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Tribal Consultation: a Review of the Department of Health and Human Services Policy

The following is the third of three papers that were written during the authors' participation in the Kaiser Family Foundation's Native American Health Policy Fellowship last year.

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As the new century begins, the relationship between the United States government and American Indian and Alaska Native tribes deserves some reflection on how or if it has changed over time.

Most recently, the United States government has dealt with this relationship through its policy of tribal consultation. The Department of Health and Human Services (DHHS), which was the first Federal agency to develop a formal Tribal Consultation Policy, has described consultation as "an enhanced form of communication which emphasizes trust, respect and shared responsibility. It is an open and free exchange of information and opinion among parties, which leads to mutual understanding and comprehension. Consultation is integral to a deliberative process, which results in effective collaboration and informed decision making."[1]

Throughout the Clinton Administration there was a concerted effort to create and support tribal consultation, and Federal agencies were directed to create their own consultation policies. As the new Bush administration moves forward, it is important to determine the effectiveness of its current tribal consultation policies in meeting the needs of tribes and in upholding the Federal responsibility to these sovereign nations.

History of the Government to Government Relationship

As a result of numerous treaties, court decisions, and legislative acts, the Federal government has a trust responsibility to provide for the health and well being of American Indians and Alaska Natives. "This relationship has been defined in case law and statute as a political relationship that further distinguishes Indians from racial classification for purposes of affirmative action laws and other Federal statutes that establish federally funded programs for the general public."[2] While this relationship has changed and has been challenged over time, it is the foundation for current policies on tribal consultation.

There are many laws and regulations that have affected Indian people since the arrival of the first Europeans. "Understanding and appreciating the historical and legal basis for treating Indians differently than other ethnic minority

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groups and the general public and the sovereign status of tribal governments is an important foundation to carry out the unique Federal government to tribal government relationship."[3]

The Snyder Act

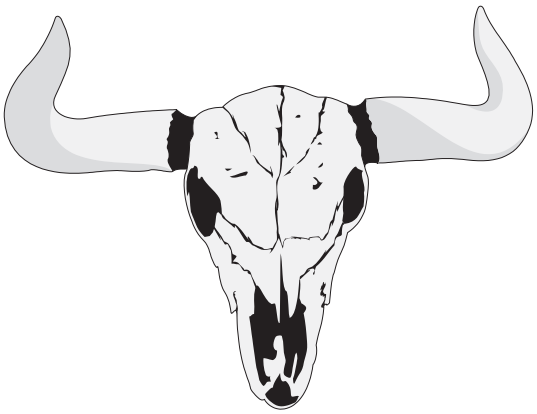
The Snyder Act, signed on November 2, 1921, was the first major legislative act by Congress that authorized appropriations and expenditures for the administration of Indian affairs and other purposes. It stated that the Bureau of Indian Affairs (BIA), under the supervision of the Secretary of Indian Affairs, " . . . would direct, supervise and distribute such money as Congress may from time to time deem appropriate, for the benefit, care, and assistance of the Indians throughout the United States for a number of purposes. This was including the relief of distress and conservation of health."[4]

The Transfer Act

The Transfer Act of 1954 transferred the responsibility for Indian health from the Bureau of Indian Affairs to the Indian Health Service (IHS), then a part of the Department of Health, Education and Welfare (now DHHS). This Act was important because it changed the lines of communication, responsibilities, and relationships within the Federal government and with Indian tribes on matters related to health.[5]

The Indian Self-Determination and Educational Assistance Act

In 1975 the Indian Self-Determination and Education Assistance Act (PL 93-638) was signed into law. This legislation provided tribes with an option of managing their own health care programs and other Federal programs under specific formal agreements with the federal government. Title 1 of this act allows tribes to "contract" with the Federal government to assume management of some or all of their programs, with continued Federal oversight and involvement. Title III of this act allowed a demonstration project for tribes to "compact" to assume management of all of their programs with significant independence and authority. Some people believe that this act is one of the most important pieces of Indian legislation, because it allows tribes to determine what is best for their own individual tribe and administer accordingly.



