnership are even formed. Consequently, this and the next two chapters should also be read in detail by tribal health leaders and other decision-makers who must take responsibility for initiating the project in the community.

References

1. Minkler, M. & Wallerstein, N. (1997). Improving health through community organization and community building. In: Health behavior and health education: Theory, research, and practice (K. Glanz, F.M. Lewis, & B.K. Rimer, Eds.). San Francisco, CA: Jossey-Bass Inc.
2. Alexandria Economic Development Partnership. (2002). Local economic indicators—December 2002. Retrieved January 7, 2003 from http://www.alexecon.org/aedp_lcl_ecn_ind.html
3. U.S. Department of Health and Human Services. Leading health indicators: Priorities for action. Retrieved January 22, 2003 from <http://www.healthypeople.gov/LHI/Priorities.htm>
4. U.S. Department of Health and Human Services. (2001). Trends in Indian health, 1998-99. Washington, DC: Indian Health Service.

The 15 Recommended Indicators

Socio-demographic

- Rate of high school graduation.
- Proportion of children (0–18) who live with both natural parents, mother only, mother and another adult, father only, father and another adult, extended family member, or other.

Health Status

- Prevalence of diabetes among all ages.
- Rate of hospitalization (discharges per 1,000) for injuries and poisonings.
- Rate of years of potential life lost (per 1,000 person-years).
- Prevalence of caries (tooth decay) in 3–4 year old and 7–8 year old children.

Mental Health and Functional Status

- Average number of healthy days for adults and seniors in the previous month.

Health risk factors and positive health behaviors

- Proportion of children (ages 2–16) who have a weight associated with good health (i.e., a Body Mass Index ≥ 18 and ≤ 25).
- Proportion of pregnancies with prenatal care beginning in the first trimester.
- Proportion of women (ages 18–65) with a Pap smear within the previous 24 months.
- Prevalence of alcohol or other drug use among adolescents.
- Prevalence of tobacco use among adolescents and adults.
- Proportion of adults who regularly engage in physical activity of a duration and intensity sufficient to promote health.
- Number and prevalence of confirmed cases of abuse and neglect in children (ages 0–18).

Environment

- Presence of tribal ordinances requiring auto safety restraint use, and prevalence of auto safety restraint use (seat belts, child safety seats) for age groups 0–11, 12–18, and > 18.

These indicators are a model only. We recommended that you use all fifteen of the indicators in order to create a comprehensive picture of community health, but you may add to, delete from, or modify the indicators to meet your needs.

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Additional Resources

Alternate community indicator project manuals

Durch, JS, Bailey, LA, & Stoto, MA (Eds.). (1997). Improving health in the community: A role for performance monitoring. Washington DC: Institute of Medicine, National Academy Press. See: www.nap.edu/catalog/5298.html or contact the National Academy Press at 1-888-624-8373 to order.

Hancock, Labonte, & Edwards. (2000). Indicators that count! Measuring population health at the community level. Toronto, Canada: University of Toronto Centre for Health Promotion. Contact the Centre for Health Promotion at 416-978-1809 to order.

Hellman, E. (1997). Signs of progress, signs of caution: How to prepare a healthy, sustainable progress report card. Toronto, Canada: City of Toronto, Ontario Healthy Communities Coalition. See: www.healthycommunities.on.ca

Join Together, Inc. (1997). How do we know we are making a difference? A community substance abuse indicators handbook. Boston, MA. Contact Join Together, Inc. at 617-437-1500 or publications@jointogether.org to order.

Kingsley, G.T. (Ed). (1999). Building and operating neighborhood indicator systems: A guidebook. Washington, DC: The Urban Institute, National Neighborhood Indicators Partnership. Contact NNIP at (202) 261-5709 or pubs@ui.urban.org to order.

MAPP (Mobilizing for Action through Planning and Partnerships) – a strategic planning tool developed by the Centers for Disease Control and Prevention (CDC) and the National Association of City and County Health Officials (NACCHO). The third phase of the MAPP process—assessment—includes instructions for conducting an indicator-based community health assessment. See http://mapp.naccho.org/MAPP_Home.asp for more information.

Redefining Progress & Earth Day Network. (2002). Sustainability starts in your community: A community indicators guide. San Francisco, CA. Contact Redefining Progress at 415-781-1181 or info@rprogress.org to order.

Redefining Progress, Tyler Norris Associates, & Sustainable Seattle. (1997). The community indicators handbook: Measuring progress toward healthy and sustainable communities. Contact Redefining Progress at 415-781-1181 or info@rprogress.org to order.

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Additional Resources

UCLA Center for Healthier Children, Families, and Communities. (Forthcoming). Development of an effective community report card. See: www.healthychild.ucla.edu/programs/programs.asp?reportCard and contact UCLA at 310-794-7201 or chcfc@ucla.edu to order.

Non-indicator-based community health assessment project manuals

Community Tool Box - an online collection of “how-to” tools organized by the University of Kansas. Includes sections on community assessment and other topics. See: <http://ctb.lsi.ukans.edu> for more information.

Minkler, M. (Ed.). (1997). Community organizing and community building for health. New Brunswick, NJ: Rutgers University Press. Call the publisher at 1-800-446-9323 to order.

PATCH (Planned Approach to Community Health) - A model for planning, conducting, and evaluating community health promotion and disease prevention programs, developed by the Centers for Disease Control and Prevention. See: www.cdc.gov/nccdphp/patch for more information.

Petersen, D.J. & Alexander, G.R. (2001). Needs assessment in public health: A practical guide for students and professionals. New York, NY: Kluwer Academic Press. Call the publisher at 1-866-269-9527 to order.

Sources for Technical & Data Support

Regional Tribal Epidemiology Centers

Alaska Native Epidemiology Center
3700 Woodland Drive, Suite 500
Anchorage, AK 99517
(907) 562-6066
www.anhp.org

Northwest Tribal Epidemiology Center
NW Portland Area Indian Health Board
527 SW Hall, Suite 300
Portland, OR 97201
(503) 228-4185
www.npaihb.org/epi/Epihome.html

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Additional Resources

Great Lakes Inter-tribal Council
Epidemiology Center
P.O. Box 9
Lac du Flambeau, WI 54538
(715) 588-3324
www.glitc.org

Seattle Indian Health Board
Epidemiology Center
P.O. Box 3364, 611 12th Ave South
Seattle WA 98114
(206) 324-9360
www.sihb.org

Inter-tribal Council of Arizona
Epidemiology Center
2214 North Central Ave, Suite 100
Phoenix, AZ 85004
(602) 258-4822
www.itcaonline.com

United South and Eastern Tribes
Epidemiology Center
711 Stewarts Ferry Pike, Suite 100
Nashville TN 37214
(615) 872-7900
www.usetinc.org

Indian Health Service Area Offices

Aberdeen Area
115 4th Avenue Southeast
Aberdeen, SD 57401
(605) 226-7531
Albuquerque Area
5300 Homestead Road NE
Albuquerque NM 87110
(505) 248-4102

Alaska Area
4141 Ambassador Drive
Anchorage, AK 99508-5928
(907) 729-3689
Bemidji Area
522 Minnesota Ave NW, Room 119
Bemidji MN 56601
(218) 444-0458

Billings Area
2900 4th Avenue North
Billings MT 59101
(406) 247-7147

California Area
650 Capitol Mall, Suite 7-100
Sacramento CA 95814
(916) 930-3945

Nashville Area
711 Stewarts Ferry Pike
Nashville TN 37214-2634
(615) 467-1500

Navajo Area
P.O. Box 9020
Window Rock AZ 86515-9020
(928) 971-5811

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Additional Resources

Oklahoma City Area
5 Corporate Plaza
3625 NW 56th Street
Oklahoma City OK 73112
(405) 951-3768

Phoenix Area
Two Renaissance Square
40 North Central Avenue
Phoenix AZ 85004
(602) 364-5039

Portland Area
1220 SW Third Ave, #476
Portland OR 97204
(503) 326-4123

Tucson Area
7900 S.J. Stock Road
Tucson AZ 85746-7012
(520) 295-2405

Health Resources and Services Administration (HRSA) - Public Health Training Centers

The HRSA Public Health Training Centers are partnerships between accredited schools of public health (and related academic institutions) and public health agencies and organizations. As of March 2003, there were 14 of these centers, serving 42 states and the District of Columbia. For a list of all centers and their contact information, go to: <http://bhpr.hrsa.gov/publichealth/phtc.htm>, or contact HRSA representative John Kress at: (301) 443-6864 or jkress@hrsa.org.

Centers for Disease Control and Prevention (CDC) - Prevention Research Centers

The CDC supports 28 Prevention Research Centers (PRCs) across the country. Each PRC consists of a network of academic centers, public health agencies, and community partners conducting applied research and practice in chronic disease prevention and control. For a list of the PRCs and their contact information, go to: <http://www.cdc.gov/prc>.

Your State, County, or Local Health Department

There are far too many health departments to list here, but tribal health officials can probably put you in contact with the ones in your area. If not, the government section of the local yellow pages should have contact information for the relevant agencies.

Local or Regional Colleges and Universities

Academic institutions can also be a sources of technical or data support for community health profile projects. If your local or regional college has a school or department of public or community health, that is a good place to start.

II. Project Planning

This short chapter contains several tools and suggestions to help you envision your version of the Indian Community Health Profile (ICHP) and organize your approach to it. Please note that some subsequent chapters also include planning tools (e.g. the Indicator Development Worksheet in Chapter IV) but that those tools are focused on specific aspects of the project. The content of this chapter is more general in scope.

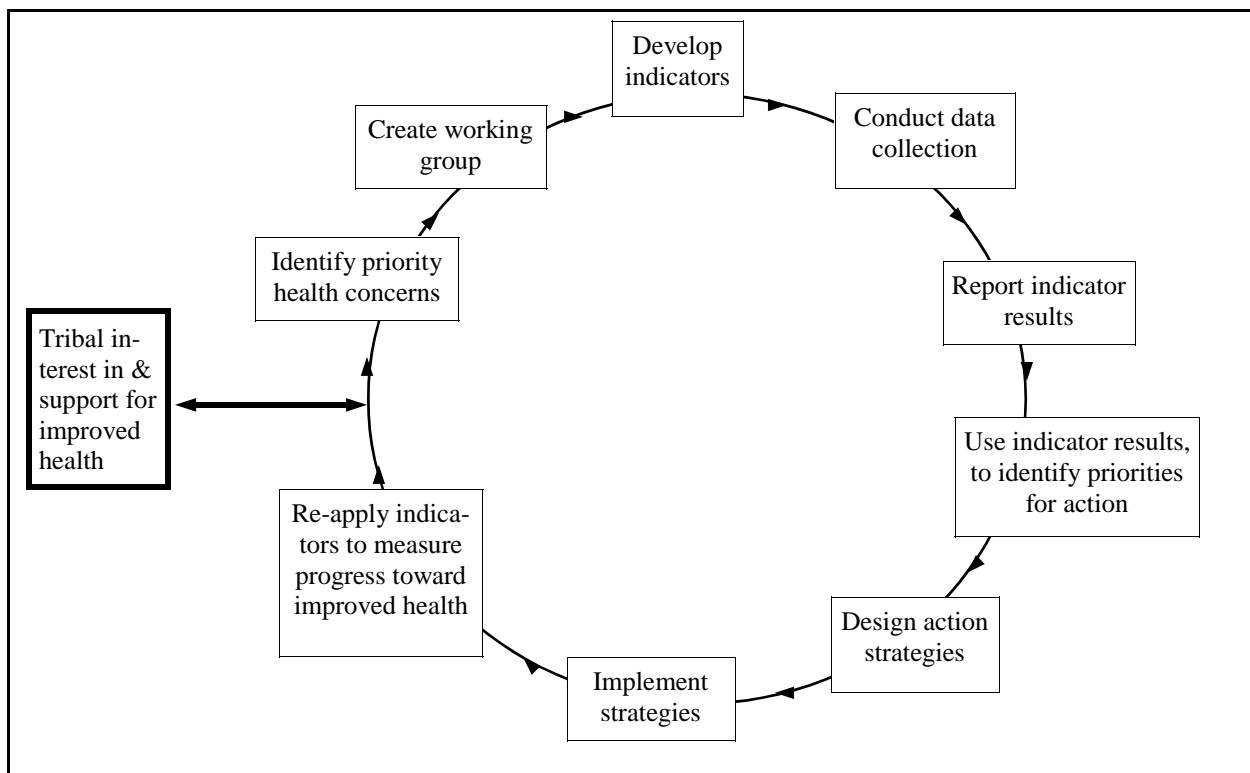
Conceptualizing the project

Simply reading over the Table of Contents for this manual is a good way to get a rough idea of what the ICHP entails. However, we encourage everyone involved in the planning of the project to read the entire manual attentively and familiarize them-

selves with each component before starting the project. Doing so will help you develop a good sense of the project's scope and should demonstrate the degree to which developing clear plans and gathering support for the project in its early stages will facilitate a smooth implementation. It will also acquaint you with the different resources needed for the project and enable you to solicit any necessary support well in advance.

Below is a diagram of how the ICHP is intended to function. This graphic may help you see how the processes and tasks of the project relate to one another and how the project as a whole might inform health planning at the tribal level. In the diagram, tribal interest in and support for improved

Figure 1. Flow diagram of the Indian Community Health Profile process.



II. Project Planning

health is outside the main cycle to indicate that it is a gateway step; the rest of the process cannot work without the support of the tribal community. However, as noted in the Introduction, the process of conducting a community health profile should in itself increase the community's feeling of accountability for its own health and its motivation to improve it.

Readiness

In the Introduction, you were asked to consider whether the ICHP was a good match for what your tribe hopes to accomplish by doing a community health profile (see "Is this the right tool for my tribe?", page 3). Now we'd like you to assess whether this is the right time to implement the ICHP in your community. Before launching the project, make sure you can answer 'yes' to all of the following questions:

- Is there interest in the project from a wide range of people in the tribal community? Consider both the people who are most likely to run the project, such as health planners or clinicians, as well as groups whose involvement will be less intense but equally important, such as community leaders, educators, and tribal members in general.
- Do tribal leaders (Council, tribal elders, and others) support the idea of implementing the ICHP in the tribe?
- Are tribal leaders and health officials willing to commit resources toward the

project (e.g. staff time, funds, office space, access to data, etc.)?

- Is there a clear vision for how the results of your community health profile will be used?
- Does the tribe have some experience with assessing or monitoring health status? If technical assistance will be needed, will the tribe be able to form a supportive partnership with a tribal Epidemiology Center or other regional organization?
- Are at least some good quality data about the health status of tribal members currently available?
- If it is anticipated that data from external sources will be used, does the tribe have a good relationship with the agencies holding those data?

In the Tools section of this chapter (page 15) and on the Tools CD, you will find a Readiness Worksheet based on the above questions that will help you keep track of the resources needed to implement the ICHP in your community at this time. See also the working example on the following page for an illustration of tribal readiness.

Timeline

Having read through this manual, considered the diagram on the previous page, and assessed the tribe's readiness to conduct

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WORKING EXAMPLE - READINESS

In one of the ICHP pilot sites, tribal readiness was part coincidence and part planning. Three different individuals at the tribe—a clinician, a health educator, and a Tribal Council member—all contacted ICHP project staff independently to express their interest in using the model to create a health profile for their tribe. When they realized that they all thought that the project would benefit the tribe, they all met with ICHP staff to coordinate their ideas.

Creating the right environment for the ICHP at the tribe involved improving inter-departmental communication and reducing some misunderstandings between different divisions within the health unit. The Tribal Council member mentioned above was able to provide a formal structure and promise of support around which different interests in the project could unite. In addition, the timing was right for implementing a community-driven health improvement process in the tribe. The tribe had recently compacted some of its health services and was ready to begin strategic planning. An excellent candidate for project coordinator—a tribal member who had good connections with a variety of tribal agencies and experience in mobilizing community participation in similar situations—was available to begin work. All of these factors combined convinced tribal officials and project staff that the community was ready to participate in the project.

such a project, you are now in a position to sketch out a project timeline. While it may not be possible to be entirely precise about timing at this stage, even a draft timeline will give project personnel a sense of how long each step should take relative to the others and a set of goals to work toward.

A sample ICHP timeline has been included in the Tools section of this chapter (page 17) and on the Tools CD. As you can see, the project workload is weighted somewhat toward the first six months, when much of the project planning and preparation for data collection takes place. When adapting this timeline for your tribe, consider what human, financial, and other resources you have available for the project and bear in mind any community characteristics that might complicate the process. For example, if the tribal community is spread out over a wide geographic area, you might need to build in extra time during data collection or other phases of the project in which community members are most active. Similarly, if many people participate in seasonal activities that take them away from home (fishing, pow-wows, Sundance, etc.), it would be best to collect data at other times. Remember also to allow time for the unexpected, such as your request for tribal council approval getting pushed back to a later meeting.

One activity that is not shown on the sample timeline but that you might want to include on your version is keeping the community

II. Project Planning

informed about the project. Announcing different project achievements as they are accomplished or reporting on the progress of various activities are good ways to remind people about the project and keep them interested in it. This interest will in turn support efforts to involve community members in project priority setting, data collection, and interpretation of results.

Formalities

In all of the ICHP pilot sites, approval was obtained from the Tribal Council before proceeding with the project. In some tribes, this may be a necessity, in others, it may be more of a courtesy, but in all cases it is probably beneficial. Tribal Council approval lends a great deal of legitimacy to projects, which will be helpful when you are asking for community information and participation. In addition, the process of obtaining an endorsement from the Council is another opportunity to raise awareness about the project. If you decide to seek Council approval, we have included a template tribal resolution for you to modify among the tools provided in this chapter (page 18) and on the Tools CD.

Documentation

We realized the importance of documentation during the pilot phase of the Indian Community Health Profile Project. Documentation may seem like a time-consuming, low priority task, but it is crucial for several reasons.

Because there are so many tasks involved in implementing the ICHP, it can be easy for those involved with the project to lose track or get overwhelmed. Good documentation can help project personnel to keep the different project activities organized and to remain aware of what is happening in areas of the project for which they may not be directly responsible.

As noted in the Introduction, the idea behind the ICHP is that the tribe will develop both a tool and a process for collecting health data that can be used repeatedly in order to track changes in tribal health status over time. In order to be able to compare data from one year to another, the procedures and measurements used need to be as similar as possible. So the better the documentation during the first implementation, the easier it will be to use your community health profile again in the future.

Good documentation can also serve as proof that the data collected for your profile are unbiased. Documenting what procedures were used, what data sources were accessed, what assumptions were made, and so on, will help others take the results of your community health profile seriously. Since one of the goals of the ICHP is that profile results will be used by community members other than those who participated directly in the project, documentation of the methods is necessary in order to help users know in what ways it is appropriate to use the data.

Finally, you will need documentation of

II. Project Planning

what was done during the project to help you evaluate how well the project was conducted and how effective it was at helping the tribe meet its goals. (See the next heading, “Evaluation”, for more on this topic.) Good documentation will make it easier to see which parts of the process worked well and which need to be improved for the next time you implement your community health profile.

This manual contains several tools to help you document your work as you proceed through the project. In addition to the tools pertaining to specific chapters (e.g. the Indicator Development Worksheet in Chapter IV), you will find an overall Project Activity Log in the Tools section of this chapter (page 19) and on the Tools CD. An example log entry has been provided and some of the major ICHP activities are shown, in the order in which they are discussed in this manual. This documentation tool will be most useful if you modify and expand it to fit your own project.

Evaluation

Michael Quinn Patton, a nationally recognized expert in program evaluation, defines the practice as: “the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future programming.”¹ Many people think of evaluation as something that happens after a program has ended, but evalua-

tion should in fact be an integral part of project design. Incorporating evaluation into your project planning will help you clarify what you want to achieve and how each project activity relates to your goals.

There are several different approaches to program evaluation and it is outside the scope of this manual to provide detailed instructions. However, we do recommend that you evaluate your community health profile project and that you plan your evaluation up front. Doing so will save both time and money and will help you keep the project on track. We have included a list of program evaluation manuals and contacts in the Additional Resources section of this chapter.

As you begin ...

Recognize that conducting a tribal health profile requires a significant commitment in terms of time, resources, and motivation. However, the positive impact of the project on your community’s health can be enormous and long-lasting. To avoid getting bogged down in the details, keep these three overall goals in mind throughout the project: you want the process to be participatory for the community, the data collected to be reliable and valid, and the resulting product(s) to be used.

References

1. Patton, M.Q. (1997). Utilization-focused evaluation: The new century text (3rd edition). Thousand Oaks, CA: Sage Publications

IHCP Readiness Worksheet

Is there interest in the project from a wide range of people in the tribal community?

Write the names of individuals and groups who have expressed interest in the project here:

Do tribal leaders support the idea of implementing the ICHP in the tribe?

Record the names of tribal leaders who have pledged their support for the project here:

Are tribal leaders and health officials willing to commit resources toward the project?

Record the source and nature of the different kinds of support that have been offered here:

Example: 8 hours/week of RPMS Specialist time offered by Tribal health department

Is there a clear vision for how the results of the community health profile will be used?

Record the intended use(s) of the results here:

Who or what organizations will provide technical assistance for data planning, collection, and analysis?

Record the names of people and organizations that will provide technical assistance here:

Are data about the health status of tribal members currently available?