Tribal Self-Governance Amendments of 2000

The Tribal Self-Governance Amendments of 2000 (PL 106-260) allowed self-governance to become a permanent program within the IHS and BIA, so that tribes could compact health services that were currently being provided by the IHS. While the Department of Interior made self-governance permanent within their department in 1994, the (IHS) did not make their self-governance program permanent until this act (PL 106- 260) in 2000. This legislation was enacted as a result of advocacy effort by tribes and Indian organizations, and increasing evidence that tribes were successfully managing their own health care programs under contracts and compacts.[6]

Tribal Consultation Policy

During the 1990s, President Clinton directed the Federal government, through several Presidential Executive Orders, to consult with tribes while developing policies and activities that might affect them.

President Clinton's First Executive Memorandum 1994

In 1994, the President executed a memorandum "Government to Government Relations with Native American Tribal Governments" for the heads of Executive Departments and Agencies directing them to consult, "to the greatest extent practicable and to the extent permitted by law, with tribal governments prior to taking actions that affect federally recognized tribal governments."[7] This memorandum represented the beginning of a new era in the relationship between the Federal government and tribes. There were six guidelines to this memo, which included ensuring that each Department operates with the government to government relationship and has open and candid conversations with tribes. The guidelines were to ensure compliance with other Executive Orders and make sure that any activity that might affect a tribe or tribes was discussed with them.

President Clinton's Executive Order 13084

In 1998, the President issued an Executive Order that would further strengthen the Administration's stance on American Indian and Alaska Native governments. The purpose of this order was to "strengthen the consultation and collaboration with Indian tribal governments in the development of regulatory practices on Federal matters that significantly or

uniquely affected their communities."[8]

In this executive order, President Clinton reaffirmed the commitment of the previous memo by expanding on those first six guidelines and defining them more appropriately to address the needs of tribes. He expanded on those by including "increasing flexibility for Indian tribal waivers, having cooperation from the departments in developing regulation, and encouraging independent agencies to comply with the provisions of this order."[9]

Executive Order 13175

On November 6, 2000 the President signed Executive Order 13175 entitled "Consultation and Coordination with Indian Tribal Governments," for the purpose of establishing ". . . regular and meaningful consultation and collaboration with tribal officials in the development of Federal policies that have tribal implications, to strengthen the United States government-to-government relationships with Indian tribes, and to reduce the imposition of unfunded mandates upon Indian tribes."[10] This was the second and last executive order of the Clinton Administration that was signed affecting tribal governments. It incorporated all of the areas of the previous executive memorandum and the previous executive worder, and included a total of nine sections: 1) definitions for the purpose of the executive order; 2) fundamental principles, which defined how policies would be guided to meet the goals of the executive order; 3) policy-making criteria, detailing how it would be implemented; 4) special requirements for legislative proposals, which stated that agencies should not submit to the Congress legislation that would be inconsistent with the policy making criteria of the previous section; and 5-9) sections similar to the previous two memorandums, but described with much greater detail.

All of these three executive actions were very similar in content, but were refined over time as the Administration gained better knowledge of working with tribes, as each new executive order included much greater detail then the previous one and seemed to better understand and define the concept of the government to government relationship.

The DHHS Tribal Consultation Policy

The DHHS established its formal tribal consultation policy on August 7, 1997 in response to the 1994 Presidential Memorandum. The goals of the DHHS's tribal consultation policy are:

1. To consult with Indian people to the greatest practicable extent and to the extent permitted by law before taking actions that affect these governments and people;
2. To assist states in the development and implementation of mech anisms for consultation with their respective tribal governments and Indian organizations before taking actions that affect these governments and/or the Indian people residing within their state. Consultation should be conducted in a meaningful manner that is consistent with the definition of "consultation" as defined in this policy, including reporting to the appropriate DHHS agency on its findings, and on the results of the consultation process that was utilized;
3. To assess the impact of the Department's plans, projects, programs and activities on tribal and other available resources;
4. To remove any procedural impediment to working directly with tribal governments or Indian people; and to work collaboratively with other federal agencies in these efforts.[11]

The DHHS has developed a number of activities through its Tribal Consultation Policy. Over the past few years DHHS has taken a number of actions in an effort to meet the above goals.