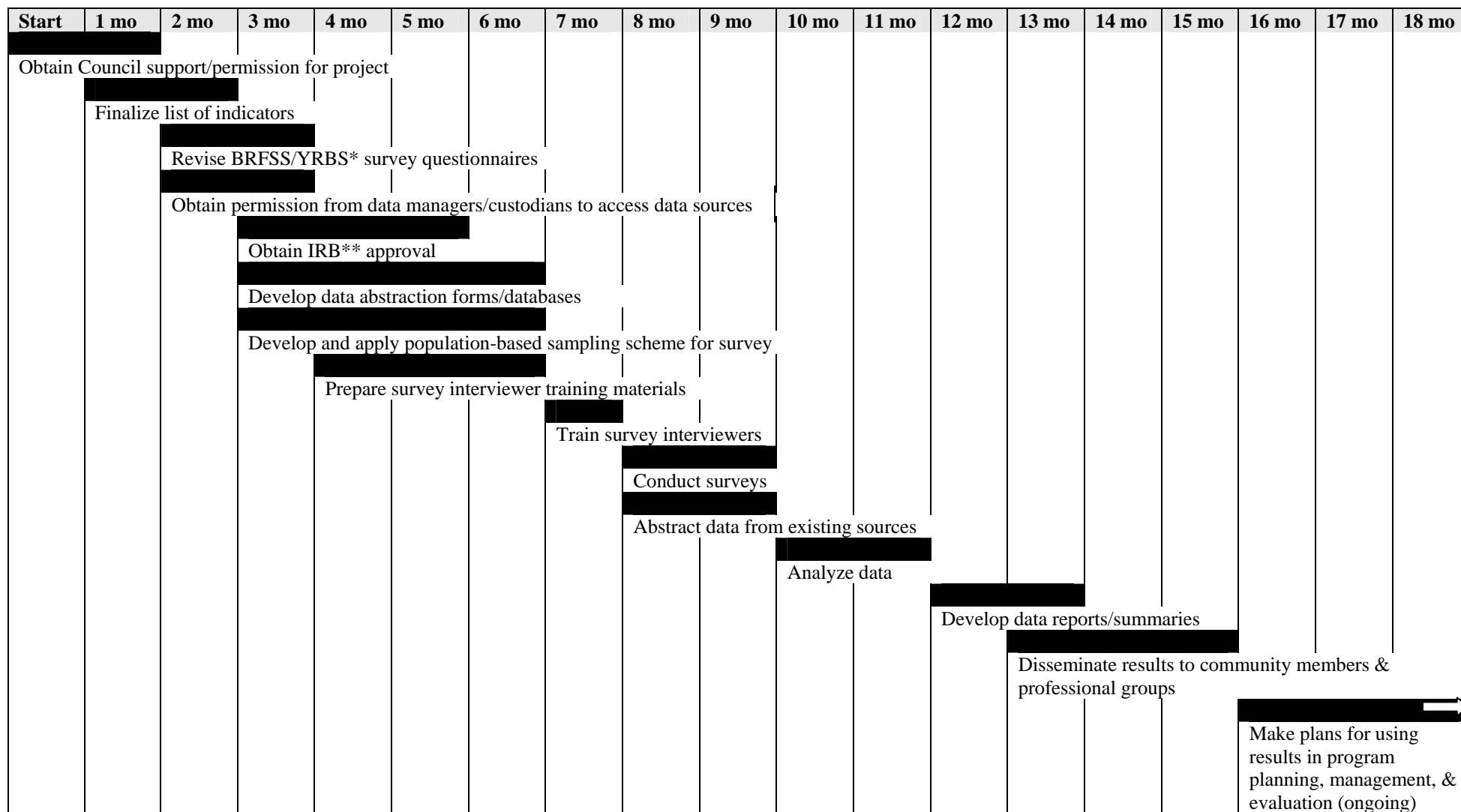
Record the topics, types, and sources of existing data here:

Example: Height & weight of Head Start children; paper records; Sept. 2002 assessment

If it is anticipated that data from external sources will be used, does the tribe have a good relationship with the agencies holding those data?

List potential data source agencies here and note nature of the working relationship:

Sample Community Health Profile Project Timeline



Note: This timeline assumes that the profile will require both original data collection and the use of existing data. The dark bars indicate the approximate start and finish dates and the approximate length of time needed for each activity.

* Behavioral Risk Factor Surveillance System (BRFSS) and Youth Risk Behavior Survey (YRBS) – the ICHP pilot sites modified these standard surveys from the Centers for Disease Control and Prevention to collect tribal-level health behavior data.

** Institutional Review Board (IRB) – an entity which protects the rights and confidentiality of research participants. See Chapter V for more information.

Template ICHP Tribal Resolution

RESOLUTION # _____

WHEREAS, the <name of governing body> is the duly elected body of the <Tribe> by the authority of _____; and

WHEREAS, _____ are primary goals and objectives of the <Tribe>; and

WHEREAS, the <tribal health board or other entity> operates under the authority provided by the <name of governing body> and acts on behalf of the <name of governing body> for health matters; and

WHEREAS, health status measures are often not available at the community or tribal level; and

WHEREAS, the Indian Community Health Profile Project was designed to provide a useful and useable tool with which tribes can measure their overall health status, and;

WHEREAS, the <name of Tribal Epidemiology Center or Indian organization with which the tribe will partner to conduct the project> will work closely with the <Tribe> to identify appropriate health indicators and to ensure that the project is conducted in a confidential and culturally sensitive manner; and

WHEREAS, the identified health indicators may be measured using community surveys, existing records, or other sources; and

WHEREAS, it is necessary to approve the indicators required in order to complete the Community Health Profile Project,

THEREFORE BE IT RESOLVED, that the <name of governing body> has reviewed this project and gives their approval to move forward with the Community Health Profile Project in collaboration with the <name of Tribal Epidemiology Center or Indian organization with which the tribe will partner to conduct the project>.

APPROVED:

<Governing Body Chairperson>

<Other relevant persons>

<DATE>

Community Health Profile Project Activity Log

Note: This is NOT a complete list of all the steps required to complete a community health profile for your tribe. For this log to be a useful documentation and organization tool, you should modify and expand the list to reflect the specific tasks necessary for your particular project.

Activity	Start Date	Anticipated End Date	Person(s) responsible	Partners	Date Complete
<i>Example: Develop sampling plan for community survey</i>	5/1/02	7/15/02	Crystal, Jim, M'kya	Tribal Epidemiology Center Tribal enrollment office Tribal land-use planners	8/3/02
Introduction					
Assess whether ICHP is appropriate tool for the tribe					
Explore possible partnerships with outside agencies for technical and data support					
Project Planning					
Read through ICHP manual					
Complete project readiness checklist					
Draft project timeline					
Obtain Tribal Council approval for project					
Customize project activity log					
Do initial planning for project evaluation					
Creating a Working Group					
Announce project to community and invite volunteer participation					
Form a working group					

Set ground rules for how working group will operate					
Choose working group leader or coordinator					
Formalize technical assistance partnership with outside agency, if needed					
Developing an Indicator List					
Revisit the project goals					
Define the community					
Get community input					
Review existing models					
Draft a list					
Get technical feedback					
Collecting & Analyzing Data					
Finalize data source (original or existing data) for each indicator					
Abstract data from existing sources					
Review data from existing sources for quality					
Design original data collection procedures					
Obtain IRB review or approval					
Design database					
Collect original data					
Conduct analyses (with technical assistance)					
Perform final calculations for indicators					

Reporting & Using the Data					
Identify audience and purpose for different reports					
Create reports (different formats)					
Publicize reports					
Support use of the project results					
Set tentative date for next round of indicator assessment					
Identify key people to regroup for next round					
Evaluation					
Assess what worked, what didn't work, and why					
Assess adequacy of project time, resources, preparation, etc.					
Assess whether changes should be made to indicator list					

II. Project Planning

Additional Resources

Program Evaluation Manuals and Tools

Center for the Advancement of Community Based Public Health. (2000). An evaluation framework for community health programs. Chapel Hill, NC. Call (919) 403-2124 for copies.

Centers for Disease Control and Prevention. (1999). Framework for program evaluation in public health. MMWR 48 (No. RR-11). See: www.cdc.gov/mmwr/preview/mmwrhtml/rr4811a1.htm

Callor, Betts, Carter, Marczak, Peterson, & Richmond. (2000). Community-based project evaluation guide. Tucson, AZ: The University of Arizona Institute for Children, Youth, and Families. <http://ag.arizona.edu/fcr/fs/cyfar/evalgde.htm>

Directorate for Education and Human Resources. (1997). User-friendly handbook for mixed-method evaluations (J. Frechling & L. Sharp, Eds.). Washington, DC: Division of Research, Evaluation, and Communication, National Science Foundation. www.ehr.nsf.gov/EHR/REC/pubs/NSF97-153/start.htm

Joint Committee on Standards for Educational Evaluation. (1994). The program evaluation standards (2nd edition). Thousand Oaks, CA: Sage Publications. Call the publisher at 1-800-818-7243 to order.

Patton, M.Q. (1997). Utilization-focused evaluation: The new century text (3rd edition). Thousand Oaks, CA: Sage Publications. Call the publisher at 1-800-818-7243 to order.

Public Health Training Network. Practical evaluation of public health programs workbook. See: www.phppo.cdc.gov/phtn/Pract-Eval/workbook.asp

University of Kansas. (2003). Community Tool Box: Part J. Evaluating Community Programs and Initiatives. See: http://ctb.lsi.ukans.edu/tools/EN/part_1010.htm

Program Evaluation Contacts (for further information)

American Evaluation Association - www.eval.org. See also www.eval.org/Affiliates/affiliates.htm for a list of AEA's regional affiliates.

II. Project Planning Additional Resources

U.S. Department of Health and Human Services, Administration for Children and Families,
Office of Planning, Research, and Evaluation (OPRE) - [www.acf.dhhs.gov/programs/
opre/](http://www.acf.dhhs.gov/programs/opre/)

III. Creating a Working Group

A community health assessment is not something that can be done by one person. Not only would the amount of work involved be too much, it would also be impossible for a single person to adequately represent the diversity of ideas and opinions that exist in the community as a whole. For these reasons, it is recommended that you form some kind of team or working group to implement the Indian Community Health Profile (ICHP) in your tribe.

Getting the word out

The first step in this process is obviously to let people know about the project and invite their participation. One way of doing so is to hold a meeting (or participate in regularly scheduled health department, tribal council or community meetings) in which you give a presentation about the ICHP and ask for working group volunteers. If you are thinking about doing this, materials for a brief talk about the ICHP are provided in the Tools section of this chapter and on the Tools CD. You may use this template as is or draw on the information to develop your own presentation. Another method is to announce the project and the need for working group members in local media (tribal newspapers, radio station, etc.) and to give interested volunteers a contact for more information.

Forming a group

When forming a working group, there are three main considerations that must be balanced: diversity, technical expertise, and

size.

1. Diversity

Since this is a *community* health profile, it is a good idea to have working group members from as many different sectors of the community as is practical. If your community is made up of more than one band or tribe, for example, you should probably invite at least one representative from each to participate (see Who to Include for other suggestions). Having a wide range of people involved in planning and conducting your health profile as part of the working group will add energy and new ideas to the project. It should also give the project credibility with the community as a whole, which means that people will be more likely to participate in the data collection process when asked, more likely to take the results of that data collection seriously, and more likely to take action on those results.

Note: Having a diverse working group is important, but there will also be stages at which input and action on the project must be provided by non-working-group members, such as tribal leaders, technical experts, or tribal members in general. The times when external participation is required will be discussed in the following chapters.

2. Technical Expertise

In addition to representing a range of

III. Creating a Working Group

community opinion, working group members should bring a variety of skills to the project. Perhaps most importantly, you will need some people who are comfortable working with numbers and statistics. A large part of the ICHP involves collecting and interpreting health data, so it is important to make sure that the data you work with are of good quality and that the conclusions you draw from those data are justified. In some cases, making these judgments requires special training. Consequently, it is a good idea to ensure that your working group either includes people with the necessary training or has access to outside support throughout the project. Your tribal health department is an obvious place from which to recruit working group members or outside advisors with these capabilities. For additional suggestions of where to look for data and statistics support, please see the Additional Resources section of the Introduction.

Other kinds of expertise that are especially useful among working group members include people skills, a talent for organization, and the ability to communicate clearly in many formats. People skills will be required in order to mobilize and unite different community groups to work toward the common goal of doing a community health profile. Organizational skills will be necessary in order to keep track of project goals

and to coordinate all the activities that are being done to meet those goals. Finally, communication skills will be needed to keep non-working group members informed about the project and to share the results of your profile with everyone in the community.

3. Size

The size of your working group is a third consideration. Adding more and more people to achieve diversity and to ensure that the necessary skills are represented can lead to a very large working group. Such groups are often difficult to coordinate and people may end up feeling like they are not truly involved in the project. On the other hand, having too few people often means that group members are overworked. The ideal working group size depends on the size of your community and the degree to which the desired range of skills and community diversity overlap in individuals. The ICHP pilot site groups ranged from approximately 5 to 10 members.

For an illustration of the process of working group formation, see the working example on the following page.

Who to include

Some examples of people you might want to include in your community health profile working group follow below. Remember though, these are only suggestions. You are

III. Creating a Working Group

the best judge of what groups and skills will be necessary for your project.

- A tribal elder
- A youth services provider
- A member of the tribal health department or health advisory board
- An RPMS specialist (if your tribe uses this Indian Health Service data system)
- A public health epidemiologist or statistician (from outside the community if necessary)
- A health services provider
- A social services provider (i.e. a social worker, drug & alcohol counselor, community health representative, etc.)
- A staff person from the Indian Health Service
- A tribal enrollment or tribal administration employee
- A tribal spiritual leader
- An elected tribal official

From our experience with the ICHP pilot sites, we learned that the commitment and enthusiasm of working group members are enormous assets to the project. When working group members are mutually supportive, dedicated to the goals of the project, and able to participate consistently, tasks tend to get accomplished in a timely manner and have good results. On the other hand, when turnover among working group members is frequent, when the bulk of the work is left to just a few people, or when working group members lose interest, the project tends to move slowly and the final results can be poor. So it is important to

WORKING EXAMPLE - GROUP FORMATION

One health planner in a Northwest Tribe initially heard about the ICHP from the IHS Area Office. She then spent some time investigating the project and obtaining the support of various tribal officials for the idea of using the ICHP tools to create a health profile for the community. An Indian organization in the region promised to collaborate with the Tribe on the profile, but the health planner still needed to form a working group at the tribal level to coordinate the project. How did she find working group members?

She decided to start by approaching the tribal Chairperson, the Health Director, and the heads of the tribe's education, youth, and social services departments for suggestions. She knew that all of those agencies would be called upon to participate in the project at some stage and wanted to invite their support and participation early on. The planner also did some research and networking to identify people who had been involved in tribal research or planning projects in the past. These individuals brought a wealth of knowledge and experience with community-based activities to the working group. Finally, she held an open community meeting to announce the opportunity for community members to participate in the working group. Among the many interested volunteers, she selected only 3 or 4 in order to keep the working group to a reasonable size.

III. Creating a Working Group

emphasize to potential working group members that the project entails a significant commitment of both time and energy.

Similarly, it is important to ensure that your working group will have the support of tribal leadership, tribal health officials, and the community at large. The most dynamic working group in the world would find it difficult to overcome a lack of political will, institutional support, and community interest in order to complete the project successfully. If you used the Readiness Checklist from Chapter II, you should already have assured yourself that this support is in place. If not, we suggest you consider the matter seriously now. For sources of further information on engaging communities in health improvement efforts, see the Additional Resources section of this chapter.

Working together

In many working groups, it is helpful to set some ground rules for communication and joint activities. For example, many tribes value consensus decision-making, so your group may want to establish a policy of giving everyone an opportunity to speak before major decisions are made. Other ground rules that many groups adopt include starting and ending group meetings on time, taking turns to facilitate or moderate the meeting, and documenting actions to be taken and persons responsible at the end of each meeting. Take a little time at your first meeting to think about how you want your group to operate.

It is also useful to choose a group leader or coordinator in many group work situations. This person does not necessarily have to direct the work of others, but she or he can help coordinate the different project activities, help keep the group focused on its goals, and serve as the point of contact for people outside the working group who want further information about the project.

If a tribal epidemiology center, a regional Indian organization, or other outside agency will be providing technical support for your community health profile project, it is a good idea to develop a Memorandum of Understanding (MOU) to clarify the roles and responsibilities of each party. Even if the project will be done entirely within the tribe, you may want to draft an MOU so the different departments involved know what to expect. A template MOU, which can be modified to fit your project, has been provided in the Tools section of this chapter and on the Tools CD. You may also want to consult some of the books and articles related to collaborations in public health, which can be found in the Additional Resources section of this chapter.

A sunset over a body of water with silhouettes of people in a canoe. The sky is filled with warm, golden light, and the water reflects the sun. In the foreground, a group of people are silhouetted against the bright light, sitting in a long, narrow canoe. The overall mood is peaceful and serene.

Indian Community Health Profile Project

Developed by:

Northwest Tribal Epidemiology Center
Northwest Portland Area Indian Health Board

Meeting Our Goals

The goal of all Indian Health programs is:

To elevate the health status of American Indians and Alaskan Natives to the highest possible level.

Are we there yet?

The goal of the Indian Community Health Profile Project is:

To give American Indian and Alaskan Native communities a useful, usable, and valid way to assess their overall health status.

One Size Doesn't Fit All



- ✦ Indian health data typically only available at the state or regional level
- ✦ Usual measures not appropriate for small communities
- ✦ Various tribal settings across the nation are all unique

AND

Health Created at Community Level

✦ “Community health is profoundly affected by the collective behaviors, attitudes, and beliefs of everyone who lives in the community.”

Healthy People 2010



If health is created at the community level, health status should be measured at the community level.

The Indian Community Health Profile

The ICHP is an instrument for assessing overall community health, which

- ◆ Uses a broad definition of health
- ◆ Generates data that are useful and useable at the community level
- ◆ Contains 15 recommended health indicators
- ◆ Works within the context and interest of communities
- ◆ Engages the community in systematic approach to eliminating health disparities

What are Indicators?

- A. Small bits of information that reflect the status of a larger system.
- B. Tools to make conditions visible when we can't examine a system directly or as a whole.
- C. Information that doesn't tell us everything, but can tell us enough to make good decisions possible.
- D. All of the above

The 15 Recommended Indicators

Grouped into five domains of health:

- ✦ Socio-demographic
- ✦ Health Status
- ✦ Mental Health and functional Status
- ✦ Health Risk Factors and Positive Health Behaviors
- ✦ Environment

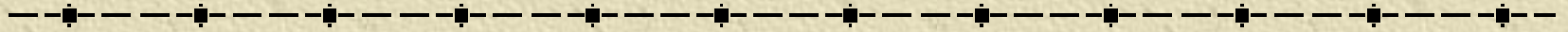
Socio-demographic

- ✦ Rate of high school graduation.
- ✦ Proportion of children (0-18) who live with natural parents, mother only, mother and another adult, father only, father and another adult, extended family member, or other.

Health Status

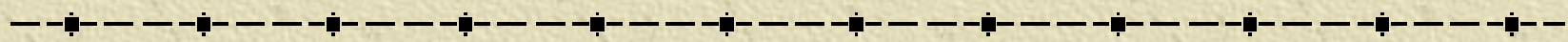
- ✦ Prevalence of diabetes.
- ✦ Rate of hospitalization for injuries and poisonings.
- ✦ Rate of Years of Potential Life Lost (YPLL)
- ✦ Prevalence of caries (tooth decay) in 3-4 year old and 7-8 year old children
- ✦ Average number of healthy days for adults and seniors in the past month

Mental Health & Functional Status



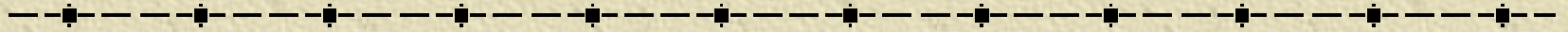
✦ Average number of healthy days for adults and seniors in the past month.

Health Risk Factors & Positive Health Behaviors



- ✦ Proportion of children ages 2-16 who have a weight associated with good health (i.e., a body mass index (BMI) <85th percentile).
- ✦ Percentage of pregnancies with prenatal care beginning in the first trimester.
- ✦ Rate of Pap smears within the past three years among women aged 18-65.
- ✦ Prevalence of alcohol and other drug use among adolescents.
- ✦ Prevalence of tobacco use among adolescents and adults.

Health Risk Factors & Positive Health Behaviors



- ✦ Proportion of adults who regularly engage in physical activity of a duration and intensity sufficient to promote health.
- ✦ Number and rate of confirmed cases of child abuse and neglect.

Environmental

-
- ✦ Presence of tribal ordinance requiring auto safety restraint use and prevalence of auto safety restraint use for infants, youth, and adults.

Note:

- ✦ The Indian Community Health Profile is not designed to collect standardized data for area level analysis; it is designed to be useful to Indian communities as a tool to assess and monitor their overall health status over time.
- ✦ The 15 indicators are recommended but not required; communities may add to, delete from, or modify the indicator list to meet their needs.

Is Your Community Interested?

- ✦ An ICHPP Toolkit is available to help tribal communities plan and conduct their own health profile.
- ✦ The Toolkit is designed to be used by tribal communities in partnership with regional Tribal Epidemiology Centers or Indian organizations that can offer technical and logistical support for the project

Are You Interested?

-
- ✦ A tribally-based working group is needed to conduct and coordinate project activities at the community level
 - ✦ Working group members should have a variety of backgrounds and skills, and perspectives on the community



MEMORANDUM OF UNDERSTANDING

The <<tribe name>> Tribe
And
<<Tribal Epidemiology Center or other agency name>>

This Memorandum of Understanding (MOU) is made and entered into between the <<tribe name>> Tribe and the <<Tribal Epidemiology Center or other agency name>>.

I. PURPOSE

The purpose of this MOU is to establish a general framework:

- (A) For coordination and cooperation between the <<tribe name>> Tribe and the <<Tribal Epidemiology Center or other agency name>> to work on the Indian Community Health Profile Project and related activities, and
- (B) Upon which the staff of the Tribe and the <<Tribal Epidemiology Center or other agency name>> can jointly plan and carry out mutually beneficial programs and activities consistent with each organization's mission and objectives.

This agreement begins on <<date>> and ends on <<date>> when it will be subject to renewal, revision and/or termination as agreed upon by the participants.

II. BACKGROUND

<<INSERT brief description of Tribe>>.

<<INSERT brief description of tribal epidemiology center or other agency>>.

The Indian Community Health Profile (IHP) was designed by staff at the Northwest Portland Area Indian Health Board as a "user friendly" set of health status measures suitable for a tribal community of approximately 1000–5000 members. The instrument is intended to provide the "average" Indian community with a feasible method of assessing its overall health status and monitoring that health status over time.

III. STATEMENT OF MUTUAL BENEFITS

- A. Promotes opportunities for communities in defining their current overall health status, implementing activities to improve overall health status, and measuring overall health status on a regular basis to determine the amount of improvement.
- B. Ensures that the <<tribe name>> Tribe has access to a useful, usable, and valid way to assess their overall health status.
- C. Promotes opportunities for community engagement in a systematic approach to eliminating health disparities.

IV. COORDINATION AND COOPERATION

A. The <<tribe name>> Tribe will:

1. Obtain Tribal Council and/or Health Advisory Committee support or permission to proceed with project, as necessary.
2. Develop a tribal implementation and evaluation plan and identify a process that supports inclusion of all stakeholders in the project.
3. Develop a project budget to include project costs, e.g., staffing, survey instrument, survey administration, etc.
4. Develop a project staffing plan. Participate in the recruitment, hiring and training of staff and volunteers, if budget permits.
5. Participate in seeking additional funds to fund the implementation of the project, if needed.
6. Select indicators and identify data sources for each indicator selected.
7. Obtain permission from Tribal Council and/or Health Advisory Committee, and data managers to access outside data sources. Provide <<Tribal Epidemiology Center or other agency>> staff with access to data sources, if needed.
8. Provide information to assist in the development of a sampling frame for a population-based survey, if needed.
9. Participate in the development and review of survey questionnaires, if needed.
10. Seek permission from schools to administer the YRBS-like survey, if needed.
11. Administer survey (if needed), analyze data, and create report.
12. Ensure that all <<Tribe name>> data are kept in a completely secure and confidential manner.
13. Conduct professional and community forums to explain results of the profile.
14. Develop plans to address health priorities identified in the profile.

B. <<Tribal Epidemiology Center or other agency>> staff will:

1. Work with Tribe in the development of an implementation and evaluation plan.

2. Participate in the development of a project budget to include project costs, e.g., staffing, survey instrument, and survey administration.
3. Participate in seeking additional funds to fund the implementation of the project, if needed.
4. Assist in the selection of indicators and assist Tribe in identifying primary and secondary data sources for each indicator. Provide support for implementing each of the indicators selected by the Tribe.
5. Examine samples of each source of existing data and assist in designing data abstraction forms.
6. Assist Tribe to develop survey questionnaires, if needed. Revise questionnaires as necessary and assist site in developing and executing sampling scheme.
7. Prepare or obtain survey interviewer training materials and program, if needed. Train interviewers, or serve as a broker to obtain services for the Tribe.
8. Assist Tribe in conducting survey, analyzing data, and preparing report.
9. Assist Tribe to calculate indicators and to conduct professional and community forums to explain profile results.

SIGNATURES

Tribal Chairperson or Health Director
<<Tribe Name>>

Date

Director
<<Tribal Epidemiology Center or other agency>>

Date

III. Creating a Working Group

Additional Resources

References on community engagement, community mobilization, and collaborations in public health

Abatena, H. (1997). The significance of planned community participation in problem solving and developing a viable community capability. Journal of Community Practice, *4*(2), 13-34. Contact a college or university library, or call the journal at 919-962-6455 to order.

Academy for Educational Development (AED), Porter Novelli, & Johns Hopkins University. (1993). Coalitions and public health: a program manager's guide to the issues. Washington DC: Academy for Educational Development. Contact AED at www.aed.org or 202-884-8000 to order.

Butterfoss, F.D., Goodman, R. M., & Wandersman, A. (1993). Community coalitions for prevention and health promotion. Health Education Research, *8*(3), 315-330. Contact a college or university library to obtain a copy.

Butterfoss, F.D. et al. (1996) Community coalitions for prevention and health promotion: Factors predicting satisfaction, participation, and planning. Health Education Quarterly, *23*(1) 65-79. Contact a college or university library to obtain a copy. Note: this journal recently changed its name to Health Education & Behavior.

Centers for Disease Control and Prevention. (1997). Principles of community engagement. Atlanta, GA: CDC, Public Health Practice Program Office. Available online at: www.cdc.gov/phppo/pce/index.htm

Community empowerment, participatory education, and health—part I. (1994). Health Education Quarterly (Special Issue), *21*(2), 141-280. Contact a college or university library to obtain a copy. Note: this journal recently changed its name to Health Education & Behavior.

Community empowerment, participatory education, and health—part II. (1994). Health Education Quarterly (Special Issue), *21*(3), 281-417. Contact a college or university library to obtain a copy. Note: this journal recently changed its name to Health Education & Behavior.

III. Creating a Working Group

Additional Resources

Minkler, M. & Wallerstein, N. (1997). Improving health through community organization and community building. In: Health behavior and health education: Theory, research, and practice (K. Glanz, F.M. Lewis, & B.K. Rimer, Eds.). San Francisco, CA: Jossey-Bass Inc. Contact a college or university library, or call the publisher at 877-762-2974 to order.

Taylor-Powell, E., B. Rossing and J. Geran. (1998) Evaluating Collaboratives. The University of Wisconsin Extension Department, Madison Wisconsin. Available online at: http://cf.uwex.edu/ces/pubs/pdf/G3658_8.PDF

IV. Developing an Indicator List

Six steps for developing your list

As you will see in the case studies for this chapter, there is more than one way to go about choosing your indicators. However, we believe that the six steps below are all necessary components of the process. If the steps outlined below seem daunting at first, remember that the time that you invest in developing, getting feedback on, and refining your list of indicators will make a big difference for the ease of data collection and the clarity of your final report or other product.

1. Revisit your overall goal or purpose

What is the tribe hoping to accomplish by implementing the Indian Community Health Profile (ICHP)? How do you envision the profile results being used? You will already have considered these questions during planning, but it is important to remind yourself of the project's ultimate goals at each stage, so that you set priorities, evaluate data, and report on the profile results in ways that will help you meet those goals.

2. Define the community

Who exactly makes up the community for which you hope to develop a health profile? Is the community for this project everyone who lives on the reservation or tribal lands? Is it only those residents who are enrolled tribal members? Defining your community at the outset will help the working group decide where to look for data and how to calculate the selected indicators. Defining community for the project as a whole does

not prevent the group from choosing to focus some of the indicators on just one group within the community (e.g. youth).

3. Obtain community input

The goal for this step is to solicit community input on which health issues should be addressed in your community health profile. It is not necessary that you finish this step with a fully defined list of explicit indicator suggestions in hand. Instead, the aim should be to develop a good understanding of which health issues are important in the community in order to guide your working group as they narrow down the potential indicators.

Most of the ICHP pilot sites chose to call a community meeting, or a series of them, to get input from tribal members. See the first working example in this chapter for examples of how such meetings fit into the overall process of indicator selection. You are the best judge of how such a meeting should be conducted in your tribe, but here are a few suggestions to help the process go smoothly:

- Start broadly - introduce the project, its goals, the working group members, and explain the purpose of the meeting.
- Introduce the idea of indicators and describe how a set of indicators can be used to provide a broad, quantitative overview of community health.
- Ask people to brainstorm about what health issues are currently important for the tribe and what issues they think will

IV. Developing an Indicator List

WORKING EXAMPLE - COMMUNITY INPUT

The means by which community input was incorporated into the indicator selection process differed in each of the ICHP pilot sites. In one of the smaller tribes, a long initial list of indicators was generated at an enormous community-wide meeting. The project working group then tried to group the suggestions into categories and pick the 1 or 2 indicators that they felt best represented each category. A second large community meeting was held for people to review and respond to the working group's work, and the final list was submitted to the Tribal Health Committee for approval.

In a different site, a public meeting was held, but did not generate many specific ideas for potential indicators. Instead, the project working group, which had been assembled to represent a wide variety of tribal health and social services, developed the indicator list. It was submitted to the Tribal Health Committee for approval and then announced to the community through various tribal media (e.g. newspapers).

As you plan your indicator selection process, take some time to consider what methods will be feasible for gathering community input and which will serve your project goals best in the long run.

be important five, 10, or 20 years down the road. Write down all the ideas on a chalkboard or on flipcharts, where people can see them.

- Have the participants help you group the issues they identified into different domains or areas of health. If people find it difficult to come up with groupings, you may want to use the headings from the ICHP recommended indicators list.
- Once you have a list of health concerns organized into different topic areas, ask people to reconsider the list and make sure that no important issues or areas of health have been neglected. Add the new suggestions as necessary.
- If many topics have been identified, consider working with participants to prioritize the health concerns identified within each domain. One relatively straightforward method of prioritization is to ask participants to vote on which three issues or concerns they would choose to represent each area or domain of health. Record the number of votes for each issue within a given domain, and use those as an indication of community priorities.
- Wrap up the meeting by thanking attendees for their participation, outlining what the project's next steps will be, and letting people know how they can contact the working group to receive further information about the project.

Even if it is several weeks after the community meeting when the list of indicators is

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finalized, it is important to let community members know how their input was incorporated by distributing or publicizing the final list. A second community meeting could be held to announce the indicators, or the list could be published through tribal media (newspapers, radio, etc.).

4. Review existing models

We highly recommend that you assess the 15 ICHP recommended indicators to see if any correspond to the health concerns identified by tribal members in the previous step. The ICHP was designed by a group of tribal leaders and Indian health experts with a great deal of public health experience among them. The recommended indicators represent several important domains of community health (physical, mental, social, behavioral, & environmental), include many of the health issues that disproportionately affect American Indians and Alaska Natives (AI/AN) today, and are feasible for use in tribes of 1000-5000 members. While you are of course free to modify the indicators to meet your needs, they are an excellent resource that should not be overlooked. A list of the 15 recommended indicators can be found in the Introduction. In addition, a list of the indicators and related data sources used by the ICHP pilot sites can be found in the Additional Resources section on page 64.

Similarly, you should review any existing sources of health indicator data that are already available for your tribe, such as pre-

viously conducted surveys or Government Performance and Results Act (GPRA) measures. Doing so might give you new ideas and let you know what to avoid. For example, if any other health data collection is going on in the community, it would be a pity to duplicate efforts by collecting the same information. The process of finding and reviewing existing data sources will also allow you to make connections with people and groups who may be helpful to you as the project progresses.

5. Compose your own indicator list

Based on your project goals and the input received from community members, and keeping in mind both the ICHP recommended indicators and any other health indicators being used locally, your working group should now come up with its own rough list of potential indicators. Each of the chosen indicators should be:

- **Relevant** to your project goals
- **Important** and **understandable** to community members
- **Readily measurable** or have existing data available
- **Valid** - truly measure what you want to measure
- **Reliable** - consistently measure the same thing
- **Calculable** without complicated statistical analysis
- **Worded positively** where possible (e.g. number of children with a healthy body weight, rather than the number of over-

IV. Developing an Indicator List

weight children)

- **Leading** - capable of highlighting issues that the tribe will have to address in the future, even if they are not currently acute problems. For example, instead of counting the number of people with diagnosed cardiovascular disease (CVD), count the number *at risk* for CVD because of high blood pressure, overweight, sedentary lifestyle, and so on.

An essential part of developing an indicator list is identifying potential data sources.

Without at least an idea of what information you will need to calculate an indicator and where you might find or collect it, you will find it difficult to evaluate whether a prospective indicator meets the criteria listed above. So as you add each new indicator to your list, take the time to discuss explicitly how you plan to calculate each measure and where the relevant data can be found or collected.

If you choose to use any of the ICHP recommended indicators, you are one step ahead; an Indicator Development Worksheet with suggestions of potential data sources and calculation methods for each of the ICHP indicators is included in the Tools section of this chapter, page 56, and on the Tools CD. If you are developing some indicators of your own, you can still use this worksheet format to help plan your strategy for each measure. Further details about data collection and indicator calculation can be found in Chapter IV. But whether or not

you choose to add any new indicators, you should still have your indicator list reviewed for validity and feasibility, which is the next step.

6. Seek technical feedback

No matter how important the topic or how many people voted for it, an indicator is of little use unless it can be measured in an accurate and meaningful way over time. For this reason, it is essential to have your proposed list of indicators and indicator data sources reviewed by people with some expertise in statistics or epidemiology and a good knowledge of local data sources. If your working group includes such individuals, the review can be done in-house, at the same time as step #5. If your tribal epidemiology center for another organization will be helping you with the technical review, you have the option of including them for the discussions in step #5 (“Compose your own indicator list,” page 52), or asking them to review the draft indicator list afterwards.

What is the right number of indicators?

As was the case for deciding how many people to include in the working group, balance is the key to answering this question. You will need enough indicators to be able to get a sense of how the community is doing in each domain of health that was identified as important. At the same time, having too many indicators means that your working group will be overburdened and the impact of your profile results will be di-

IV. Developing an Indicator List

minished by the amount of information your audience will have to digest. For tribal communities of approximately 1000 - 5000 members, we think 15 - 18 indicators is about the right number.

Challenges

Following these six steps should help you produce an indicator list that is both technically sound and reflective of community health priorities. However, the process of selecting indicators is not always straightforward.

It can be difficult to come up with a list of indicators that reflects everyone's priorities and satisfies all the relevant criteria. For example, there may be some topics that the working group thinks are important, but that community members are not concerned about or feel are too sensitive to include in the profile (e.g. child abuse, suicide, or income). On the other hand, there may be some issues that have really captured the community's attention (e.g. fetal alcohol syndrome), but that the working group or technical experts think cannot be measured accurately at the tribal level. In such situations, political and interpersonal skills will be necessary in order to make sure that all parties have their voices heard and that the final list of indicators is acceptable to all.

Settling on a final list of indicators can also be challenging because the process of indicator selection overlaps fairly heavily with that of data collection. As noted earlier, it is

WORKING EXAMPLE - CHALLENGES

One of the ICHP recommended indicators is the rate of hospitalizations for injuries and poisonings. You have decided to adopt this indicator and have identified a linkage with a highly-regarded outside data source as the primary means by which you will collect the necessary information. However, it often takes a considerable amount of time (and a formal application) to access outside data, so your project is well past the indicator selection stage by the time you actually receive the data. When you examine the information, you realize that only those hospitalizations that were paid for by Contract Health are included. Community members who were hospitalized for an injury but who paid out of pocket or with private insurance will not be counted, and you have reason to believe that this is a large number of people. What can you do at this point?

One option is to use the indicator as it was originally written and simply plan to emphasize the limitations of the data you will report. Another is to find a different source of data, such as questions about past-year hospitalizations on a community survey. Finally, you could acknowledge that good data were not available for the indicator as written and report instead an alternate measure of the burden of injuries in the community, such as the rate of injury-related visits to the tribal clinic. Once again, the decision rests with your project working group and its technical advisors.

IV. Developing an Indicator List

often necessary to examine samples of data to determine whether or not a particular indicator is feasible as written. In some cases—especially when you plan to collect your own data—this makes it difficult to decide when to stop revising your indicator list and start data collection in earnest. See the text box on the previous page for a concrete example of this situation.

In spite of these challenges, selecting and refining your indicators can be one of the most exciting phases of a community health profile project. Enjoy it!

Indicator Development Worksheet

This worksheet provides suggestions of data sources and calculation methods for the 15 Indian Community Health Profile (IHP) recommended indicators. Blank lines are included at the end of the worksheet for your profile working group and its technical advisors (a tribal epidemiology center or other organization with public health expertise) to use when planning new indicators or variants of the recommended ones.

Please note: for the purposes of the examples in this worksheet, the community of interest was assumed to be tribal members living on a reservation. If you have defined community differently for your project, you will have to change some of the suggested calculations, and in some cases the data sources, to reflect the community for which you are creating a health profile.

Rate of high school graduation			
	Calculation	Data source(s)	Notes
A.	$\frac{\text{Total number of graduates from reservation high schools in years } X + 4, Y + 4, \text{ and } Z + 4}{\text{Total number of graduates from reservation middle schools in years } X, Y, \text{ and } Z} \times 1,000$	School records; tribal education office	This calculation will produce a rate* per 1,000 students. It does not count students who receive a GED, or those who take more or less than 4 years to graduate.
B.	$\frac{\text{Number of survey participants aged 18 - 25 who report having a high school diploma}}{\text{Total number of survey participants aged 18 - 25}} \times 100$	Representative** survey of adult tribal members living on reservation	This calculation is restricted to ages 18-25 in order to approximate the <i>current</i> graduation rate for the tribe.

Proportion of children (0-18) who live with (a) both natural parents, (b) mother only, (c) mother and another adult, (d) father only, (e) father and another adult, (f) other.			
	Calculation	Data source(s)	Notes
A.	$\frac{\text{Number of survey participants who report each category of living arrangement}}{\text{Total number of survey participants}} \times 100$	Representative survey of adult tribal members	It is usually not feasible to survey young children directly, so using a youth survey as the data source here will restrict the age range for which this indicator can be stated. Consider surveying the caretakers of younger children if it is important to the tribe to have data for that age group.

Prevalence of diabetes			
	Calculation	Data source(s)	Notes
A.	$\frac{\text{All tribal members on reservation who are active users of the tribal or IHS clinic and have been diagnosed with diabetes}}{\text{All tribal members on reservation who are active users of tribal or IHS clinic}} \times 100$	RPMS or tribal clinic records	Only active clinic users (i.e. those people who have sought medical attention) are included in this calculation, which may result in an overestimate of the true prevalence of diabetes in the community.
B.	$\frac{\text{Number of survey participants who report having diabetes}}{\text{Total number of survey participants}} \times 100$	Representative survey of tribal members living on reservation	It is usually not feasible to survey young children about their medical diagnoses, so using a survey as the data source for this indicator will restrict the age range for which diabetes prevalence can be stated.

Rate of hospitalization for injuries or poisonings			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{All tribal members on reservation who are active users of tribal or IHS clinic and whose records indicate hospitalization for injury or poisoning in past year (ICD - 9 - CM codes 800 - 999)}}{\text{All tribal members on reservation who are active users of the tribal or IHS clinic}} \times 1,000$	RPMS or tribal clinic records; Linkage with hospital discharge database	This calculation produces a rate per 1,000 people. Before using RPMS or tribal clinic records as the data source, find out whether these records are regularly updated with data from all hospitals in the area that might treat injured tribal members. If accurate data cannot be obtained from RPMS or clinic registries, consider a linkage with your state's hospital discharge data, or consider reporting the rate of clinic visits instead of the rate of hospitalization.
B.	$\frac{\text{Number of survey participants who report hospitalization for injury or poisoning in past year}}{\text{Number of survey participants}} \times 100$	Representative survey of tribal members on reservation	It is usually not feasible to survey young children about their medical diagnoses, so using a survey as the data source for this indicator will restrict the age range for which injury rates can be stated.

Rate of YPLL (Years of Potential Life Lost)			
	Calculation	Data Source(s)	Notes
A.	$\frac{\sum (65 - \text{age at death for each tribal member on reservation who has died within time period of interest})}{\text{Total number of tribal members aged 65 and under on reservation in time period of interest}} \times 1000$	IHS or tribal death records; Linkage with state vital statistics data	<p>If a person dies at age 65 or older, zero (0) years of potential life are assumed to be lost.</p> <p>This calculation produces a rate per 1,000 people.</p> <p>If tribal death records are not complete or up-to-date, it may be necessary to do a linkage with state death records in order to get accurate death information for tribal members.</p>

Prevalence of caries (tooth decay) for 3-4 year olds and 7-8 year olds			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of 3 - 4 year old dental patients ever diagnosed with caries}}{\text{Total number of 3 - 4 year old dental patients}} \times 100$ $\frac{\text{Number of 7 - 8 year old dental patients ever diagnosed with caries}}{\text{Total number of 7 - 8 year old dental patients}} \times 100$	Tribal or IHS dental clinic records	It is a good idea to assess what proportion of children in these age groups regularly goes to the dental clinic before doing this calculation.
B.	$\frac{\text{Number of 3 - 4 year olds examined who were found to have caries}}{\text{Total number of 3 - 4 year olds examined}} \times 100$ $\frac{\text{Number of 7 - 8 year olds examined who were found to have caries}}{\text{Total number of 7 - 8 year olds examined}} \times 100$	On-sight dental exam of a representative group of 3-4 and 7-8 year old tribal members on reservation	If IHS or tribal dental records are not complete or up-to-date and you have the necessary resources, a direct dental assessment of eligible children may be a better data source for this indicator.

Average number of healthy days in past month for adults and seniors			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Total number of days in past month when survey participants reported that both their physical and mental health were good}}{\text{Total number of survey participants}}$	Representative survey of adult tribal members on reservation	This indicator is based on a self-report measure developed by the Centers for Disease Control and Prevention. ¹ Data for this indicator can only be collected by means of a community survey.