The Department formed an Interagency Tribal Consultation workgroup. This is co-chaired by the Director of the Indian Health Service and the Director of the Office of Intergovernmental Affairs, and its membership consists of representatives from all agencies in DHHS. This workgroup was designed to keep each agency informed about policies that were affecting AI/AN and to inform each other on what each agency was doing to improve this relationship.

DHHS also requires all of its agencies to create their own consultation policy. The Indian Health Service was the first agency to create their policy, which was used as a guide by other DHHS agencies. All other agencies have since developed their own specific policies.

In addition to the internal actions taken, DHHS used regional and national conferences as a vehicle for consultation with tribes. In 1997, the Deputy Secretary of DHHS held a series of five "Regional Listening Forums" throughout the country to listen to the needs of American Indians and Alaska Native tribes. A National Listening Conference was then host-

ed by the DHHS to allow agencies under its umbrella to respond to the concerns raised in these forums. A follow-up report to the National Listening Forum was distributed in 2001 to every tribal government, national Indian organization, and each DHHS Agency.

Each year DHHS holds a department-wide budget consultation with Indian tribes. At this consultation, tribal leaders and national Indian organizations develop their budget priorities, prepare testimony, develop an agenda, and then present their recommendations for the DHHS budget. The Assistant Secretary for Management and Budget and the Director of Intergovernmental Affairs co-chair this meeting. The meeting takes place before each agency has submitted its budget, so that tribes have a chance to influence the DHHS budget.

A Strategy for Determining the Effectiveness of the DHHS Tribal Consultation Policy

DHHS policy outlines several plans of action that each agency should take to further tribal consultation, but it does not state how it will measure the effectiveness of the policy. Eight tasks were outlined for each agency to follow in their tribal consultation activities: 1) preparation of a draft policy/plan for a consultation process; 2) consultation with tribes on their plan; 3) inclusion of provisions such as the purpose of consultation, assisting states in developing a mechanism to consult with tribes, defining a process for inclusion of tribes in decision making and specifying mechanisms to consult with tribes; 4) inclusion of a time frame, a statement of advice, and a clear indication of who should receive information from tribes; 5) plans that should include timely feedback provisions; 6) dissemination of the completed plan, including on web sites if this is available; 7) establishment of a single point of contact for tribal governments at the agency level; and 8) submission of an annual report by December 31 on consultations held during the previous fiscal year.[12] While the tasks for agencies have been outlined in detail, a specific strategy to measure the effectiveness of the DHHS tribal consultation policy and the achievements of each agency does not currently exist.

To assess the value of this policy, this project asked various stakeholders their perspectives on the effectiveness the DHHS Tribal Consultation Policy. The two main stakeholders in this process are: 1) American Indian/Alaska Native tribes; and 2) DHHS agencies.

In order to determine the effectiveness of the DHHS Tribal Consultation Policy from the perspectives of these stakeholders, a series of informal interviews were conducted with elected tribal officials representing a broad range of tribes, and representatives from DHHS and its agencies that are responsible for Indian issues. The individuals interviewed were asked for their opinions on the effectiveness of the DHHS Tribal Consultation Policy, and whether they had any problems or concerns, or any suggestions or solutions to the issues they raised. All interviews were conducted during the summer of 2001 by the author, and the names of the individuals interviewed were kept confidential. Participation by all individuals interviewed was completely voluntary, and tribal officials were asked for their personal opinions, not as official representatives of their tribes.

A total of five elected tribal officials were interviewed, representing a diverse group of leaders from both large and small tribes, communities served by both Indian Health Service and tribally managed programs, and diverse regions around the country. A total of five DHHS representatives were interviewed, and they represented both DHHS and agency staff.

Has Consultation Been a Valuable Tool for Tribes? The Tribal Stakeholders View

Today there are currently 561 tribes throughout the United States. These tribes represent diverse cultural and socioeconomic positions, and, in terms of health care, they can be defined by whether their health services are managed by the IHS or by the tribe through P.L.93-638 contracts or compacts. These tribes are all sovereign nations and consider themselves very different and independent; one tribe cannot speak for another. Therefore, the tribal leaders interviewed for this project, while representing a diverse group of tribes, are only examples of the perspectives of tribal officials on the DHHS Tribal Consultation Policy.