Proportion of children (ages 2-16) who have a weight associated with good health			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of active clinic users aged 2 - 16 with a recent Body Mass Index (BMI) measure } \geq 18 \text{ and } \leq 25}{\text{Total number of active clinic users age 2 - 16}} \times 100$	RPMS or tribal clinic records	Only those children who are active clinic users and have had recent height and weight measurements taken will be included in this calculation. If a significant proportion of tribal children do not fall into this category, consider a different data source.
B.	$\frac{\text{Number of survey participants whose reported height & weight result in a BMI of } \geq 18 \text{ and } \leq 25}{\text{Total number of survey participants}} \times 100$	Representative survey of tribal youth on reservation	Very young children are often not able to report their height and weight accurately, so using a survey as the data source will restrict the age range for which this indicator can be reported.
C.	$\frac{\text{Number of youth whose measured height & weight result in a BMI } \leq 25}{\text{Total number of youth measured}} \times 100$	Direct assessment of a representative sample of youth (e.g. Head Start enrollees, elementary or high school students)	

Proportion of pregnancies with prenatal care beginning in the first trimester			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of female tribal members on reservation who have been pregnant in the last } X \text{ years and who started prenatal care in the first trimester}}{\text{Number of female tribal members on reservation who have been pregnant in the last } X \text{ years}} \times 100$	RPMS; Tribal clinic, MCH clinic, or WIC clinic records.	<p>If using these data sources, find out whether they will include data on women who receive prenatal care from an outside organization or give birth off the reservation.</p> <p>If only a small number of pregnancies occur each year in your tribe, several years of data will be necessary in order to make this calculation meaningful.</p>
B.	$\frac{\text{Number of female survey participants who report a pregnancy within the past } X \text{ years for which they started prenatal care in the first trimester}}{\text{Number of female survey participants who report a pregnancy within the past } X \text{ years}} \times 100$	Representative survey of tribal members on reservation	If only a small number of pregnancies occur each year in your tribe, several years of data will be necessary in order to make this calculation meaningful.

Rate of women age 18-65 who have had a Pap smear in the past 2 years			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of 18 - 65 year old active female users of tribal or IHS clinic who have received a Pap smear in past 24 months}}{\text{Number of 18 - 65 year old active female users of tribal or IHS clinic}} \times 1,000$	RPMS or tribal clinic registry	<p>This calculation produces a rate per 1,000 women.</p> <p>Only active clinic users are included in this calculation, which may lead to an overestimate of the proportion of women in the tribe who have had a recent Pap smear.</p>
B.	$\frac{\text{Number of female survey participants aged 18 - 65 who report a Pap smear within the past 2 years}}{\text{Number of female survey participants aged 18 - 65}} \times 100$	Representative survey of adult tribal members on reservation	

Prevalence of alcohol and other drug use among adolescents			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of youth survey participants who report using alcohol or drugs at least once within the past month}}{\text{Total number of youth survey participants}} \times 100$	Representative survey of tribal youth on reservation	<p>Anonymous or confidential surveys usually provide more accurate data about teenage substance use than clinical data sources.</p> <p>Depending on the level of substance use in which the tribe is interested, you might want to change the frequency of drug use in the numerator of this calculation to 2 or 3 times a month.</p>

Prevalence of tobacco use among adolescents and adults			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of youth survey participants who report smoking cigarettes or chewing tobacco within the past month}}{\text{Total number of youth survey participants}} \times 100$ $\frac{\text{Number of adult survey participants who report smoking cigarettes or chewing tobacco within the past month}}{\text{Total number of adult survey participants}} \times 100$	<p>Representative survey of tribal youth on reservation</p> <p>Representative survey of adult tribal members on reservation</p>	Anonymous or confidential surveys usually provide more accurate data about tobacco use than clinical data sources.

Proportion of adults who regularly in physical activity of a duration and intensity sufficient to promote health			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of survey participants who report at least 30 minutes of moderate exercise 5 times a week or 20 minutes of vigorous exercise 3 times a week}}{\text{Total number of survey participants}} \times 100$	Representative survey of adult tribal members on reservation	

Number and rate of confirmed cases of child abuse and neglect			
	Calculation	Data Source(s)	Notes
A.	$\frac{\text{Number of confirmed cases of child abuse or neglect among tribal youth on reservation}}{\text{Total number of tribal youth on reservation}} \times 1,000$	Tribal or other court records; Tribal or other child protection agency records	Child abuse is typically under-reported, so this calculation may be an underestimate of the true amount of abuse or neglect. The rate produced in calculation is per 1,000 children
B.	$\frac{\text{Number of youth survey participants who report having ever experienced physical or or sexual abuse at the hands of an adult}}{\text{Total number of youth survey participants}} \times 100$	Representative survey of youth on reservation	Anonymous or confidential surveys usually provide slightly more accurate data about abuse and neglect than law enforcement or social service data, but underreporting is still a concern. It is usually not feasible to survey young children about these topics, so using survey data will restrict the age range for which this indicator can be reported.

Presence of tribal ordinance requiring automobile safety restraint use; prevalence of restraint use			
	Calculation	Data Source(s)	Notes
A.	<i>None for presence of tribal ordinance</i>	Tribal code or other tribal government documents	
B.	$\frac{\text{Number of survey participants who report "always" or "mostly" wearing seatbelts and making children wear seatbelts or use child safety seats}}{\text{Total number of survey participants}} \times 100$	Representative survey of adults and youth on reservation	
C.	$\frac{\text{Number of car drivers and passengers observed to be wearing safety restraints}}{\text{Total number of drivers and passengers observed}} \times 100$	Representative, observational survey of motor vehicle occupants on reservation	

	Calculation	Data Source(s)	Notes
A.			
B.			
C.			

	Calculation	Data Source(s)	Notes
A.			
B.			
C.			

* A rate is a fraction in which the numerator (top number) is those people who have the disease or other characteristic of interest and the denominator (bottom number) is those people who are at risk for having the disease or characteristic.

** A representative survey is one in which a relatively small group of people are selected for participation in such a way that they represent the entire community. This means that the data from the survey can be *generalized* to the whole community.

References

1. Centers for Disease Control and Prevention. (2000). Measuring healthy days. Atlanta, GA: CDC. Accessed 12/15/02 at: <http://www.cdc.gov/nccdphp/hrqol/pdfs/mhd.pdf>

IV. Developing an Indicator List

Additional Resources

ICHP Pilot Site Indicators & Data Sources

Indicator	Tribe A	Tribe B	Tribe C
Socio Economic			
School Attendance Rate	School records	School records	
* High School Graduation Rate	School records		School records
Male Presence in Household	Population-based survey		Population-based survey
* Family Structure	Population-based survey	Population-based survey	Population-based survey
Employment Status	Population-based survey	Population-based survey and Tribal Census data	Population-based survey and Census data
Health Status			
Teen Birth Rate	Contract health data		
Prevalence of Asthma	Population-based survey	Population-based survey	
* Years of Potential Life Lost	Linkage with state death records	Linkage with state death records	Tribal health records
* Prevalence of Caries in Children	Head Start and Elementary School Measure	Dental and Head Start data	Dental Clinic
* Prevalence of Diabetes	Community Health Nurses	Population-based survey	Population-based survey
* Rate of Hospitalizations for Injury and Poisoning	Data linkage	Population-based survey	Population-based survey
Rate of Hospitalizations for Alcohol-related Injuries	Data linkage		
Mental Health and Functional Status			
Suicide Ideation and Attempts	Population-based survey and youth survey		
* Average Number of Healthy Days for Adults and Seniors	Population-based survey	Population-based survey	Population-based survey

* Signifies that the indicator is one of the 15 ICHP recommended indicators

	Health Risk Factors, Positive Health Behaviors			
*	Prevalence of Alcohol and Drug Use	Population-based survey and youth survey	Population-based survey and youth survey	Population-based survey and youth survey
*	Prevalence of Tobacco Use	Population-based survey and youth survey	Population-based survey and youth survey	Population-based survey and youth survey
*	Number and Rate of Confirmed Cases of Child Abuse and Neglect	ICW, Tribal Police	Unknown as of to date	Tribal Court Records
*	Proportion of Adults and Youth who Regularly Engage in Physical Exercise	Population-based survey and youth survey	Population-based survey and youth survey	Population-based survey and youth survey
	Number of Hours Spent Viewing TV, computer, Video Games	Population-based survey and youth survey		
*	Percentage of Pregnancies with Prenatal Care in First Trimester	Population-based survey	Population-based survey and RPMS data	RPMS records
*	Rate of Cancer Screening in Adults (Pap in all sites; breast and colon in Tribe A)	Population-based survey	Population-based survey	Population-based survey
*	Prevalence of Children who Have a Weight Associated with Good Health	Head Start and Elementary School Measure	MCH and youth survey data	RPMS
	Environment			
	Number and Rate of Alcohol-related Arrests	Tribal police data and Court records		
	Number and Rate of Violent Crimes (including, domestic, and youth violence)	Tribal Police Data		
	Presence of Tribal Ordinance Requiring Auto Safety Restraints Use, and Prevalence of Auto Safety Restraint Use (adult, youth, infant)	Tribal Police Data and Population-based survey	Tribal Police Data and Population-based survey	Tribal Police Data and Population-based survey
	Tribal Health Service Use		Population-based survey	
	Source of Drinking Water			Population-based survey
	Type of housing			Tribal Census

* Signifies that the indicator is one of the 15 ICHP recommended indicators

V. Collecting and Analyzing Data

By this point, your working group has developed a list of indicators that will provide a broad picture of health at the community level. The next step is to collect the information needed for each indicator. In this chapter, we present the two primary means by which the Indian Community Health Profile (ICHP) pilot sites gathered their information and we discuss some of the things you will need to keep in mind for each method. Please note, however, that we do *not* provide step-by-step instructions about how to abstract data from existing records, design a community survey, or conduct data analysis. For this level of support, your working group will need to make use of the technical experts to whom it has access (either internally or externally). You may also wish to consult the list of data collection and analysis manuals that is included in the Additional Resources section of this chapter.

New data vs. existing data

In the ICHP pilot sites, information was gathered in two primary ways: from existing records and through original surveys or assessments. There are advantages and disadvantages to each method. Gathering information from existing records is generally much cheaper and much quicker than collecting your own data, and the process can help you build relationships with the community agencies that hold the information. In many cases, however, the information you want may not have been collected before. If it has, it may not be organized in

the way you need (e.g. you can find the rate of tobacco use on the reservation, but not for youth specifically). It can also be difficult to find out how and from whom the information in existing records was collected, details that are crucial for judging the quality of the data.

Planning and conducting your own data collection, whether it be a community survey or a dental assessment of preschool-aged children, means that you will have a better chance of getting the information that you want in the format that you need and for the time period in which you are interested. Community health surveys are particularly valuable because they can represent the whole tribe, not just the people receiving medical services, and they can provide information about health behaviors and attitudes that you simply cannot get any other way. These advantages are part of the reason that several of the ICHP recommended indicators were designed to be measured through community-based surveys.

Doing original data collection is often expensive and very time-consuming. Significant input from survey design or statistical experts is required for the resulting data to be of high quality. For most community health assessment projects, a mix of original and existing data is used. Your working group and its technical support partners will have to decide which type of data is most appropriate for each of the indicators they have chosen. Further details about working

V. Collecting and Analyzing Data

with both kinds of data are provided below to help you make this decision.

Considerations for using existing data

Finding it

If you want to use existing information in your tribal health profile, you have to find it first. There are many places to look and people to ask for health data pertaining to your tribe. Suggestions of potential data sources for the 15 recommended ICHP indicators can be found in the Indicator Development Worksheet in the Tools section of Chapter IV and a list of more general ideas is provided below:

Medical or Clinical Data

- Clinical databases used by the Indian Health Service (IHS) or your tribal health department, e.g. RPMS (Resource and Patient Management System).
- Records from hospitals, clinics, or health maintenance organizations that serve tribal members.
- County or state health department files, e.g. hospital discharge data or death records.
- Health projects or research studies that the tribe has conducted in the past.
- Special disease registries or information systems, e.g. the National Cancer Institute's SEER (Surveillance, Epidemiology, and End Results) Registry.

Legal and Social Service data

- Tribal, state, or county law enforcement and court records.
- Records of social service agencies, e.g. Child Protective Services or Elder Affairs office.

Socio-demographic Data

- Tribal or national census.
- School records from Head Start through high school or from the tribal education office.
- Tribal enrollment, administration, and housing office records.
- Tribal labor force reports.
- Local BIA (Bureau of Indian Affairs) office information.

Assessing the quality of existing data

Once you find information that seems to fit your needs, you'll need to review it to ensure that it can be used with confidence. This is an important step, because your profile will only be as accurate as the information on which it is based. Again, you'll want to ask the technical experts available to your working group for a definitive evaluation, but there are two main sources of data error that you should keep in mind.

Selection bias

Selection bias occurs when there is a systematic problem in how subjects were chosen to participate in a study or otherwise provide data. Here are some general questions to ask when assessing whether the data you hope to use suffer from selection bias:

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WORKING EXAMPLE - Assessing the quality of existing data

You have chosen to include an indicator relating to gang membership in your community health profile. You think you can use existing data to satisfy this indicator because a survey including questions about community violence was recently conducted at the tribal high school and your working group has access to the data. Specifically, you know that 36% of the participants in the survey answered ‘yes’ to the question: “During the past 12 months, have you been a member of a gang?”

This may seem like the very information you are looking for, but consider how the question was asked before you accept the statistic. How certain are you that the student participants understood “gang” to mean the same thing you do? If any of the students were thinking of a gang simply as a group of friends, you don’t want to use that number for your indicator. Similarly, do you think the participants understood the question to be asking about gang membership *at any time* during the past 12 months, or during the *whole* past year? A student’s answer might change depending on which time period she or he had in mind.

Sometimes, the questionnaires or criteria used to collect existing data will have been pilot tested to test for possible bias. If so, you can have more confidence in the data. More often, however, you are unable to discover how well the statistic you are interested in—gang membership in this case—has been measured. In this situation, it is up to working group members and technical experts to judge whether or not the data are acceptable for use in your Profile.

- ⇒ If you are hoping to use information that comes from just a portion (sample) of the people in the population of interest, was that sample selected in a way that would adequately represent the community for which you are creating a health profile? For example, if you want to pull records from a clinical source like RPMS, are you confident that the people in the RPMS database are a good representation of the whole community and not just those people who regularly seek health services?
- ⇒ Are the data you hope to use based on enough people or records? Statistics that are derived from only a few people are not very meaningful. For example, the results of a community survey might tell you that in 2002, 75% of pregnant women started prenatal care in the first trimester. This sounds good, until you find out that a total of only eight pregnant women were selected to participate in the survey. As a general rule, be cautious about using information that is based on fewer than 25 people or cases. More specifically, ask your technical advisors to judge whether the data are based on enough people or cases for you to generalize the results to the community as a whole.
- ⇒ Were people selected to participate in data collection in such a way that no one group inadvertently became more likely to be asked to provide data than any

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other? For example, if you are planning to use data from a household telephone survey, be aware that people who did not have working phones at the time of the survey were obviously not eligible for selection. If people without telephone are somehow different than people with phones in a way that relates to the study topic (e.g. health status), then the survey data will contain significant selection bias.

- ⇒ Continuing with the above survey example, did most of the people who were selected to participate actually go on to provide data? If not, do the non-respondents differ from respondents in any important way? In one of the ICHP pilot sites, for example, Indian community members responded to a survey at a higher rate than non-Indians. Be cautious about using data from a survey in which the overall response rate was low and in which participants and non-participants were not similar.

Information bias

Information bias occurs when there is a systematic problem in how information is obtained from study subjects. Here are some general questions to ask when assessing whether the data you hope to use suffer from information bias:

- ⇒ When were the data collected? If the most recent data about violent crime on the reservation are eight years old, they

won't paint a very accurate picture of the current situation. Even if you have longitudinal data—repeated measurements of the same variable over time—try to make sure that the most recent piece of information is as up-to-date as possible.

- ⇒ Are the questions or criteria that were used to generate the data you are interested in clear, understandable, and not slanted in a way that would influence the results? If, for example, you are hoping to use the results of a previous community skin cancer screening for one of your indicators, are you certain that the criteria for diagnosing skin cancer were clear and followed consistently by all examiners? See the working example on the previous page for an illustration of this concept in relation to survey data.

Considerations for collecting new data What methods should be used?

There are many ways to collect your own data about the health status, behaviors, and beliefs of people in the community. Since most of the ICHP indicators relate to what proportion of the community has a particular health condition or engages in a particular health-related behavior, the ICHP pilot sites relied primarily on community surveys and direct assessments when collecting their own data. All three pilot sites conducted surveys with both youth and adults, and a few sites carried out direct measurement ac-

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tivities as well (e.g. going to schools to measure students' heights and weights, or stationing observers at an intersection to count how many people are wearing seat-belts).

If you are planning a survey with either youth or adults, we suggest that you consider the survey instruments used in the Behavioral Risk Factor Surveillance System (BRFSS) and the Youth Risk Behavior Surveillance System (YRBSS), conducted by the Centers for Disease Control and Prevention. Many tribes conduct their own versions of these surveys, and the ICHP pilot sites modified the BRFSS and YRBSS questionnaires to help them collect the information needed for their indicators. Because the BRFSS and the YRBS questionnaires probably cover a wider range of health topics than your chosen indicators, you might want to look for partners in the community who would help you mount the surveys in return for access to some of the data. For more information on the BRFSS and YRBSS, please see the Additional Resources section of this chapter.

Planning for quality data

When collecting your own data, the best way to reduce bias is to design your project carefully and monitor the process closely. We strongly recommend that you make use of the statistical, epidemiological, or survey design expertise of your technical advisors in order to ensure that every step of your data collection produces good quality infor-

WORKING EXAMPLE - Original Data

You are planning to conduct a survey of adult community members to collect data for your health profile indicators. Your profile working group has defined the community as anyone living on the reservation, regardless of race or tribal membership. So you will need some kind of list of all people living on the reservation from which to select a representative group of survey participants. Where can you find such a list?

A list of patients from RPMS or your tribal clinic database will only include those people who regularly use health services, and the health status of those people tends to differ significantly from non-users. In addition, many clinic users may not actually live on the reservation, but just return to get health care. If that is the case, you may end up selecting many people from the list who are not actually part of the community as it was defined for your project. Using a geographic list (such as a register of all residences on the reservation) is another option, but it can be resource-intensive and the planning becomes complicated by the need to go from selected residences to selected individuals.

One of the ICHP pilot sites faced a similar situation and chose to use an RPMS-based list. It was a very reasonable choice, but one consequence was that the site had to be very careful when presenting the results to explain exactly to whom the data did and did not apply. If you are planning some survey data collection, your working group's technical advisors should be able to help you decide among the different options for selecting participants.

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mation. The same general principles that you would use to judge existing data (see page 68) apply when you are making plans to collect new data. These principles are restated below in the form of things to keep in mind when planning for quality data.

Selection bias

- ⇒ How do you plan to select the people who will participate in your data collection? Make sure that the group of people from which you will choose participants is a good representation of the community. See the working example on the previous page for more details on this topic.
- ⇒ How many participants will you need to be able to have confidence in the accuracy of your results? Make sure that you sample enough people and select them in a way that does not unintentionally favor one group over another. The statisticians or survey specialists with whom you are working can help you calculate the number of participants or cases needed, but remember to recruit even more to allow for those who decline, drop out, or cannot be located.
- ⇒ How will the data be collected? If you are conducting a survey, which method do you think will result in the best response rate: face-to-face, over the telephone, or self-administered? If you plan to use survey interviewers, would community members or outside personnel be

better received by participants?

Information bias

- ⇒ What questions or criteria will you use to collect the information you are interested in? Make sure that the questions or criteria are clear, not constructed in a way that would make some responses more likely than others, and that they ask for the information you really want. If you are doing a survey, you should also ensure that the language you use is at the right level, neither too complicated nor too simple, for the intended respondents.
- ⇒ How will you ensure that the data are as complete as possible and contain a minimum of errors and inconsistencies? Monitor the data collection process closely to check whether all the information is being recorded accurately. It is also an excellent idea to provide training for anyone involved in collecting the data or entering it into a database.

In addition to these considerations, there are many logistical and administrative decisions to make when collecting your own data. However, these decisions are not covered in detail here. See the references provided in this chapter's Additional Resources section for more information on those topics.

Human subjects protection

If you are hoping to collect new data for your community health profile project, one

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of the most important things to think about is how to protect the rights and confidentiality of the people from whom you want to collect data. In some cases, it may be *required* that your plans for data collection be formally approved by an Institutional Review Board (IRB), a committee that reviews research activities to ensure that people will be well-informed about the risks and benefits of their participation. Whether or not your project requires IRB review depends on several things including who will be participating and what you want to do with the data. But even if your data collection process does not require official review, many IRBs are willing to read over proposals informally and offer their suggestions.

Each IHS Area, as well as many universities and research institutions, administers an IRB. To find out whether the data collection activities you have in mind will need formal IRB approval, or to ask for advice, contact the IHS IRB in your area. A list of these Boards and their contact information is provided in the Additional Resources section of this chapter.

Calculating the indicators

Once all the relevant data have been collected, it will be necessary to make a few final calculations in order to produce the number, proportion, or rate specified in each indicator. For the most part, these calculations are very straightforward and this step should be a snap after all the work that has been done to collect the data. If you

have chosen to use any of the 15 ICHP recommended indicators, suggestions for how to calculate the final figures are included in the Indicator Development Worksheet in Chapter IV. If you have added your own indicators, the technical or data experts with whom you are collaborating should be able to assist you with the final calculations.

Documentation

As a final activity after all the data have been collected and all the calculations have been performed, we strongly suggest that you document both the indicator results and all the steps that were taken to produce the results. This documentation will be an excellent resource when you are developing reports (see the next chapter), when different community agencies are making use of the data, and when the tribe wants to implement its community health profile again in the future. A blank Indicator Documentation Page has been provided in the Tools section of this chapter and on the Tools CD for you to copy and use. An example of a completed Indicator Documentation Page is included in both places as well. Although some of the information on these pages will overlap with your Indicator Development Worksheet, the tools differ in that the Worksheet is a preliminary planning aid, whereas the Documentation Pages are intended as a final, formal record of the indicator methods and results.

Indian Community Health Profile Indicator Documentation Page

Use this format to record the final definitions, data sources, and results for each of the indicators that make up your community health profile.

Indicator:

Justification:

Definitions:

Data sources:

Calculation:

RESULT:

Assumptions:

Limitations:

Other notes:

Indian Community Health Profile Indicator Documentation Page

* * * * * EXAMPLE * * * * *

Indicator: Rate of high school graduation

Justification: This indicator was chosen because high school graduation is a strong predictor of future educational attainment, employment, and financial stability.

Definitions: For this profile, community is defined as all residents of the <name> reservation, regardless of tribal membership status or race. The rate was calculated per 1,000 and the years for which it was calculated were 2002-2004.

Data sources: Tribal education office data, cross-checked with records from <name> high school and <name> middle school on the reservation.

Calculation:

$$\frac{\text{Total number of graduates from reservation high school in 2002, 2003, and 2004}}{\text{Total number of graduates from reservation middle school (grade 8) in 1998, 1999, and 2000}} \times 1,000$$

$$= (327 / 414) \times 1,000$$

RESULT: From 2002 to 2004, the rate of high school graduation on the <name> reservation was approximately 790 per 1,000; OR

For every 1,000 students eligible to enter the <name> high school from 1998 to 2000, approximately 790 entered high school and graduated in four years.

Assumptions: The number of new students who moved into the catchment area for the reservation high school during the relevant time period is roughly the same as the number of students who moved out of it.

Limitations: Students who take more or less than 4 years to graduate and students who do not graduate but who complete a GED are not included in this measure

Other notes: In a representative survey of adults (over 18) living on the reservation conducted in 2003, 68% of women and 63% of men reported that they had a high school diploma.

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Additional Resources

A selection of guides for data collection and analysis

Fowler, F.J., Jr. (2002). Survey research methods (third edition). Thousand Oaks, CA: Sage Publications. Consult a college or university library, or call the publisher at 1-800-818-7243 to order.

Gertsman, B.B. (1998). Epidemiology kept simple: An introduction to classic and modern epidemiology. New York, NY: Wiley-Liss. Consult a college or university library, or call the publisher at 1-877-762-2974 to order.

Oregon Department of Human Services. The data difference. The data users guide: Using data for better decisions. Salem, OR: Oregon Department of Human Services, Data Users Task Group. Available online at: www.hr.state.or.us/pubs/dataguide.pdf

Salant, P., & Dillman, D.A. (1994). How to conduct your own survey. New York, NY: John Wiley & Sons, Inc. Consult a college or university library, or call the publisher at 1-877-762-2974 to order.

Salant, P. & Walker, A.J. (1995). Guide to rural data (revised edition). Washington, DC: Island Press. Consult a college or university library, or call the publisher at 1-800-828-1302 to order.

Statistics Canada/Statistique Canada. Statistics: Power from data! Available online at: <http://www.statcan.ca/english/edu/power/toc/contents.htm>

Trochim, W.M. The Research Methods Knowledge Base (2nd edition). Available online at: <http://trochim.human.cornell.edu/kb/index.htm> (version current as of February 10, 2002).

Voss, P., Tordella, S., & Brown, D. (1987). Role of secondary data. In: Needs assessment, theory, and methods (D. Johnson et al., Eds.). Ames, IA: Iowa State Press. Consult a college or university library, or call the publisher at 1-800-862-6657 to order.

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Additional Resources

Indian Health Service Area IRBs

This list of IHS regional Institutional Review Boards (IRBs) was taken from the IHS website on May 17, 2005. <http://www.ihs.gov/MedicalPrograms/Research/areairb.cfm>

Aberdeen Area IRB

Contact: Dr. Elaine Miller

Phone: (605) 226-7341

Email: Elaine.miller@ihsabr.ihs.gov

Alaska Area IRB

Contact: Dr. David Barrett

Phone: (907) 729-2062

Email: dbarrett@anmc.org

Albuquerque Area IRB

Contact: Dr. Roger E. Gollub

Phone: (505) 248-4539

Email: Roger.gollub@mail.ihs.gov

Bemidji Area IRB

Contact: Jennifer J. Jenkins

Phone: (218) 759-3396

Email: Jennifer.jenkins@mail.ihs.gov

Billings Area IRB

Contact: Diane Jeanotte

Phone: (406) 247-7125

Email: Diane.jeanotte@mail.ihs.gov

Cherokee Nation IRB

Contact: Dr. Paul Weathers

Phone: (918) 456-0671 x2557

Email: Paul.weathers@mail.ihs.gov

IHS Headquarters IRB

Contact: Dr. Phillip R. Smith

Phone: (301) 443-6258

Email: Phillip.smith@mail.ihs.gov

Nashville Area IRB

Contact: Dr. Palmeda Taylor

Phone: (615) 467-1534

Email: palmeda.taylor@mail.ihs.gov

Navajo Area IRB

Contact: Beverly Becenti-Pigman

Phone: (928) 871-6650

Email: not available

Oklahoma Area IRB

Contact: Samuel Hope

Phone: (405) 951-3829

Email: Samuel.hope@mail.ihs.gov

Phoenix Area IRB

Contact: Dr. Kenneth Simpson

Phone: (602) 364-5045

Email: ken.simpson@mail.ihs.gov

Portland Area IRB

Contact: Dr. Joshua Jones

Phone: (503) 228-4185

Email: jjones@npaihb.org

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Additional Resources

Tucson Area IRB
Dr. Lois Steele
Phone: (520) 383-7211
Email: Lois.steele@mail.ihs.gov

BRFSS and YRBS information

The BRFSS (Behavioral Risk Factor Surveillance System) is an ongoing, nationwide, telephone survey of the health-related behaviors of U.S. residents, coordinated by the Centers for Disease Control and Prevention (CDC). The survey questionnaire consists of standard, core items and a set of additional questions that differ from state to state. More information about the BRFSS, including training guides and the latest questionnaires and data, can be found at: www.cdc.gov/brfss/index.htm.

All three of the ICHP pilot sites used a modified version of the BRFSS as part of their data collection process. One of the modifications made by each site was to change the method of survey administration from telephone to in-person interviews. To support this change, Indian Community Health Profile Project staff worked with BRFSS experts at the CDC to develop a training manual for the survey interviewers. A copy of this manual can be obtained by contacting ICHPP staff at: (503) 228-4185 or langus@npaihb.org or tlutz@npaihb.org.

The YRBSS (Youth Risk Behavior Surveillance System) is a nationwide, biannual survey of youth in grades 9-12 and is also coordinated by the CDC. Like the BRFSS instrument, the YRBSS questionnaire contains some standard items as well as set of additional, state-specific questions. More information about the YRBSS, including the latest questionnaires and data, can be found at: www.cdc.gov/nccdphp/dash/yrbs/index.htm.

VI. Reporting & Using the Profile Results

“The fact that you are measuring something, even if it is very important, doesn’t mean that anyone will care about it. And even if your indicator can make people care about what you are measuring, it is a big step getting from concern to action. You need to get the right people (those in a position to do something) to care and then somehow compel them to act. My feeling is that indicators are simply tools that need to be used as part of a strategic plan for helping to effect change.”

- Member of the Santa Monica, CA Taskforce on the Environment

Your working group and its partners have identified community health priorities, developed indicators to measure and describe those priorities, and collected and analyzed data to complete the indicators. You are now ready to report and take action on the results of your tribal health profile. This chapter provides suggestions for reporting on your indicator results and introduces some issues to consider when putting the new information to use.

Developing a report

As you will recall from the first two chapters, the Indian Community Health Profile (IHP) was developed in order to give tribes a tool with which to collect good-quality health data that could then be employed in efforts to improve community health. Accordingly, you were asked at the very beginning of the project to make plans for exactly how the profile results would be used. The time you spent making those initial plans will serve you well now, because the plans will help you identify the audience for your report, anticipate what the audience needs to know and clarify the message you want to convey.

A note about the number of reports: if your tribe resembles the IHP pilot sites at all, you probably had more than one use in mind for the project results. You also most likely collaborated with several groups of stakeholders in the community to plan and conduct the profile. If so, you will need to develop a few versions of your report in order to reach different audiences and accomplish each of your project’s distinct goals. A good first step for planning the different versions is to schedule meetings with some of the primary intended users of the profile results (e.g. tribal health planners) to discuss what reporting format would help them make best use of the information.

No matter what the purpose or who the audience, you should endeavor to make your reports clear, interesting, and to the point. Beyond that, however, your reports should be tailored to your audience and purpose. For example, if one of the goals of your community health profile project was to encourage individuals to take greater interest in and responsibility for their health, think about developing a brief report for community members that highlights the main findings in a visually appealing way (e.g.

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graphs) and that includes a little background information on the health topics covered in your profile. Some technical information will probably be necessary in order to explain who the indicator results apply to and what their limitations are, but try to describe this with as few specialized terms as possible.

If another goal of your community health profile project was to provide health administrators with a solid basis for long-range planning, you can create a second version of the report aimed at a more specialized audience. This version should include more details about the project methodology and an in-depth analysis of the data. Methods should be detailed and clear enough so that someone could repeat your project and obtain the same results as you did. If you ever want to repeat the study in the future, you will be glad to have a detailed report of your methods.

Remember that your reports do not all have to be written documents. Sometimes it is easier to arouse interest and get your point across in person, so think about creating an oral presentation of the project results (perhaps with a visual backup like overheads or Microsoft PowerPoint® slides). You could also consider creating a website to showcase the community health profile results. Posters and brochures are other reporting options, especially if you want to highlight one particular result or aspect of the project.

When working with the ICHP pilot sites, we developed template information sheets for sites to use when reporting the profile and indicator results to tribal members and other general audiences. There is one information sheet for each of the ICHP recommended indicators except “family composition” and “overall community health profile.” These templates are included as Tools in this chapter and are on the Tools CD. If you are working on a more technical report, you can draw on or even insert the Indicator Documentation sheets that you completed in Chapter V. For other examples of community indicator project reports, see this chapter’s Additional Resources section.

Publicizing the results

Producing reports is one thing; getting people to read and react to them in the way you want is another. The quote at the beginning of this chapter demonstrates the importance of making the right people aware of the results of your community health profile project. Here are a few suggestions for promoting your reports:

- Have key tribal officials (such as the Chairperson or the Health Director) read the final draft of the reports and ask them to provide an endorsement or a comment about the report’s importance. Quote this comment when advertising the reports or print it on the report’s cover page.
- Hold a community-wide event to announce the completion of the project, present some of the results, and intro-

VI. Reporting & Using the Profile Results

duce the different reports you have created. Such a forum is also a good opportunity to begin planning for how to put the profile data to use (see the next heading).

- Publicize the reports in local newspapers, on the radio, or even TV. Post flyers about the reports in the tribal health department, or insert a notice in the clinic newsletter.
- Have working group members attend meetings of local community and professional groups to promote the version of the report that is most relevant for that group or to give an in-person presentation of the results.
- Actively follow up with groups and individuals to whom you have given reports or made presentations. Remind them of the goals of the project, answer any questions they might have, and ask them to let you know in what ways they are using the information or data produced by the project.

Next steps

At this point, the project working group has achieved much of what the ICHP was designed to help tribes accomplish. Having chosen indicators to reflect community priorities, gathered good quality data, and summarized the results in various formats, you have produced useful and useable baseline data on the overall health status of the tribal community. And if you reflect back now on the number of relationships that were created, the amount of knowledge that

WORKING EXAMPLE - Using the results

As tribal and ICHPP staff worked to analyze survey data collected in one of the ICHP pilot sites, it became clear that non-ceremonial tobacco use was very common among survey participants. Further analyses showed that the Indian members of the community were significantly more likely to smoke than non-Indians, and that most smokers began at a young age.

These results prompted tribal health planners to step up efforts to reduce the prevalence of tobacco use among Indian community members. They developed a new tobacco program for this population with two main components: a community-based prevention and education campaign; and an individualized smoking cessation intervention to help people quit. The prevention campaign targeted elementary and junior-high aged children and their parents, since the survey data indicated that many smokers had become addicted before high school. The smoking cessation program was available to all ages, but had both an adult and a youth track with materials, messages, and strategies appropriate for each group.

Using the survey results as justification of the need for such a program, the tribe applied to the state for financial support. Their proposal was fully funded and the state representative was so impressed with the tribe's application and program that he invited them to speak at a national tobacco conference. The tribe declined, preferring to wait a few years until they could demonstrate the effect of their program by re-measuring the tobacco indicator on their community health profile.

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was gained, and the degree to which the community's awareness of different health issues was raised simply by doing the project, we hope you will agree that the ICHP has increased tribal capacity and motivation for improving community health.

What is left now is the task of seeing to it that the Profile results are used to inform future health planning and promotion efforts at the tribal level. This is clearly an ongoing activity. However, you have already started it by establishing a clear purpose in the initial planning stages of the project, creating tailored and informative reports, and actively following up with report recipients. Following are some further suggestions for encouraging the tribe to make good use of its community health profile:

- Make people aware of the range of potential uses for the profile data. The ICHP pilot sites used their indicator and profile results to inform short and long-term tribal health planning, augment health services outreach, change tribal policies, and shift the focus of health education efforts. For a specific illustration of how some of the indicator results were used in one of the pilot sites, see the working example on the previous page.
- Continue to hold working group or project meetings, albeit less frequently. Working group members make excellent ambassadors and advisors for use of

the profile results. If the group continues to meet every few months or so, members can help maintain the project's momentum and visibility by updating each other on applications of the profile data in different areas. Every so often, the group can arrange to advertise the ways in which the profile data have been used in local media. This will remind officials and tribal members of the value of the information.

- Set a tentative date now for when the tribe will evaluate its profile again. Doing this will reinforce the idea that the profile can be used repeatedly to measure changes in community health status over time. When setting the date, consult with people who are planning programs or applying for funding on the basis of the profile results to see when would be a good time to assess what effects their programs or grants might have had.

Your working group, its partners, and the tribe as a whole have worked hard to design, implement, and make use of their community health profile. Your efforts will continue to make a positive difference in the tribe's health for years to come.

<<name of tribe>>

Community Health Profile

A Broad Picture of Health in <LOCATION>

<<Date>>

Background

How healthy is the <Tribe>? What should be done to maintain the health of the tribal community and improve it where necessary? In <year>, the <Tribe> started work on a Community Health Profile to help answer these kinds of questions. This document contains a summary of the results of that Community Health Profile; other factsheets with more detailed information about the specific health topics covered in the Profile are also available.

How was the <Tribe> Community Health Profile done?

To begin, a core group of [LIST TYPES OF PEOPLE INVOLVED—TRIBAL HEALTH, COMMUNITY MEMBERS, ETC.] developed a list of X community health indicators—individual pieces of information that they felt would reflect overall health in <Location>. (These X indicators are listed on the reverse page.) Next, the group collected data to see how the community was doing on each indicator. Some information was available in existing records (GIVE EXAMPLE). Other data were gathered through two community surveys, one with # adult

[INSERT POPULATION-was it tribal members?] and the other with # youth in grades X-X attending school [WHERE]. [USE THE FOLLOWING SENTENCE ONLY IF APPLICABLE; IF NOT, INSERT SOME COMMENT ABOUT HOW GENERALIZABLE THE RESULTS ARE:] Both of these surveys were representative, meaning that it is reasonable to assume that the survey results apply to all adult [INSERT TARGET POPULATION] and all Xth—Xth grade students attending school [WHERE] respectively, even those who did not participate in the survey. Now that all the data have been collected, the working group [OR INSERT APPROPRIATE NAME] is sharing what they found with the community.

Results

On the back of this page, you will

INSERT a PICTURE HERE— SOMETHING WITH LOTS OF PEOPLE —A HEALTHY COMMUNITY :-)

find a brief indication of how the Tribe is doing on each of the health indicators that were selected. More detailed results and discussion can be found in the # indicator-specific factsheets, which are available from [INSERT WHO OR WHERE]. Overall ... [HIGHLIGHT THE OVERALL RESULTS HERE - mention things that were interesting or unexpected, or make connections between various indicators].

Next Steps

[BRIEFLY DESCRIBE WHAT PLANS ARE BEING MADE TO ADDRESS HEALTH ISSUES IDENTIFIED THROUGH THE PROFILE].

**Indicators of Community Health
Selected by the <Tribe>**

**How are we doing?
Brief Summary of Indicator Results**

Socio-demographic

- Rate of high school graduation <in location>
- Family composition [DEFINE]

Health Status

- Percent of <population> that has diabetes
- Rate of hospitalizations <in location> for injuries and poisonings
- Years of Potential Life Lost (YPLL) <in location>
- Dental cavities in 3-4 and 7-8 year olds

Mental Health and Functional Status

- Average number of healthy days per month for adults and seniors

Healthy Behaviors and Health Risk Factors


- Percentage of children who have a weight associated with good health
- Percentage of women who get prenatal care in the first 3 months of pregnancy
- Percentage of women over 18 who have had a Pap test in the last 3 years
- Alcohol and other drug use among teens
- Tobacco use among all ages
- Physical activity among adults
- Frequency of cases of abuse and neglect among children


Environmental


- Presence of a tribal law requiring seat belt use and frequency of seat belt use for infants, children, and adults.

[MODIFY LIST FOR YOUR SITE]

[TWO EXAMPLES OF INDICATOR SUMMARIES ARE SHOWN HERE AND ON THE NEXT PAGE. CHOOSE THE VERSION THAT IS MOST APPROPRIATE FOR YOUR TRIBE, OR DEVELOP YOUR OWN FORMAT].

 Prenatal Care—Since <year>, 89% of women who have been pregnant got prenatal care in the first three months of their last pregnancy. This is very close to the Healthy People 2010 goal of 90%.

 Diabetes—34% of adult Tribal members have diabetes, but most of these people are exercising and changing their diet in order to control the condition.

 Tobacco Use—almost 3/4 of adult Tribe members currently smoke cigarettes or use chewing tobacco.

To learn more about these health topics and the Community Health Profile Project, please contact: [PERSON at PHONE NO.]. If you would like to become involved in the next stage of tribal community health planning, you may contact [PERSON] or come to [IF THERE IS SOME FORUM OR MEETING HELD, INSERT THAT].

How are we doing? Brief Summary of Indicators and Results

Community Health Indicators Selected by <Tribe> [MODIFY FOR YOUR SITE]	Result
Socio-demographic	
Rate of High School Graduation (define, year)	X per 1,000
Family composition (define, year)	X%
Health Status	
Prevalence of diabetes among adults (19-65, year)	X%
Rate of hospitalizations for injury and poisoning (year)	X per 1,000
Rate of Years of Potential Life Lost (YPLL) (year – year)	X per 1,000
Prevalence of Dental Caries among 3-4 and 7-8 year olds (year)	X% (3-4 year olds) X% (7-8 year olds)
Mental Health and Functional Status	
Average number of healthy days in previous month for adults 19-65 (year)	X
Healthy Behaviors and Health Risk Factors	
Proportion of children (2-18) who have a weight associated with good health (BMI ≤ 25) (year)	X%
Proportion of pregnant women who received prenatal care in the first trimester (year-year)	X%
Proportion of women 18-65 who had a Pap test in the previous three years (year)	X%
Prevalence of alcohol and drug use among adolescents (age range) (year) (Current use was defined as using a substance X or more times in the month prior to the survey.)	X% currently use alcohol X% currently use marijuana X% currently use methamphetamine X% currently use other drugs
Prevalence of tobacco use (year) (Current use was defined as using commercial tobacco products X or more times in the month previous to the survey.)	X% (12-18 year olds) X% (19-65 year olds)
Prevalence of regular physical activity (define) among adults 19-65 (year)	X%
Number of cases of abuse and neglect of children (year)	X
Environmental	
Presence of tribal ordinance requiring safety restraint use in automobiles (year)	Yes or No
Frequency of safety restraint use (using restraints “always” or “most of the time”) (year)	X% among adults (age range) X% among youth (12-18) X% for toddlers (age range) X% for infants (age range)

To learn more about these health topics and the Community Health Profile Project, please contact: [PERSON at PHONE NO.]. If you would like to become involved in the next stage of tribal community health planning, you may contact [PERSON] at [INSERT CONTACT INFORMATION].

High School Graduation

Rate of high school graduation among <Tribe> youth.

<date>

INSERT QUOTE FROM TRIBAL MEMBER/OTHER RELEVANT PERSON RE: VALUE OF EDUCATION.

Background

In <year>, approximately X <Tribe> youth entered 9th grade, according to tribal education records. In <year>, X of this group graduated from 12th grade, for an overall graduation rate of X% (see: A note about graduation rates, below). Graduating from high school is a critical step toward future education, employment, and financial stability. For students who want a college or technical degree, a high school diploma is usually a prerequisite for admission. Graduating is also important for those who intend to work; nationally in the year 2000, only 13% of high school graduates who were not in college were unemployed, compared to 28% of those who

had not graduated from high school.¹ Having a high school diploma also leads to a higher income; in 1999, men who had completed high school made approximately \$30,000 a year, whereas men without a high school diploma made about \$22,000.¹ **Contributing factors**

It is difficult to say what exactly causes some youth to stay in school while others drop out. However, many related factors probably play a role. Some factors are individual; for example, students who dislike school or find it difficult are more likely to drop out than those who enjoy it.² Students who have children or who have a history of involvement with the law are also less likely to complete high school.² Characteristics of the school, teachers, or curriculum may also have an

effect; if students are bored or feel that teachers are insensitive, they may have less motivation to remain in class. Finally, larger community and economic realities also influence graduation rates. In areas where unemployment is high and few jobs require a high school diploma, students may see little benefit to remaining in school.²

Improving Graduation Rates

Head Start programs, which aim to give young children skills that will prepare them for long-term school success, are one way to improve graduation rates. Efforts to make classes and the overall school environment more interactive may also help to keep students attached to the school.