What does consultation mean and why is it important? The tribal leaders who were interviewed shared similar thoughts on the importance of tribal consultation. They felt that through its Tribal Consultation Policy, the Federal government recognizes that tribes are sovereign nations and are capable of managing their own affairs. Tribal consultation also ensures that tribes have an opportunity to provide their perspective on various policy/budget issues, and it is a process that symbolizes that the Federal Government honors and respects its relationship with tribes.

The tribal leaders interviewed also see positive benefits to the tribal consultation process. They felt that the DHHS had become more responsive to tribal needs and that tribes have been more effective with the DHHS Secretary's Office on budgetary and legislative matters. Overall, they felt that there has been more of a willingness of DHHS agencies to discuss policies that affect tribes and an increasing awareness of how policy is applied to tribes.

Problems and Concerns. The tribal leaders also discussed their concerns and problems with the tribal consultation policy. They felt that IHS is the only agency within DHHS to fully participate in the consultation process. They had concerns about the staffing capacity of the Office of Intergovernmental Affairs to address the countless issues raised within the DHHS. Lastly they felt that there are so many programs and activities within the DHHS as a whole that it is hard to address compliance or adhere to the DHHS Tribal Consultation Policy.

Solutions/Suggestions. The tribal leaders overall felt that the policy could be improved in several ways, and suggested some strategies for doing so and measuring its success:

- All DHHS agencies that affect Indian health should move to address the true needs of tribes.
- DHHS should document what has been accomplished in response to requests by tribes, including both positive and negative outcomes.
- The DHHS and each agency should document on an annual basis all of its activities related to consultation with tribes, including regional or national meetings, communications via phone or mail, and individual meetings.
- The Secretary of DHHS should implement a policy to schedule regular meetings with tribes, not just at the request of tribes.
- Tribes should be able to evaluate the tribal consultation process themselves on an annual basis.

Is Tribal Consultation an Effective Tool for DHHS? Federal Stakeholders View

The Five DHHS employees who were interviewed came from a broad range of offices, including an agency, the Offices of the Secretary, and the Immediate Office of the Secretary. All of these individuals have participated in some manner in DHHS Tribal Consultation Policy activities, including implementation of the process and participation in the annual budget consultation meeting.

What does Consultation mean and why is it important? The employees of DHHS felt that consultation was important because it creates an equal partnership between DHHS and the tribes. They felt that consultation was important because it takes place on every level when dealing with tribes, and that decisions about tribes should be made with their input. Most importantly they believe that tribal consultation is the foundation of mutual trust and respect and that it leads to conversation with a purpose. The employees surveyed also felt that consultation was a critical tool for the government-to-government relationship and that this relationship cannot have dialogue without partnership of the two entities. They also felt that the government-to-government relationship is what drives the entire consultation policy.

Problems or Concerns. The employees surveyed were concerned that at times they were not consulting with all of Indian Country when meeting with a small group of tribal leaders. They saw an inability to sort out all the issues related to consultation in such a large department, and that the time and energy of both parties could be totally consumed by the process itself, when only a few people participate in consultation.

The employees felt that they had experienced many positive aspects of consultation, including the ability to establish a personal relationship with tribal participants. This process has allowed people to develop these relationships that make the process very rewarding and help prevent criticism of unfamiliar people. They felt that tribal consultation helps build an appropriate and historical bridge to trust, and this leads to both sides being able to rationally deal with the issues at hand. But, most of all, it reminds agency heads of the unique relationship and responsibility that DHHS has to tribes.

Solutions/Suggestions. The DHHS employees also had suggestions about how they felt that the policy could be improved and be measured for success or failure. One of the employees felt that DHHS was not yet in a position to measure its success or failure, but the others provided positive suggestions:

1. **All** agencies should be at the same level with the IHS with regard to consultation.
2. More enforcement of the policy is needed, because without enforcement, success or failure cannot be measured.
3. Other agencies should participate in consultation voluntarily.
4. Crossing department lines to benefit tribes should create partnerships.
5. The level of satisfaction of all parties should be measured.
6. Determine the desired outcomes of tribal consultation.
7. Determine if tribes think that the process is working and worth the effort.
8. Measure items that are quantitative. Did budgets increase over the years? Did tribes have greater access to programs throughout the entire department?