A note about graduation rates:

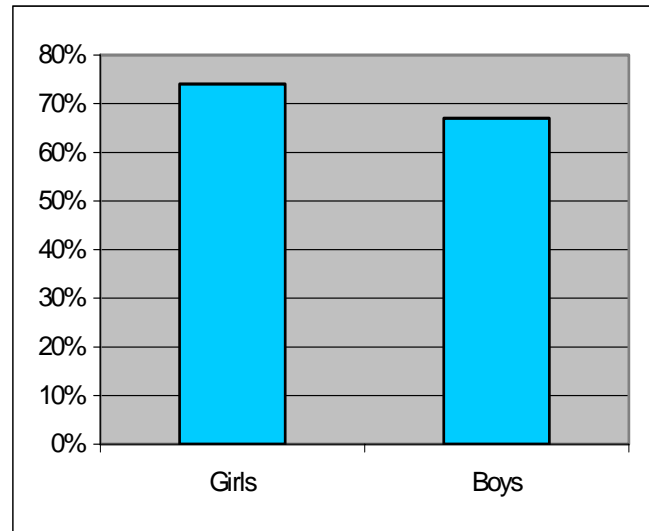
There are many different ways of calculating rates of high school graduation and drop-out. In addition, it is often difficult to distinguish between students who have truly dropped out and those who have switched schools, left temporarily due to illness or family matters, or even entered college early. For the purposes of this document, graduation rate has been calculated as [EXPLAIN HOW]. For more information on the estimation of graduation rates, please see the Wall Street Journal article cited in footnote #3.

INSERT SITE-SPECIFIC PICTURE HERE (E.G. GRADUATION CEREMONY??)

Summary: High School Graduation in <Location>

- X% of <Tribe> students who entered high school in <year> graduated in <year>.
- [If possible] The majority of students who left school before graduating did so in grades X and X.
- [If possible] The rate of graduation was higher for [gender x] (X%) than for [gender y] (X%).
- In a <year> survey of adult Tribal members, X% had less than a high school education, X% had a high school diploma or GED, X% had a technical or a college degree, and X% had a graduate degree.

High School Graduation Rate in <location>, (YEAR)



Note: The data shown above and on the first page come from tribal education records [OR OTHER] and from a [representative] survey of # tribal members aged x-x, conducted in <year>.

Efforts to Promote High School Completion in <Location>

Tracking: Describe tracking efforts.

Interventions: Describe what practices, programs and community-based efforts there are to improve graduation rates.

Partnerships: Describe partnerships in the community and how these partnership opportunities have helped develop, implement and evaluate local education efforts.

Future Directions in Secondary Education

Goal:

Objectives:

Activities:

1. National Center for Education Statistics. (2002). Digest of Education Statistics, 2001. Washington, DC: U.S. Department of Education.
2. Gaustad, J. (1991). Identifying potential dropouts. ERIC digest. Washington, DC: Office of Educational Research and Improvement.
3. Kronholz, J. (2001, December 18). Politics & policy: Various ways of calculating dropout rate leaves subject open to much

Diabetes

Prevalence of Diabetes among [Ages]

<<date>>

Definition: Diabetes is a chronic condition characterized by high levels of blood glucose (blood sugar), which is caused by the body's inability to produce or properly utilize the hormone insulin. Type 1 diabetes (5% - 10% of cases nationwide) occurs when the body does not produce enough insulin. Type 2 diabetes (90% - 95% of cases) develops when cells in the body become resistant to insulin production.¹

Impact

Diabetes has a major impact on everyday life. In a <year> survey, X% of <Tribe> adults reported being told by a healthcare provider that they had diabetes. People who have Type 1 diabetes (see above) must take several shots of insulin every day and monitor their food intake carefully. Some people with Type 2 diabetes (see above) can manage their blood sugar levels with diet changes and regular exercise; others must take oral medication or insulin shots every day. If diabetes is not controlled, it can cause serious health problems including decreased vision or blindness, kidney disease, and nerve damage that can lead to foot problems or amputation. Unfortunately, native groups in the U.S. have been hard hit by diabetes; American Indians and Alaska Natives (AI/AN) are 2.6 times more likely than non-Hispanic whites to have

diabetes,¹ and diabetes is the fourth leading cause of death for AI/AN individuals.²

Contributing factors

Type 1 diabetes is associated with genetics and other factors that are hard to control. In contrast, some of the risk factors for Type 2 diabetes are things you can avoid. Some Type 2 risk factors are:¹

- Overweight or obesity
- Lack of physical activity
- Older age
- Family history of diabetes
- Being a woman who had diabetes during pregnancy (gestational diabetes)

According to data from the <year> survey, X% of <Tribe> adults are overweight or obese, and X% report doing regular aerobic exercise. Approximately X% of <Tribe> women who have been pregnant had gestational diabetes.

Prevention

Several studies have shown that a reasonable diet and regular physical activity can prevent or delay the onset of diabetes among high-risk individuals.¹ Diet and regular exer-

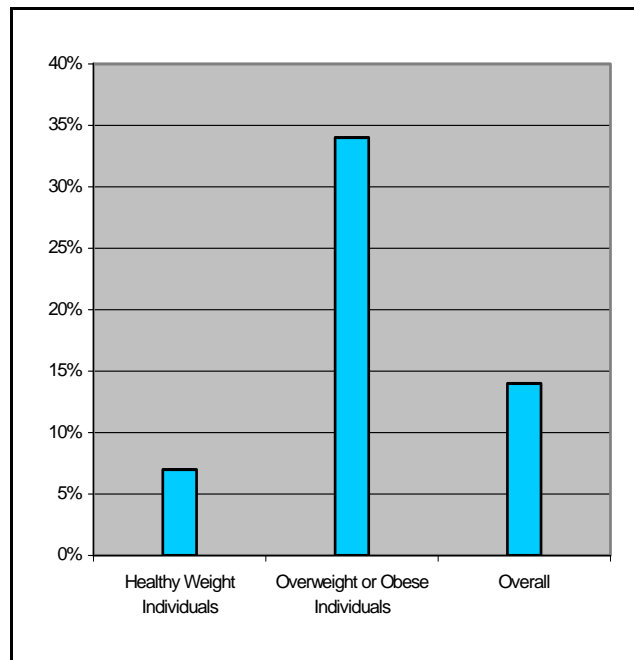
cise can also help control diabetes even after it has been diagnosed. It is important for diabetics to test their blood glucose, take their insulin or other medication, and take good care of their eyes, kidneys, and feet in order to avoid complications. Indian Health Service standards of care state that feet should be checked at each clinic visit, and eyes examined annually.³ Among <Tribe> members with diabetes who were surveyed in <year>, X% had had an eye exam in the past <time period> and X% check their feet for damage every <time period>.

1. Centers for Disease Control and Prevention. (2002). National diabetes fact sheet: General information and national estimates on diabetes in the United States, 2000. Atlanta, GA: DHHS, CDC.
2. Anderson, R.N. (2001). Deaths: Leading causes for 1999. National vital statistics reports, 49(11). Hyattsville, MD: National Center for Health Statistics.
3. <http://www.ihs.gov/medicalprograms/diabetes/2001soc.pdf>

Summary: Impact of Diabetes in <Location>

- X% of adult <Tribe> members have been told by a healthcare provider that they have diabetes. X% of <Tribe> women who have been pregnant developed gestational diabetes during at least one of their pregnancies.
- An additional X% are at risk because of overweight or obesity.
- Adult <Tribe> members with diabetes are working to control their diabetes by watching what they eat (X%), exercising (X%), trying to lose weight (X%), or taking insulin (X%). Only X% have had eye problems as a result of their diabetes and only X% have had foot sores or irritations that took over a month to heal.

Prevalence of Diabetes among <Tribe> Members ages X—X, (year)



Note: The data shown above and on the first page come from a [representative] survey of # <Tribe> tribal members ages X-X conducted in <year>, and from [ADD OTHER SOURCES AS APPROPRIATE—RPMS, etc.].

Diabetes Control Efforts in <Location>

Tracking: Describe tracking (including source of information in factsheet).

Interventions: Describe what public health practices, programs and community-based efforts there are to reduce the burden of diabetes.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local diabetes prevention efforts.

Future Directions in Diabetes Control

Goal:

Objectives:

Activities:

Injuries

Rate of Hospitalization for Injury and Poisoning

<<date>>

“Injuries are a leading cause of death for Americans of all ages, regardless of gender, race, or socioeconomic status. But injury deaths are only part of the picture. Millions of Americans are injured each year and survive. For many of them, injury causes temporary pain and inconvenience, but for some, the injury leads to disability, chronic pain, and a profound change in lifestyle”¹.

Sue Binder, M.D., Director, National Center for Injury Prevention and Control

Background

Injuries can be caused by a wide variety of mechanisms—motor vehicle crashes, fires, drowning, suicide, fights, etc. At the national level, the injury death rate among American Indians and Alaska Natives (AI/ANs) is 2.5 times greater than the all-races rate,² and AI/ANs are particularly at risk for injuries resulting from residential fires, pedestrian and/or motor vehicle crashes, and (among youth) suicide.¹ The <Tribe> is also concerned about injuries from [INSERT WHATEVER TRIBE IS INTERESTED IN AND FOLLOW UP IN NEXT SECTIONS].

Contributing Factors

Many behaviors can increase the risk of being injured. For example, not wearing a life-jacket increases the risk of drowning when you are involved in a boating— or water-related activity. Similarly, alcohol use contributes to many

drownings.² In a <year> survey of youth (ages x-x) in <Location>, only X% reported that they “always” wear a lifejacket while boating, and X% had drunk alcohol while boating in the month prior to being asked. On the other hand, many behaviors can reduce the risk of being injured. Wearing a helmet while riding a bicycle, for example, can reduce the risk of serious head injury by as much as 85%.¹ In the <year> survey, X% of <Tribe> youth reported that they always wore a helmet when riding a bike. [REPORT ON OTHER INJURY RISK FACTORS THAT THE TRIBE IS INTERESTED IN].

Hospital records indicate that X% of all <Tribe> members were hospitalized for injuries or poisonings in <year>. Other tribal members may have been injured but not severely enough to be admitted to the hospital.

Prevention

Strategies for preventing injuries obviously depend on the activity in question. However, the most suc-

cessful injury prevention efforts are those that address each of the following three factors: 1) individual behavior (e.g. increase seatbelt use), 2) the injury mechanism (e.g. make cars safer by installing antilock brakes), and 3) the environment or context (e.g. make roads safer by improving lighting and surface conditions).

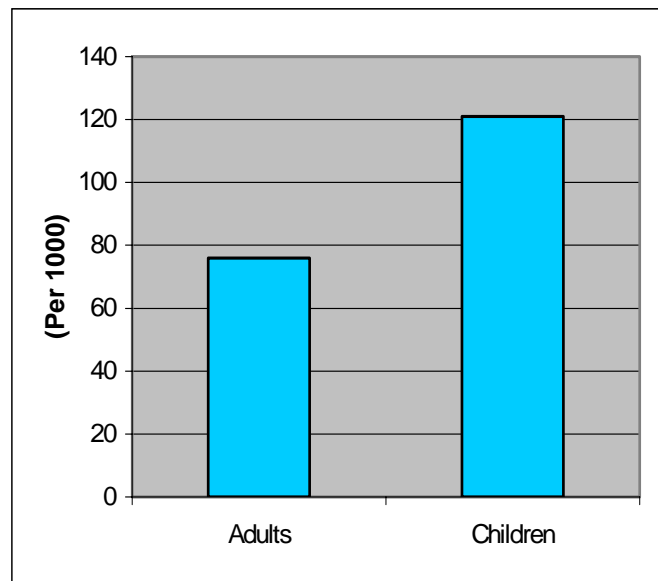
1. National Center for Injury Prevention and Control. (2001). Injury Fact Book 2001—2002. Atlanta, GA: Centers for Disease Control and Prevention.
2. Indian Health Service. Trends in Indian Health 1998-99. Rockville, Maryland: DHHS.

INSERT SITE-SPECIFIC PICTURE OF SAFE ACTIVITIES (E.G. KIDS WEARING BIKE HELMETS)

Summary: Injuries and Poisonings in <Location>

- In <year>, X% of <Tribe> members said that they had been hospitalized for an injury or poisoning within the last year.
- [Data on other injuries or risk factors that Tribe is interested in].

Rate of Hospital Discharges for Injuries and Poisonings among <Tribe> Members (year)



Note: The data shown above and on the first page come from hospital discharge records for [LIST HOSPITALS] in <year>, and from two [representative] surveys of <Tribe> members conducted in <year>; one with # adults aged x-x and the other with # youth ages X-X.

Injury Control Efforts in <Location>

Tracking: Information on tracking activities.

Interventions: Describe what public health practices, programs and community-based efforts there are to reduce the burden of injuries.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local injury prevention efforts.

Future Directions in Injury Prevention

Goal:

Objectives:

Activities:

Years of Potential Life Lost

An Overall Measure of Years of Life Lost to x Injury or Disease

<<Date>>

Definition: Years of Potential Life Lost is a measure that reflects the impact of disease on life expectancy in a community. It is calculated by adding together the additional years that each individual in the community who died prematurely would have been expected to live, had they not been affected by disease or poor health.

Background

Years of Potential Life Lost (YPLL) is an indicator used frequently by public health officials. It can show the impact of one particular disease (e.g. the years of life lost due to cancer) or of a range of diseases taken together. Things that usually cause death early in life, such as HIV/AIDS, will add many years to the total Years of Potential Life Lost, even if only a few people had the disease. In contrast, conditions that cause death later in life, like pneumonia, will not contribute heavily to the total YPLL, even if several people were affected. As part of the <Tribe> Community Health Profile Project, the Tribe decided to look at Years of Potential Life

Lost as a result of [THE FOLLOWING DISEASES OR CONDITIONS—LIST OR ALL CAUSES OF DEATH]. This was done by looking at the causes of death and age at death for community members from <year> to <year>.

Analysis

Overall, it is estimated that X years of potential life were lost to disease and injuries during the years from <year> to <year>. INSERT ADDITIONAL COMMENTS REGARDING QUALITY OF DATA RELATED TO THIS INDICATOR, WHAT DISEASES OR CONDITIONS MIGHT BE THE LARGEST CONTRIBUTORS TO YPLL FOR THE COMMUNITY, ETC.

Reducing YPLL

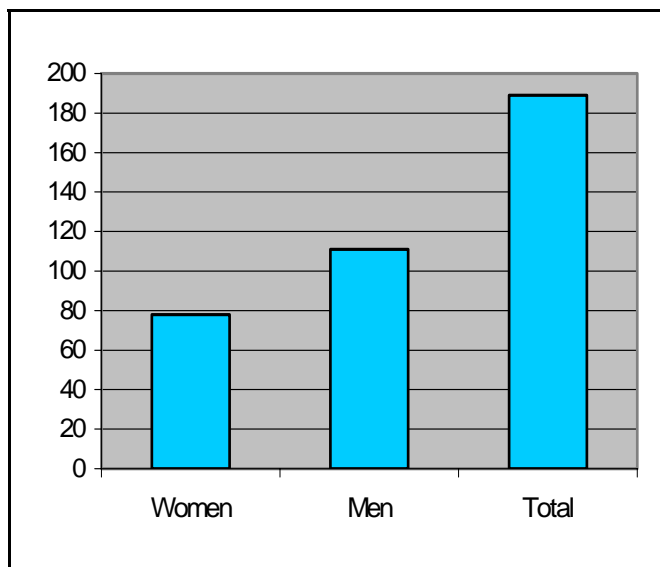
To reduce Years of Potential Life Lost, communities must work to: 1) prevent new cases of disease or injury; and 2) improve the outlook for those already injured or affected by disease. The tribal health department and [LIST RELEVANT OTHERS] have many programs aimed at accomplishing both these goals. Current efforts to prevent X, one of the leading contributors to Years of Potential Life Lost in <location>, include: [LIST EXAMPLES OF PROGRAMS ETC.]

INSERT PICTURE HERE—SOMETHING WITH LOTS OF PEOPLE—A HEALTHY COMMUNITY!

Summary: Years of Potential Life Lost in <Location>, <year>—<year>

- Overall, x years of potential life were lost to disease or injury during the years above.
- [Disease X or Risk Factor X] was a heavy contributor to YPLL
-
-
-

Years of Potential Life Lost (All Causes) in <location>, <year>—<year>



In calculations performed to obtain the result shown above, life expectancy in <location> was assumed to be 65 years for both women and men.

Note: The data shown above and on the first page come from an analysis of the <state> mortality files for <year>-<year> and from [INSERT OTHER SOURCES AS APPROPRIATE].

Efforts to Reduce Premature Mortality (Death) in <Location>

Tracking: Describe ...

Interventions: Indicate the range of existing public health practices, programs and community-based efforts to promote good health.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local health promotion efforts.

Future Directions for Health Promotion in <Location>

Goal:

Objectives:

Activities:

Childhood Dental Caries

Prevalence of Dental Caries in Children Ages X-X

<<date>>

Dental caries, otherwise known as cavities or tooth decay), is a disease that occurs when bacteria living in the mouth feed on sugars or carbohydrates and produce acid, which eats into the surface of teeth.

Background

We use our teeth every day for eating and speaking, so teeth need to last a lifetime. Unfortunately, many children develop tooth decay at an early age, when new teeth are particularly vulnerable. In <year>, X% of <Tribe> children were caries free; the remainder had one or more cavities. If left untreated, tooth decay can cause pain and loss of both baby and permanent teeth. There are many steps that children, parents, and communities can take to ensure that children's teeth stay healthy for a lifetime.

Contributing factors

Because cavities are caused by acid-producing bacteria, anything that helps to feed the bacteria or keep it on teeth for longer periods of time is a risk factor for tooth decay. Sweetened beverages, such as pop, fruit juice, formula, and milk can contribute to tooth decay, especially if they are left to cling on

teeth for a long time.¹ For example, when babies fall asleep with bottles in their mouths, the liquid pools around their teeth and feeds the bacteria that living there. Solid foods, especially sticky ones that are high in sugars or carbohydrates (like candy), can also cause tooth decay.² The more times people snack on these kinds of foods throughout the day, the more opportunities bacteria have to feed and produce damaging acid. Most importantly, not cleaning your teeth thoroughly and regularly allows large amounts of bacteria to build up in the mouth and increases the likelihood of tooth decay.

Prevention of caries

Tooth decay can be prevented with a healthy diet, limited snacking, thorough cleaning of teeth and gums, and regular dental checkups. Parents and caretakers can give their children water instead of pop or sweetened fruit juice, and can put babies down to sleep with a pacifier instead of a bottle. Children can reduce the build-up of bacteria in their mouths by snacking less frequently and by eating healthy foods, such as fruit or fresh vegetables, when they

do snack. This will also help kids to maintain a healthy weight. Children can also prevent tooth decay by brushing at least twice a day with a fluoride toothpaste and flossing every night. Finally, parents can help keep children's teeth healthy by taking them in for dental check-ups every 6 months. In <year>, approximately X% of <Tribe> children aged x-x had been to the dentist in the previous year.

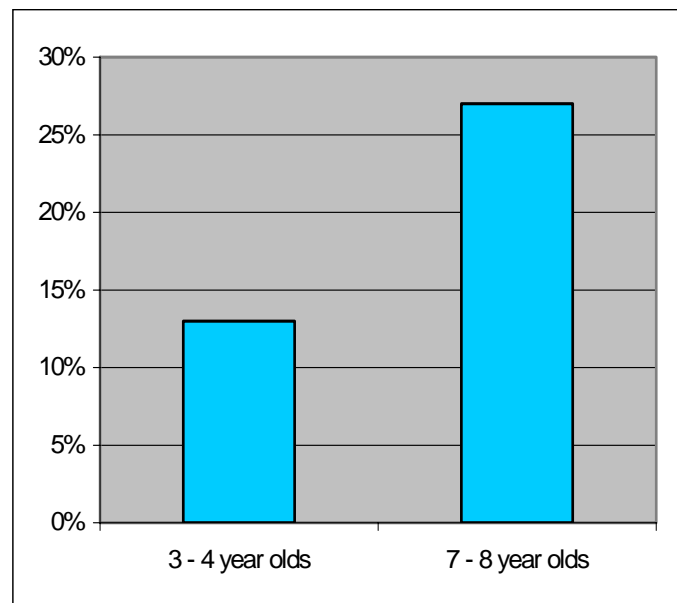
1. American Dental Association. (2002). Early childhood tooth decay. <http://www.ada.org/public/faq/bottle.html>
2. American Dental Association. (2002). Tooth Decay (cavities/caries). <http://www.ada.org/public/faq/decay.html>

INSERT PICTURE OF KID WITH A GREAT SMILE HERE!

Summary: Dental Caries among Children in <Location>

- In <year>, x (X%) of <Tribe> children aged X - X had received a dental check-up within the previous year.
- X% of this group of children were caries-free (had never had a cavity).
- X% of this group had no untreated cavities at their last dental exam
- INSERT OTHER RELEVANT INFORMATION THAT WAS COLLECTED.

Prevalence of Dental Caries among <Tribe> Children (year)



Note: The data shown above and on the first page come from a special dental assessment study [OR INSERT APPROPRIATE SOURCE] of <Tribe> children aged x-x, conducted in <year>.

Prevention of Dental Caries in <location>

Tracking: Describe tracking activities.

Interventions: Describe what public health practices, programs and community-based efforts there are to reduce cavities among children.

Partnerships: Describe partnerships in the community and how these partnership opportunities have helped develop, implement and evaluate local oral health efforts.

Future Directions in Children's Oral Health

Goal:

Objectives:

Activities:

Healthy Days

Average Number of Healthy Days for Adults and Seniors

<date>

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. [OR SUBSTITUTE TRIBAL DEFINITION OR QUOTE]

World Health Organization, 1948.

Background

Health professionals often gauge health using objective, external measures. For example, doctors usually decide if you have a fever by taking your temperature with an external device (a thermometer), which produces an objective reading in degrees Fahrenheit. When considering health-related quality of life, however, it is important to get a more subjective sense of how people themselves feel about their health, no matter what the external signs or diagnoses are. The <Tribe> did this as part of a survey conducted in <month, year>. Survey participants

were asked about their general sense of health, overall physical and mental health in the previous month, and any limitations in activities as a result of health problems.