Conclusions

The DHHS Tribal Consultation Policy was developed to strengthen the government-to-government relationship and ensure that tribes are consulted on matters that affect them. DHHS has participated in many consultation activities since

the implementation of its Tribal Consultation Policy, including both department-wide and agency-specific activities. However, an evaluation of the effectiveness of these activities has not occurred. In this paper, the perspectives of the two major stakeholders, tribes and DHHS staff, have been reviewed. Overall, while both stakeholders acknowledged the importance of tribal consultation, they also indicated many suggestions for improvement.

It is timely to review the status and effectiveness of the DHHS Tribal Consultation Policy due to the recent change in the administrations and staffing of the Federal government and its agencies. Many people wondered what would happen to the DHHS consultation process with a new administration. DHHS Secretary Thompson has made large strides in ensuring that tribal consultation continues in an effective manner by attending key tribal meetings, such as the National Congress of American Indians Mid-year Banquet; holding a roundtable discussion with tribal leaders in April 2001; and continuing the 3rd Annual Tribal Budget Consultation, which was chaired by DHHS Deputy Secretary Claude Allen. In August, Secretary Thompson became the first DHHS Secretary to visit Indian Country when he visited tribes in Michigan, Wisconsin, and South Dakota. These efforts demonstrate that the new administration and DHHS will continue the process of tribal consultation.

While it is encouraging that tribal consultation has continued under the new administration, tribal consultation is an important tool that advocates for the future of American Indians and Alaska Natives. That tool needs to be evaluated on a regular basis to ensure that it is an effective forum for the government-to-government relationship.

Recommendations

In summary, the DHHS Tribal Consultation Policy could be improved through the following strategies:

- Record all consultations held by each DHHS agency annually and monitor by comparing accomplishments with previous years.
- Create an annual "fact sheet" that shows what programs and policies have positively affected tribes during the fiscal year, with comparisons to previous years.
- Host a biennial DHHS national meeting to listen to tribes so that all the agencies can participate and show what they have done to improve tribal consultation.
- Convene a yearly meeting of the DHHS Secretary and tribal leaders to discuss current issues and priorities that are affecting them. This meeting would be with the Secretary himself and his key staff.
- Reevaluate consultation efforts on an annual basis.

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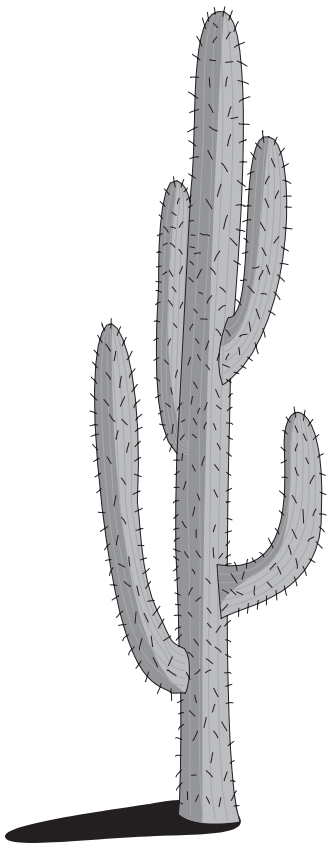

Chronic Kidney Disease: Definition and Classification

This is the second in a series of 12 brief articles about chronic kidney disease.

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In the past, the absence of a widely accepted definition of chronic kidney disease and the lack of classification of the stages of chronic kidney disease have impaired efforts to diagnose and treat persons with kidney disease early in the course of their illness. The National Kidney Foundation (NKF) has recently published a "Clinical Practice Guideline for Chronic Kidney Disease: Evaluation, Classification, and Stratification." This article will describe the highlights of the NKF Guideline, the purpose of which is to "provide a common language for communication among providers, patients and their families . . . for developing a public health approach to affect care and improve outcomes of chronic kidney disease."

Terminology

- Use "kidney" instead of "renal."
- Chronic Kidney Disease (CKD) replaces "pre-end stage renal disease," "pre-dialysis," or "chronic renal failure."
- End-stage renal disease applies only to patients treated by dialysis or transplantation.

The Definition

Chronic kidney disease is kidney damage for *3 months* as defined by structural or functional abnormalities with or without decreased glomerular filtration rate (GFR), or a GFR of 60 mL/min/1.73 m^2 or less, with or without kidney damage.

The NKF Guideline proposes a definition and classification based on a measure of kidney function, the glomerular filtration rate (GFR). The kidney is usually described as "a filter" and GFR is a measure of the kidneys' ability to filter blood, which can be expressed on a continuous scale. Serum creatinine alone does not provide enough information for diagnosis and classification. GFR can be estimated by using the serum creatinine, the body weight, and age. Pharmacists and physicians are familiar with the Cockcroft-Gault equation, which also accounts for gender, as follows:

$$\text{Estimated GFR} = \frac{(140 - \text{age})\ (\text{body weight in kg})}{72 \times \text{serum creatinine}}$$

Multiply result by 0.85 for women

Various other equations have been developed for estimating GFR. None of the equations have been tested extensively in American Indians and Alaska Natives. The Cockcroft-Gault equation above is simple and can be used in any clinic setting. Once GFR is estimated, the patient's kidney function can be classified, and ultimately tracked over time.

The new guidelines classify the stages of CKD by GFR, as listed in Table 1.

Table 1. Stages of Chronic Kidney Disease and Metabolic Consequences

Stage	Description	GFR (mL/min/1.73 m2)	Metabolic Consequences
1	Kidney damage w/ normal or ↑ GFR	>90	
2	Kidney damage with mild ↓ GFR	60 - 89	• ↑parathyroid hormone (GFR 60 ≈ 80)
3	Moderate ↓GFR	30 - 59	• ↓calcium absorption (GFR<50) • ↓lipoprotein activity • malnutrition • onset of LVH • ↓erythropoietin → anemia
4	Severe ↓GFR	15 - 29	• ↑triglycerides • hyperphosphatemia • metabolic acidosis • potential hyperkalemia
5	Kidney failure	< 15 (or dialysis)	• azotemia

Patients with a GFR between 60 - 89 but *without* markers of CKD are considered to have "decreased GFR." A nephrologist or other provider with special interest in kidney disease should be consulted when the GFR is less than 30 mL/min/1.73 m^2.

What is normal GFR?

"Normal" values vary based on the reference used. GFR varies with age, gender, and body size. The following list provides a point of comparison for "normal" mean GFR.

- For young adults, the normal mean GFR is 120 - 130 mL/min/1.73m^2.
- Adult values are reached by age 2 in children.
- Women have lower GFR values that can be assumed to be 8% lower at all ages.
- After age 20 - 30, the GFR decreases by about 1 mL/min/1.73m^2 per year.
- By age 70, the normal mean GFR is approximately 70 mL/min/1.73 m^2.
- GFR is transiently elevated after a high protein meal.

As the GFR falls to 60 mL/min/1.73 m^2 and below, multiple metabolic complications develop, and additional evaluation is required as part of routine care. Virtually all organ systems can be affected. Initial signs include hypertension and laboratory abnormalities. As the GFR continues to decline, the patient needs to be evaluated for anemia, malnutrition, bone disease, neuropathy, and decreased overall functioning and well-being (see Table 1 for a listing of the metabolic consequences associated with the CKD stages). Upcoming issues of *The IHS Provider* will address these specific topics.

An IHS Quality Initiative and Medical Informatics Tool: The PCC+

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The Goal and Vision of the ITSC

The goal of the Information Technology Support Center (ITSC) is to improve the delivery and the quality of health care to American Indian and Alaska Native (AI/AN) individuals and populations, as well as to improve the documentation of this health care. The ITSC recognizes the need to gather information, from the point of clinical contact through and including the billing process, in order to provide a complete, accurate, and detailed information resource for each clinic visit. This wealth of information can increase the effectiveness of the clinical visit, thus improving the consistency and continuity of care for the patient and family.

PCC+ Background

PCC+ ("PCC Plus") is a new application, formally released by ITSC for IHS-wide deployment in July 2001, that enables PCC users to build a customized encounter form in real time for each patient visit. This application combines the best features of the PCC encounter form, the superbill, and a health summary, all in one integrated document. A new version of PCC+ was released in June 2002.