Results

X% of <Tribe> members over [age] rated their general health as good, very good, or excellent. [Age group x—adults or seniors] and [gender x] reported better general health than [age group y] and [gender y]. The average number of healthy days in the previous months for all respondents was X (see: A note about healthy days, below). X% of the group reported that their activities had been limited in the past month because of some health problem or impair-

ment; for the majority of these people, X, Y and Z were what held them back from their regular or desired daily activities.

Improving health-related quality of life

People's answers to questions about health-related quality of life questions probably reflect the impact of a wide range of factors, including health services, economic climate, and individual lifestyle. For this reason, making improvements in health-related quality of life requires active participation from all key players in the community.

A note about healthy days: To produce this measure, survey participants were asked to give the number of days in the past month that they felt their physical health was not good and the number of days in the past month that they felt their mental health was not good. These two numbers were added together (up to a maximum value of 30) and subtracted from 30 days to come up with the total number of healthy days in the past month for each individual. It was assumed that physically unhealthy and mentally unhealthy days did not overlap; that is, a person reporting 4 physically unhealthy days and 2 mentally unhealthy days would have a total of 24 (30 - 6) healthy days for the month.¹

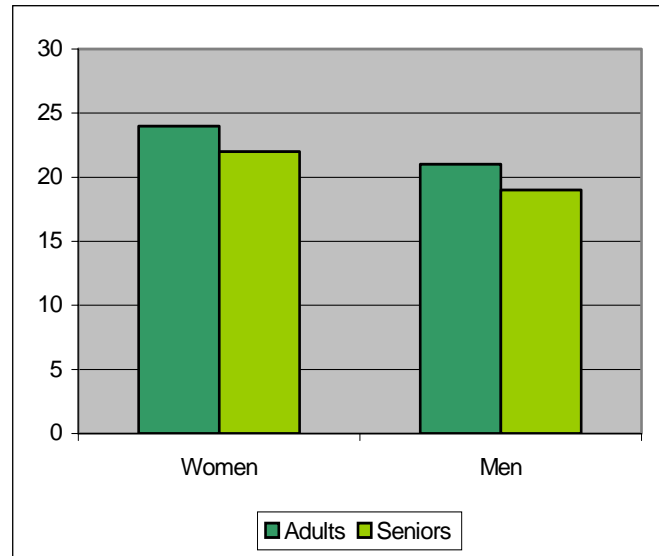
INSERT SITE-SPECIFIC PICTURE
HERE

Summary: Healthy Days in <Location>

In <month, year> ...

- X% of <Tribe> members over [age] felt that, in general, their health was good, very good, or excellent.
- On average, <Tribe> members over [age] had X healthy days in the month prior to being asked.
- [Gender x] tended to report feeling healthier or having more healthy days than [gender y].
- Among tribal members who felt that their daily activities were limited by poor health in the past month, X and X were the most common health problems.

Average Number of Healthy Days for Adults and Seniors in <location>, <month, YEAR>



Note: The data shown above and on the first page come from a [representative] survey of # <Tribe> members aged x-x conducted in 200x, and from [INSERT OTHER SOURCES AS APPROPRIATE].

Efforts to Promote Healthy Days in <Location>

Tracking: Describe tracking efforts.

Interventions: Describe what practices, programs and community-based efforts there are to improve personal health.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local health promotion efforts.

Future Directions in Health-related Quality of Life

Goal:

Objectives:

Activities:

1. Centers for Disease Control and Prevention. (2000). Measuring healthy days. Atlanta, GA: CDC. Accessed 12/15/02 at: <http://www.cdc.gov/nccdphp/hrqol/pdfs/mhd.pdf>

Healthy Weight in Children

Prevalence of Children Who Have a Weight Associated with Good

<<date>>

As defined by the Centers for Disease Control and Prevention's Division of Nutrition and Physical Activity¹, obesity occurs when the amount of body fat (adipose tissue) is excessively high in relation to overall body mass. Overweight is defined as excessive body weight in relation to height.

Impact

The proportion of children and adolescents in the U.S. who are overweight or obese has increased dramatically over the last 20 years. The National Center for Health Statistics estimates that 15% of all children aged 6–19 are overweight or obese. These children are likely to remain overweight or obese into adulthood, when they will be at an increased risk for a variety of health problems, including heart disease, diabetes, pregnancy complications, strokes, and several kinds of cancer.¹ In <year>, X% of <Tribe> youth aged 2–16 had a weight associated with good health; the remaining X% were overweight, obese, or at risk for these conditions.

Contributing factors

Behavior, environment, and genetics all play a role in causing overweight or obesity.¹ Inactive behavior patterns, such as watching TV instead of engaging in physical activity can contribute to overweight or obesity. According to a <year> of <Tribe> youth aged X–X, x% of youth

watch an average of X hours of TV per day and participate in exercise an average of X times per week. Environmental factors, such as whether school lunches contain high-fat foods, can also contribute to overweight since youth are more likely to eat well and to engage in physical activity if healthy food options and fun exercise facilities are available. Genetic factors such as the rate at which your body burns energy, though obviously difficult to change, also contribute to obesity and overweight.

Prevention

Because overweight and obesity in children are closely linked to unhealthy eating habits and lack of physical activity, a well-balanced diet and regular exercise are the first options that should be considered to maintain a healthy weight. A well-balanced diet is high in fruits and vegetables, and low in foods that contain a lot of fat or sugar. Based on the <year> survey, only about X% of <Tribe> youth aged X–X eat 5 servings of fruits and vegetables per day, as recommended by the Surgeon General.² For youth, regular physical exercise should consist of about an hour of

regular physical activity on most days of the week. School physical education (PE) classes are one way to get this exercise and X% of <Tribe> youth report that they have PE 4 or more days a week. Above all, the strategies that youth use to achieve a healthy weight should be healthy in themselves; vomiting or abusing diet pills and laxatives will severely damage a child's health and are not effective for long-term weight control.

<http://cdc.gov/nccdphp/dnpa/obesity/index.htm>

Department of Health and Human Services. (2001). The Surgeon General's call to action to prevent and decrease overweight and obesity. Rockville, MD: U.S. Public Health Service.

INSERT SITE-SPECIFIC PICTURE
IN THIS SPACE

Summary: Weight and Body Mass of Youth in <Location>

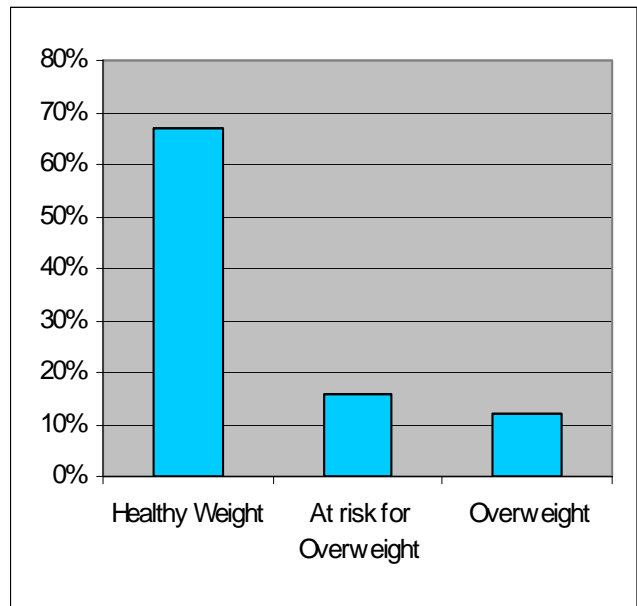
In <year>, X% of <Tribe> youth aged X–X had a healthy weight for their age and growth. X% were at risk for overweight, and X% were overweight.

X% of <Tribe> youth watch more than 2 hours of TV per day.

X% of <Tribe> youth engage in vigorous physical activity at least 3 times a week or moderate physical activity at least 5 times a week.

X% of <Tribe> youth eat at least 5 servings of fruits and vegetables per day, as recommended by the Surgeon General.

Healthy Weight, Overweight, & Obesity Among <Tribe> Youth X–X (year)



Note: The data shown above and on the first page come from a [representative] survey of # <Tribe> youth ages x–x conducted in <year>, and [INSERT OTHER SOURCES AS APPROPRIATE].

Efforts to Promote Healthy Weight among Youth in <Location>

Tracking: Describe

Interventions: Describe what public health practices, programs and community-based efforts there are to promote healthy weight.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local efforts.

Future Directions in Overweight & Obesity Prevention

Goal:

Objectives:

Activities:

Prenatal Care

Percentage of Pregnancies with Prenatal Care in First Trimester

<<date>>

The goal of prenatal care is to promote the health and well-being of pregnant women, fetuses, newborns, and their families. Typically, prenatal care consists of early and continuing risk assessment, health education and promotion, and medical or psychosocial interventions and follow-up as needed.¹ OR SUBSTITUTE QUOTE FROM TRIBAL SOURCE.

Background

Getting appropriate medical care before and during pregnancy is one of the best ways to ensure that mother and baby are as healthy as possible. The American College of Obstetricians and Gynecologists (ACOG) recommends that prenatal care begin in the first trimester (first three months) of pregnancy and that it include a range of screenings for different health problems, information about healthy behaviors for pregnancy, and any necessary treatment.² In a survey conducted in <year>, # (x%) of <Tribe> women who had been pregnant in the previous X years indicated that they had received prenatal care beginning during the first three months of their most recent pregnancy.

What happens during prenatal care?

At the first visit, women usually have a physical exam and discuss their medical history with their healthcare provider. Often

the mother's blood is tested to check blood type, iron level, and immunity status. As the pregnancy progresses and the mother's health continues to be monitored, other tests can be done to assess fetal health and development. At all visits, women receive information about keeping themselves and the baby healthy during pregnancy and after birth. It is recommended that most women visit a doctor 8-10 times during the course of their pregnancy, starting during the first trimester.²

Benefits & other considerations Reduced Complications

Getting prenatal care gives medical providers the chance to identify and address potential problems before they harm the mother or baby. For example, pregnancy complications such as high blood pressure, diabetes, excessive vomiting, infection, and premature labor can all be reduced with the appropriate prenatal care. Because American Indian and Alaska Native women are twice as likely to die from these

pregnancy complications as white women,³ prenatal care can make a big difference for maternal and child health among Native populations.

Pregnancy planning

When women have a pregnancy that is unexpected, they tend to begin prenatal care later⁴. In the <year> survey, # (x%) of <Tribe> women who had been pregnant in the previous X years said that they had planned on their most recent pregnancy.

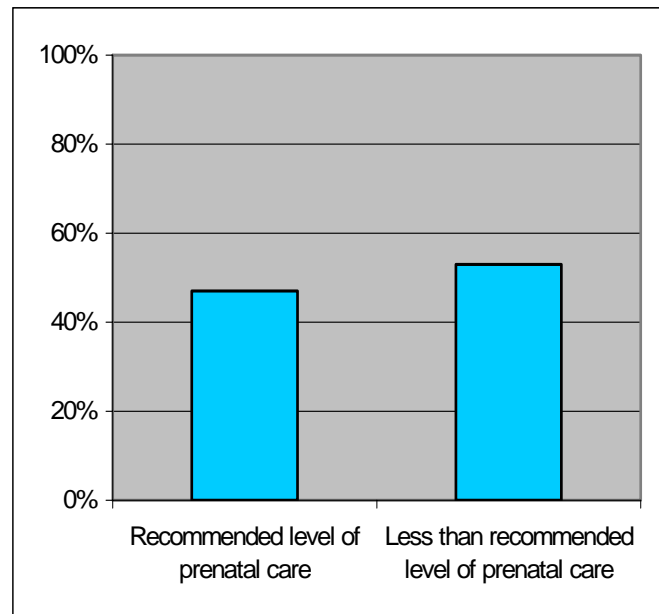
1. Expert Panel on the Content of Prenatal Care. (1989) Caring for Our Future: The Content of Prenatal Care. Washington DC: Public Health Service.
2. American Academy of Pediatrics and American College of Obstetricians and Gynecologists. (1997). Guidelines for Perinatal Care, 4th Ed. Elk Grove, IL: AAP & ACOG.
3. CDC (2002). Safe Motherhood: Promoting Health for Women Before, During and After Pregnancy 2002.

INSERT SITE-SPECIFIC PHOTO HERE (MOTHER & CHILD?)

Summary - Prenatal Care in <Location>

- # (x%) of <tribe> women who have been pregnant started prenatal care in the first 3 months of their most recent pregnancy and had the recommended number of visits.
- # (x%) of <tribe> women who have been pregnant started prenatal care late or did not get the recommended number of visits during their last pregnancy.
- # (x%) of <tribe> women who have been pregnant did not get any prenatal care during their last pregnancy.
- # (x%) of <tribe> women who have been pregnant said they had planned their most recent pregnancy.

Prenatal Care among <Tribe> Women (YEAR)



Note: The data shown above and on the first page come from a [representative] survey of X adult <Tribe> members conducted in <year>, and from [INSERT OTHER SOURCES AS APPROPRIATE].

Promotion of Prenatal Care in <Location>

Tracking: Describe tracking of who gets prenatal care, when, where, how often, etc. Also any info on why not getting, if that is relevant.

Interventions: Describe what public health practices, programs and community-based efforts there are to promote prenatal care/ healthy motherhood.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local prenatal care services and education.

Future Directions for Prenatal Care

Goal:

Objectives:

Activities:

4. Brown, S.S. & Eisenberg, L. (Eds). (1995). The best intentions: Unintended pregnancy and the well-being of children and families. Washington, DC: National Academy Press.

Cancer Screening

Rate of Pap Tests, Mammograms, and Colorectal Screenings

<<Date>>

Cancer is a group of more than one hundred diseases that occur when normal cells become transformed into malignant cells. Transformed cells grow and multiply without control or order. Without treatment to stop this growth, cancer cells can spread throughout the body, resulting in illness and death.¹

Background

Cancer is the second leading cause of death among American Indians and Alaska Natives.¹ There are many kinds of cancer but this factsheet focuses on breast, cervical, and colorectal cancer because the <Tribe> tribe has identified these as health priorities.

Screening Guidelines

Breast cancer

There are three main ways to screen for breast cancer and these methods are most effective when used in combination. According to the American Cancer Society (ACS), every woman over 20 should do a breast self exam each month to check for any changes in how their breasts feel or look. In a <year> survey of adult <Tribe> members, X% of the female participants reported doing this every month. Women should also have a clinical breast exam done by their healthcare provider every three years (or every year if they are over 40). X% of <Tribe> women who participated in the

<year> survey indicated that they had had a clinical breast exam in the past three years. Finally, the ACS recommends that women over 40 also get a mammogram (an x-ray of the breast) every year.² X% of the surveyed women over 40 have received a mammogram in the past year. Although the recommendations above apply to women only, it is important to note that men can develop breast cancer too.

Cervical Cancer

The screening test for cancer of the cervix (the opening of the womb) is called a Pap test. It is recommended that women get Pap tests every 1-3 years beginning at age 18 or at the start of sexual activity, whichever is earlier.² In the <year> survey, X% of <Tribe> women who were eligible for Pap tests reported that they had had this test within the last three years.

Colorectal Cancer

Cancer of the colon and rectum (lower sections of the digestive tract) affects both men and women. The ACS recommends that

people age 50 and older get a fecal occult blood test every year and a colon exam every five years in order to screen for colorectal cancer.² Approximately X% of surveyed <Tribe> residents over 50 have been screened for colorectal cancer within the recommended time period.

Prevention

Each cancer is different, but there are some healthy habits that seem to reduce the risk of developing many kinds of cancer. Among these are:

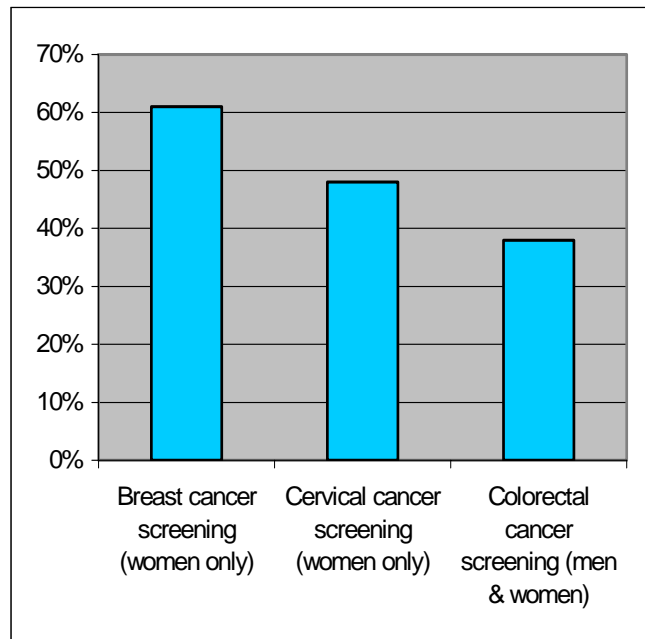
- Not smoking or chewing tobacco
- Eating many vegetables and minimizing foods that are high in animal fat
- Exercising regularly
- Not consuming more than 1 or 2 drinks of alcohol per day
- Getting regular cancer screening tests

1. Anderson, R.N. (2001). Deaths: Leading causes for 1999. National vital statistics reports, 49(11). Hyattsville, MD: National Center for Health Statistics.
2. The American Cancer Society, <http://www.cancer.org>

**Summary: Cancer Screening in
<Location>**

- X% of <Tribe> women age 20 and older report that they do a self breast exam every month.
- X% of <Tribe> women report that they have had a clinical breast exam in the past 3 years.
- X% of <Tribe> women over 40 report that they have had a mammogram in the past year.
- X% of <Tribe> women report that they have had a pap smear within the last 3 years.
- X% of <Tribe> men and women over 50 report that they have been screened for colorectal cancer within the recommended time period.

**Cancer Screening Rates in
<Location>
(year)**



Note: The data shown above and on the first page come from a [representative survey of # <Tribe> members ages X-X conducted in <year>, and from [ADD OTHER SOURCES AS APPROPRIATE-RPMS, etc.].

**Cancer-related Activities in
<Location>**

Tracking: Describe tracking efforts.

Interventions: Describe what public health practices, programs and community-based efforts there are to reduce the burden of cancer.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local cancer control efforts.

**Future Directions in
Cancer Control**

Goal:

Objectives:

Activities:

Adolescent Substance Use

Prevalence of Alcohol and Drug Use among Adolescents

<<Date>>

INSERT QUOTE FROM TRIBAL SOURCE REFLECTING TRIBE'S POSITION ON ADOLESCENT SUBSTANCE USE.

Background

Many adolescents experiment with alcohol or drugs. According to a <year> survey, approximately x% of <Tribe> youth have had a full drink of alcohol and X% have tried marijuana or some other drug in their lifetime. Because adolescent alcohol and drug use is illegal in the U.S., kids and teens who use these substances at all risk arrest, fines, and detention. But those who go beyond experimentation to regular use or overuse of drugs and alcohol risk more serious short and long term health effects. Methamphetamine use, for example, causes very fast heart beat and high blood pressure in the short term and can lead to permanent heart damage and blood clots over the long term.¹ For this reason and others, it is often useful to distinguish between adolescents who use drugs and alcohol heavily or frequently, those who use moderately, and those who use only occasionally or not at all. In the <year> survey, approximately

X% of <Tribe> youth aged X - X reported that they did not use any drugs or alcohol in the month prior to being asked. X% reported moderate use of either alcohol or drugs, or both ^{*[put footnote of how tribe decides to define this]} and X% reported heavy use. ^{*[put footnote of how tribe decides to define this]}

Contributing factors

Research has revealed several factors that are associated with drug and alcohol use among adolescents. Among the strongest risk factors are having friends who use, having friends who accept drug or alcohol use, local availability of drugs, the perception that drug use is not very harmful, and the perception that parents would not be very upset about occasional substance use. On the other hand, youth are less likely to use drugs or alcohol when their friends do not use or support use, when drugs are difficult to obtain or perceived as harmful, or when they feel that their parents would strongly disapprove.³

Prevention

Because adolescent substance use seems to be so heavily influenced by peer norms and community availability,³ prevention efforts need to be community-specific. Prevention programs that address social influences related to drug and alcohol use and that include social skill-building components are in general more effective than programs which simply present information or attempt to scare kids away from drugs and alcohol.³ When thinking about prevention, however, it is also important to incorporate substance abuse treatment to help youth who have already have problems with drugs or alcohol overcome their addictions.

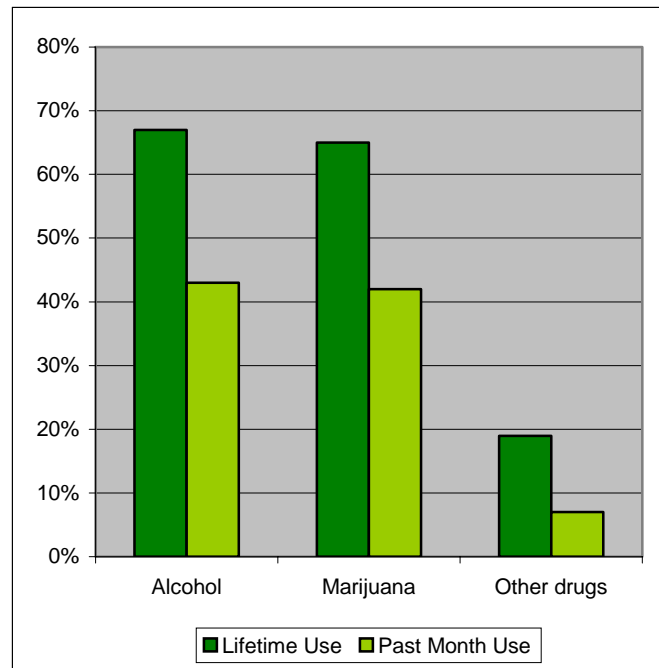
1. Koch Crime Institute. (2002). Methamphetamine: Frequently asked questions. http://www.kci.org/meth_info/faq_meth.htm
2. Lane et al. (2001). Risk and protective factors for adolescent drug use: Findings from the 1997 National Household Survey on Drug Abuse. DHHS: Substance Abuse and Mental Health Services Administration.