The typical deployment at a facility involves site self-assessment, technical installation, and an on-site pre-deployment visit. ITSC recommends that, initially, PCC+ be introduced in one clinic, or one specialty, or with one provider. After this initial deployment has occurred, the PCC+ can be rolled out to other clinics and providers.

Further information, including the reference templates, is available from the PCC+ website at *http://www.ihs.gov/CIO/pccplus*.

PCC+ Design and Implementation

PCC+ interacts with all individuals in the entire health care visit process, including registration, nursing, providers, coders, data entry, billing, laboratory, x-ray, and pharmacy. In addition, this single, but very detailed, encounter and superbill form impacts and creates changes in the day-to-day workflow process for all these individuals and departments.

The PCC+ application encompasses a wide and diverse process, making it imperative for each service unit or clinic to develop a team to guide its implementation. This ongoing team, utilized prior to, during, and after the implementation process, reviews issues, discusses changes and change options, prioritizes, and collectively resolves problems, as well as makes changes to improve the workflow process. Furthermore, this same team is instrumental in facilitating the easiest possible transition during implementation. This team, representing the different disciplines, is one of the best ways to ensure that introduction of new processes will be successful.

PCC+ as a QA Tool

PCC+ is an excellent resource to document patient information and to gather specific data elements. It can be used as a quality assurance tool to support JCAHO, NCAAA, and GPRA requirements. Once documented in PCC+, the data will enable IHS and HHS as a whole to measure the outcomes and results of patient care. For example, Have diabetic complications declined through earlier detection, preventive care, and clinical interventions? Has the access to dental care and sealants reduced tooth decay for the children? Will preventive screenings such as Pap smears and mammograms reduce the incidence of cancer?

The display of clinical reminders on the PCC+ form facilitates provider compliance with agreed upon recommendations for diagnostic and screening tests. Therefore, PCC+ is not only an integrated legal document of the visit, but also a robust data tool that can provide the needed data and results that, in the past, have been undocumented, poorly documented, or misdocumented, causing skewed outcome results.

Clinical data and outcome measurements incorporated into PCC+ forms, such as cancer screening services, diabetic follow-up and care, and immunizations will be further discussed in subsequent IHS Provider articles.

PCC+ as Clinical Tool

In the previous section, the value of PCC+ as a tool in the QA process was emphasized. We believe that PCC+ has tremendous value as a tool in the clinical quality improvement process, as well.

Communication/Documentation. Any strategy or element that increases communication between health professionals over time and/or which increases documentation of health information and services will improve the quality of health care for patients and their families. The construction of a PCC+ form allows for a unique display of critical health information as well as documentation using condition-specific

forms (e.g., diabetes, well woman) with preprinted checklists and frequently used codes.

Integration of Standards of Care. Secondly, one powerful feature of PCC+ is its potential for delineation of standards of care. Ideally, the clinicians would have reached a consensus on the management of a specific condition. This consensus should be consistent with national or professional guidelines and might also reflect unique community needs. These standards of care can be built into the form, providing a consistent framework of care as well as reminders to health providers. For example, the standards of care for adult diabetic patients can be organized in the PCC+ form in a variety of ways, such as a checklist; headings, in parentheses, in the abbreviated health summary in the upper left corner; or in a reminder/plan section at the bottom of the form.

One of the risks to building "standards" of care into the form is the lack of consistency with national or professional standards of care. Each portion of the PCC+ form that indicates criteria, rating scales, or clinical guidelines needs to have been soundly researched prior to implementation, and would need to be reviewed regularly to make sure that it remains the standard of care.

Prevention Services/Monitoring Disease. The abbreviated health summary can be tailored to the significant health needs of the community or tailored to the form's health condition focus. Many of the items in the abbreviated health summary may be prevention services such as immunizations and screening tests that are due, and prior laboratory tests (dates and results). The abbreviated health summary may also include critical tests or services related to a diagnosis, such as results of A1C tests, or blood glucose screens for diabetes.