Summary: Adolescent Substance Use in <Location>

According to survey results from <Month>, <year>,

- X% of <Tribe> youth have never tried alcohol or illegal drugs. X% did not drink or use any illicit drugs in the previous month.
- X% of <Tribe> youth X-X drank alcohol X or more times in the previous month, and X% of this group had 5 or more drinks on at least one of those occasions.
- X% of youth had ever tried marijuana, and X% used it X or more times in the previous month.
- X% of youth had ever tried methamphetamine, and X% used it X or more times in the previous month.

Substance Use among <Tribe> Adolescents (YEAR)



Note: The data shown above and on the first page come from a [representative] survey of # <Tribe> youth aged x-x, conducted in <year>, and from [ADD OTHER SOURCES AS APPROPRIATE-RPMS, etc.].

Efforts to Prevent Adolescent Substance Use in <Location>

Tracking: Describe ...

Interventions: Describe what public health practices, programs and community-based efforts there are to prevent alcohol and drug use.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local drug prevention efforts.

Future Directions for Substance Use Prevention

Goal:

Objectives:

Activities:

3. Hansen, W.B., and O'Malley, P.M. (1996). Drug use. In R.J. DiClemente, W.B. Hansen, & L.E. Ponton (Eds.), Handbook of adolescent health risk behavior (pp. 161—192). New York, NY: Plenum Press.

Tobacco

Prevalence of Tobacco Use among Adolescents and Adults

<<Date>>

“Tobacco use causes devastating disease and premature death in every population in the United States.”¹
Claire V. Broom, Acting Director, Centers for Disease Control and Prevention, 1998.

Impact

While the occasional use of ceremonial tobacco is typically not too harmful, long-term use of cigarettes, cigars, “chew,” and other commercial tobacco products is extremely damaging. Smoking has been shown to increase the risk of cancer (especially lung cancer), heart disease, and respiratory diseases like emphysema and is the leading cause of preventable death in the U.S.² Commercial tobacco even has a negative health impact on those who do not use it, through their exposure to secondhand smoke. Unfortunately, American Indians and Alaska Natives (AI/ANs) have the highest smoking rate of any of the 5 major racial and ethnic groups in the U.S..¹ Results from a <year> survey in <Location> indicate that X% of <Tribe> adults are current users of cigarettes, snuff, or other commercial tobacco products. X% of this group also report that their daily activities are limited by lung or breathing problems, heart problems or high blood

pressure, or cancer, all of which can be caused by smoking. Among <Tribe> youth, X% had smoked or used other commercial tobacco products at least 3 times in the month before the <Month>, <year> survey.

Prevention

Because the nicotine in tobacco is so addictive, quitting smoking or chewing can be very difficult. So the best way to avoid the negative health consequences associated with tobacco use is to never start using. Many states have succeeded in reducing smoking rates by increasing the taxes applied to tobacco products, passing laws prohibiting the sale of tobacco products to minors, and launching educational campaigns about the dangers of tobacco use.³ [OR INSERT REGIONALLY/TRIBALLY SPECIFIC EXAMPLE]. At the individual level, parents can combat the aggressive marketing techniques of commercial tobacco companies by monitoring their children’s behavior and providing a positive, non-smoking example. For those who already smoke, there are many resources to help with quitting or

cutting down. For example, [INSERT TRIBALLY-SPECIFIC RESOURCE, OR NPAIHB EXAMPLE]. Current smokers can also help protect others from the negative effects of commercial tobacco by not smoking indoors or in the car.

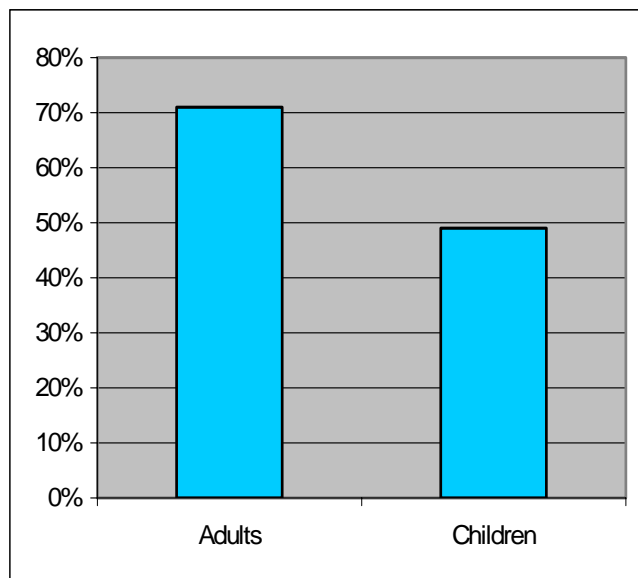
1. U.S. Department of Health and Human Services. (1998). Tobacco use among U.S. racial/ethnic minority groups: A report of the Surgeon General. Atlanta, GA: Centers for Disease Control and Prevention, Office on Smoking and Health.
2. Centers for Disease Control and Prevention. (2002). Annual smoking-attributable mortality, years of potential life lost, and economic costs, United States, 1995-1999. MMWR 51: 300-303.
3. U.S. DHHS. (2000). Reducing tobacco use: A report of the Surgeon General. Atlanta, GA: Centers for Disease Control and Prevention, Office on Smoking and Health.



Summary: Impact of Tobacco in <Location>

- In <year>, X% of <Tribe> adults and X % of <Tribe> adolescents aged X-X smoked, chewed tobacco, or used other tobacco products.
- X% of adults tried to quit smoking in <year>.
- On average <Tribe> adults who used tobacco products had been using for X years.
- X% of adolescent smokers in <Location> smoke more than 5 cigarettes per day.
- X% of adolescent smokers in <Location> get their cigarettes from stores, X% from vending machines, and X% from a friend or family member.

Prevalence of Current Tobacco Use among <Tribe> Members (year)



Note: Current tobacco use is defined as using cigarettes, cigars, or chewing tobacco X or more times within a month. The data shown above and on the first page come from two [representative] surveys conducted in <year>; one with # adult <Tribe> members and the other with # tribal youth ages X-X. Additional information was gathered from [ADD OTHER SOURCES AS APPROPRIATE—RPMS, etc.].

Tobacco Control Efforts in <Location>

Tracking: Describe

Interventions: Describe what public health practices, programs and community-based efforts there are to reduce tobacco use.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local tobacco control efforts.

Future Directions in Tobacco Control

Goal:

Objectives:

Activities:

Physical Activity

Proportion of Adults who Regularly Engage in Physical Activity

<<Date>>

“Regular physical activity, fitness, and exercise are critically important for the health and well-being of people of all ages. ... Millions of Americans suffer from chronic illnesses than can be prevented or improved through regular physical activity.”¹ [OR SUBSTITUTE QUOTE FROM TRIBAL SOURCE]

U.S. Department of Health and Human Services

Background

Being physically active is one of the best things you can do for your health. The Department of Health and Human Services (DHHS) recommends that adults do at least 30 minutes of moderate physical activity 5 days per week or 20 minutes of vigorous physical activity 3 times per week¹. Unfortunately, many people do not exercise enough. In a <Year> survey of adult <Tribe> members, X% indicated that they participate in the recommended amount of physical activity.

Risks of inactivity

Inactivity has negative consequences for physical, mental, and economic health. A sedentary (inactive) lifestyle increases your risk for heart disease, cancer, obesity, and many other chronic diseases including depression.¹ These conditions can quickly become expensive; one national study found that obese individuals spent 36% more on health

services and 77% more on medications than the general population.² Inactivity is also a financial burden at the community level because it increases the number of hospital stays, doctor’s visits, and medications for which the tribe must pay.

Benefits of physical activity

Regular physical activity (see definition above) has been shown to decrease the risk of developing *and* dying from heart disease, diabetes, high blood pressure, and several kinds of cancer. In addition, regular physical activity promotes healthy weight, strong bones and muscles, good balance, and reduces depression and anxiety.¹ According to the <year> survey, X% of <Tribe> members were overweight or obese, X% had diabetes, and X% were suffering from heart disease, but only X% of this combined group engaged in the recommended amount of physical activity. In contrast, X% of <Tribe> adults without these health problems exercised regularly. There are

many ways to get the recommended amount of physical activity each week, including simple things like taking the stairs instead of the elevator or mowing the yard. Among <Tribe> members who are physically active, the most popular forms of activity are X, X, X, and X.

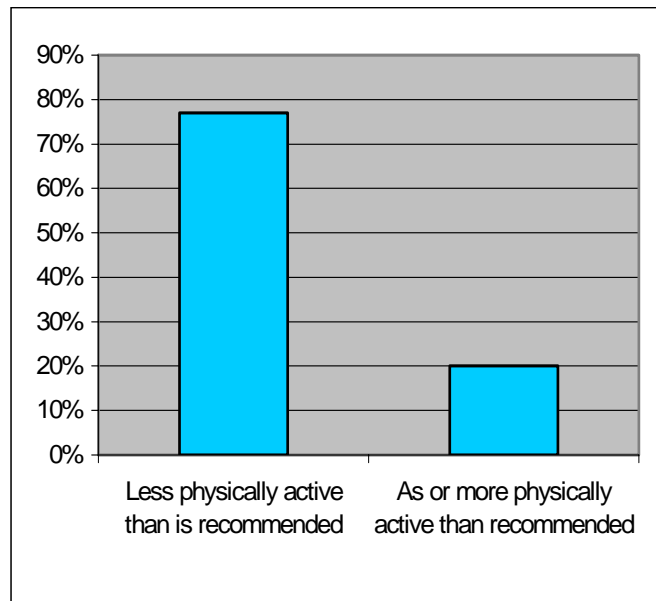
1. Department of Health and Human Services. (2002). Physical activity fundamental to preventing disease. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation.
2. Strum, R. (2002). The effects of smoking, obesity, and problem drinking on chronic medical problems and health care costs. *Health Affairs*, 21(2), 245-253.



Summary: Physical Activity in <Location>

- X% of <Tribe> adults engage in the recommended amount of physical activity (see Background) each week.
- X% get less than the recommended amount of physical activity, but are occasionally active.
- X% did not engage in any moderate or vigorous physical activity in <Month, Year>.
- X% of <Tribe> adults are overweight or obese.
- X% suffer from heart disease, high blood pressure, diabetes, and/or cancer, all of which are associated with a lack of physical activity.

Physical Activity among Adult <Tribe> Community Members (200X)



Note: The data shown above and on the first page come from a [representative] survey of X adult <Tribe> members aged x-x, conducted in <year>, and from [INSERT OTHER SOURCES AS APPROPRIATE].

Efforts to Promote Physical Activity in <Location>

Tracking: Describe ...

Interventions: Describe what public health practices, programs and community-based efforts there are to promote physical activity.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local physical activity promotion efforts.

Future Directions for the Promotion of Physical Activity

Goal:

Objectives:

Activities:

Child Abuse and Neglect

Number and Rate of Confirmed Cases of Child Abuse and Neglect

<<date>>

Federal legislation (42 U.S.C.A. 5106g) defines child abuse and neglect as, minimally, “Any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation,” or “An act or failure to act which presents an imminent risk of serious harm.”

Background

Child abuse is a sensitive topic. This is particularly true in Indian Country, where children have historically suffered abuse from outside agencies rather than from family or tribal members.¹ Today, many groups are taking a more positive approach to child abuse by focusing on creating a supportive community environment in which abuse is less likely to occur.

Impact

Child abuse is generally divided into four categories: physical abuse, sexual abuse, emotional abuse (e.g. excessive yelling or criticism), and neglect, which occurs when a child’s physical, emotional, or educational needs are not met. Unfortunately, these different kinds of abuse often occur in combination.² Furthermore, abuse and neglect in childhood has a long-lasting impact, in addition to the immediate injuries it causes. Adults who were

abused as children are more likely than non-abused adults to suffer from depression and post-traumatic stress disorder, to engage in risky health behaviors, and to have problems relating to other people.² In <Location>, tribal court records indicate that there were # confirmed cases of child abuse and neglect in <year>.

Protective Factors

It would be very difficult to say what causes abuse, but we do know of many family and community characteristics that can act together to help protect children against abuse and neglect. These include:³

- Support of extended family for parents or caretakers
- No history of childhood abuse in parents or caretakers
- Adequate job opportunities and good access to health care and social services
- No alcohol or drug abuse by parents or caretakers

Prevention

Resources for children (e.g. mentor-

ing or education) and parents or caregivers (e.g. financial and childcare support) are more likely to be effective in preventing child abuse when they are offered at two levels: informally by individuals and more formally by community agencies.

1. Earle, K.A. & Cross, A. (2001). Child abuse and neglect among American Indian/Alaska Native children: An analysis of existing data. Portland, OR: National Indian Child Welfare Association.
2. Kendall-Tackett, K. (2002). The health effects of childhood abuse: Four pathways by which abuse can influence health. *Child Abuse & Neglect*, 26(6-7), 715—729.
3. National Clearinghouse on Child Abuse and Neglect Information. (2002). <http://www.calib.com/nccanch/pubs/factsheets/childmal.cfm>



Summary: Child Abuse and Neglect in <Location>

- INSERT ANY TRIBAL DEFINITIONS OF ABUSE & NEGLECT, OR RESOLUTIONS CONCERNING THE TRIBE'S GOALS FOR CHILDREN, ETC.
- There were # confirmed cases of child abuse and neglect in <Location> in <year>. [HIGHLIGHT POSITIVES— LOWER THAN NAT'L AVERAGE, REDUCED FROM PREVIOUS YEARS, ETC.]

Tips for Supporting Children and Caregivers

- INSERT SITE-SPECIFIC RECOMMENDATIONS (see National Indian Child Welfare Association website at www.nicwa.org for ideas).

Child Abuse Prevention Efforts in <Location>

Tracking: Describe

Interventions: Describe what public health practices, programs and community-based efforts there are to reduce child abuse and neglect.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local child abuse prevention efforts.

Future Directions in Child Abuse Prevention

Goal:

Objectives:

Activities:

Auto Safety Restraint Use

Tribal Ordinance and Prevalence of Restraint Use among Adults & Children

<<Date>>

Each year, more than 40,000 people are killed in motor vehicle crashes in the United States. In addition, motor vehicle crashes result in approximately 50,000 hospitalizations and 4 million emergency department visits annually.¹

Background & impact

Correct and consistent use of passenger restraint devices significantly reduces the likelihood of being injured in a motor vehicle crash. Seatbelts reduce the risk of fatal injury by 45% and the risk of moderate to severe injury by 50%,² while child safety seats reduce the risk of fatal injury by 71% for infants and 54% for toddlers.² Unfortunately, use of restraint devices is not as high as it could be among <Tribe> members. In surveys conducted in <year>, X% of adults and X% of youth (ages X—X) said that they always wear a seatbelt while driving or riding in a car. X% of adults reported that when children under 8 ride in their car, these children are always in a child safety seat. <Tribe> tribal law requires that ... [INSERT WHATEVER ORDINANCE TRIBE HAS].

Contributing factors

Laws & Education

Research has shown that people are more likely to use seatbelts and child safety seats when lo-

cal laws require their use, when drivers can be stopped just for not following the seatbelt law (primary enforcement), and when special steps are taken to monitor and enforce safety restraint use (e.g. seatbelt checkpoints).¹ <Tribe's> safety restraint ordinance is a [PRIMARY/SECONDARY] law [EXPLAIN SECONDARY IF NECESS]. In addition, educational campaigns, child safety seat loans or giveaways, and reward programs have also increased safety restraint use at the community level.¹ Educational programs are particularly important for child safety seats because it takes a little time to learn how to fit the seat correctly to your child as well as to your car.

Alcohol

Alcohol influences safety belt and other restraint use. People who have been drinking are less likely to wear a seatbelt. In an analysis of 1990-94 data from the National Highway Traffic Safety Administration and the National Center for Health, researchers found that only 11% of Native Americans involved in alcohol-related traffic accidents

were wearing their seatbelt at the time of the accident.³ In the <year> surveys, X% of <Tribe> adults and X% of <Tribe> youth ages X—X reported that they had driven a car while drunk or ridden with a driver who had had too much to drink in the month prior to being asked.

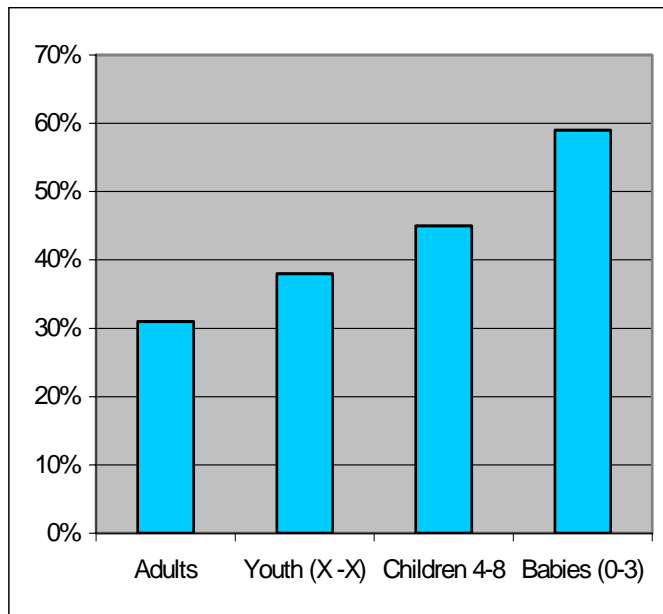
1. Taskforce on Community Preventive Services. (2001). Motor vehicle occupant injury: Strategies for increasing use of child safety seats, and reducing alcohol-impaired driving. MMWR 50 (RR07), 1-13.
2. National Highway Traffic Safety Administration. Traffic safety facts 2001—Occupant protection. <http://www-nrd.nhtsa.dot.gov/pdf/nrd-30/NCSA/TSF2001/occpro.pdf>
3. Kalagher, S. (1999, July 23). New study examines alcohol-related traffic accidents and ethnicity. The NCADI Reporter. <http://www.health.org/newsroom/rep/107.html>

INSERT TRIBE-SPECIFIC PHOTO HERE (E.G. KIDS IN SAFETY SEATS).

Summary: Safety Restraint Use in <Location>

- X% of adult Tribal members always wear a seatbelt while driving and X% always wear a seatbelt when riding in a car.
- X% of <Tribe> youth ages X—X always wear a seatbelt while driving and X% always wear a seatbelt while riding in a car.
- X% of <Tribe> members always put children aged 0 to 3 in a child safety seat and X% always put 4 to 8 year olds in a booster seat.
- X% of adults and X% of youth drank and drove or rode with a driver who had had too much to drink in the month prior to beings asked.

Proportion of <Tribe> community members always protected by safety restraints (year)



Note: The data shown above and on the first page come from two [representative] surveys conducted in <year>; one with # adult <Tribe> members and the other with # tribal youth ages X-X. Additional information was gathered from [ADD OTHER SOURCES AS APPROPRIATE—RPMS, etc.].

Promotion of Seatbelts and Child Safety Seats in <Location>

Tracking: Describe ...

Interventions: Describe what public health practices, programs and community-based efforts there are to increase seatbelt and child safety seat use.

Partnerships: Describe partnership in the community and how these partnership opportunities have helped develop, implement and evaluate local injury prevention efforts.

Future Directions in Passenger Safety

Goal:

Objectives:

Activities:

VI. Reporting & Using the Profile Results

Additional Resources

Reports and websites of existing community indicator projects

The following is a very brief list of publications and Internet sites for community-based indicator projects that are ongoing or have already been conducted. It is by no means complete, but you may want to look at the material from these and other projects to get ideas for your own community health profile reports.

Mizoguchi, Nobuko, Mia Luluquisen, Sandra Witt, and Liz Maker. *A Handbook for Participatory Community Assessments: Experiences from Alameda County*. Oakland, CA: Alameda County Public Health Department, 2004. Available online at: <http://www.acphd.org/user/data/datareports.asp>

Owens, J.S. & Phillips, F.B. (2002). Report card of community health indicators. Annapolis, MD: Anne Arundel County Department of Health. Also available online at: http://www.aahealth.org/App_pdfs/ReportCard3_02.pdf

Public Health - Seattle and King County. (2002). Communities count: Social and health indicators across King county. Seattle, WA: Public Health - Seattle and King County, Epidemiology, Planning, and Evaluation Unit. Also available online at: <http://www.communitiescount.org>

Putting Your Healthy Youth Survey Results to Work: Interpreting and Using Your Data. Exercise Workbook, Spring 2005 Regional Workshops, Washington State Healthy Youth Survey, 2004. Available at: <http://www.rmccorp.com/hys04/Workshops/MaterialsList2004.htm>

UCLA Center for Healthier Children, Families, and Communities. (1998). National directory of community health report cards. Los Angeles, CA. - This publication contains 1-page summaries of 65 community health report cards. Information for this document was collected in 1995-1998, so some may now be out of date. Contact the Center for Healthier Children, Families, and Communities at 310-825-8042 to ask for a copy.

www.naccho.org/prod96.cfm - This site contains information about the Community Health Status Indicators Project, which produced county-specific community health reports for counties all across the nation. The reports and the entire project dataset can be ordered

VI. Reporting & Using the Profile Results Additional Resources

from the Public Health Foundation through a link on this webpage.

www.cdc.gov/hrqol/community.htm - On this site, the Centers for Disease Control and Prevention (CDC) provide links to national and state-specific community health report cards in which the CDC's *Healthy Days Measures* have been used.

www2.co.hennepin.mn.us/hcharts/hcharts.jsp - An interactive community health indicator reporting site developed by the Hennepin County Community Health Department in Minnesota.

<http://iisd1.iisd.ca/measure/compindex.asp> - This site, which was created by the International Institute for Sustainable Development, Environment Canada, the World Bank, and the United Nations Division for Sustainable Development, features a searchable database of indicator projects and publications around the topic of sustainable development.