Integration of Preventive Services. A fourth advantage is the ability to integrate preventive services into a PCC+ form for acute and chronic care. Typically, when providers and facilities are overwhelmed with a high volume of acute and chronic diagnoses, the level of prevention is low, due to the pressure of immediate needs and time constraints. With prevention reminders related to diagnosis, age, and/or gender included in the PCC+ form, the provider and support staff are more likely to address deficiencies – either patient education regarding the need for such services (e.g., mammograms), delivering services during that visit (e.g., immunizations), or scheduling an appointment later in order to provide these services (e.g., annual well woman examination with Pap smear and breast exam).

Medication Prescriptions. The medication list section is of tremendous clinical value. Current medications, dosages and timing are pre-printed. Refills can be ordered with a check mark. Changes and additions can be written on the forms, to be updated within 24-48 hours with data entry. This preprinted medication list is a timesaver as well, and reduces errors.

Record Legibility. A related clinical benefit is the increased legibility of notes and marks on the PCC+. This feature is important for quality clinical care and for enhanced communication among health professionals, and thus is part of the QA process.

Form Adaptability. Since this PCC+ form represents the dynamic interaction of medical diagnosis and treatment, there will need to be planned reevaluation of the tool based on medical advances. The PCC+ form, as a result of its being a "merging" in MS Word, lends itself to modification without tremendous costs of time, energy, or money.

This adaptability feature is also useful when adjustments need to be made in coding sections. If there are code revisions, text and numbers can be changed or additions made. If a provider's frequently used diagnoses and procedures codes change, this section's text and numbers can be easily modified.

Patient Education. With the PCC+ form, patient education can be easily documented, including the length of time and the provider. If the PCC+ is condition-specific, such as for a well woman visit, the consensus of the clinical staff could be included as a checklist of required or recommended patient education topics to be addressed during that visit. Patient education materials designated to be used during annual female visits could be also listed. A check mark by a handout would document that the patient received that health care literature. Patient education across disciplines could be described on the same PCC+ form, so that nursing staff, providers, and pharmacists could coordinate efforts to maximize educational efforts.

Future Articles about PCC+

The second part of this series of articles on the PCC+ will appear in an upcoming issue of *The IHS Provider.* Part II will focus on using the data in PCC+ as part of ongoing QA/clinical feedback and improvement efforts. The metrics selected and the format for analysis and feedback can be highly relevant to clinical practice and can help a facility to conduct critical self-appraisals within a fast turnaround time. Parts III and IV will present more advanced concepts of return on investment (ROI), the value of investment (VOI) and ripple/change effects in a system as these concepts relate to PCC+ design and implementation.

Personal Digital Assistants: a Survey about Utilization

Scott Hamstra, MD, Whiteriver, Arizona; Chris Lamer, PharmD, CDE, Cherokee, North Carolina; and Carol Miller, BSN, MBA, McLean, Virginia; all with the Information Technology Support Center, Tucson, Arizona

Last month in *The Provider* ("Personal Digital Assitants in the Indian Health Service" Volume 27, Number 9, September 2002, pages 189-191), we reviewed a brief history of the development of personal digital assistants (PDAs) and some of the many differences among the PDAs that are currently available. This month, we will share the results of an initial survey distributed among Indian health care providers who were using PDAs throughout the course of their workday.

In June 2002, as part of a pilot test project, ITSC in Albuquerque provided approximately 57 PDAs to twelve different Area sites and providers. To participate in this pilot, each provider was requested to complete a four-page survey related to the PDA and their utilization of it. Fifty-four providers completed the survey. However, the providers who responded were not only from the pilot test sites, but also included providers who purchased their PDAs on their own during the past several years. In addition, not all sections of all surveys were completed, and multiple responses were sometimes checked in various sections when only one response was requested. The following is a summary of the survey results.

It is interesting to note that 59% of the providers favored having the patient and clinical care information available on both the PDA and the Internet, whereas only 23% preferred having this same information only on the PDA, and less than 10% liked having it only on the Internet. From these comments, one might conclude that the majority of providers still prefer having the Internet as a means of backup for the PDA.

Other very interesting findings were that most providers (82%) felt that the PDA was useful in clinical situations, while 80% felt the non-clinical applications were very useful.

General Comments from Survey Respondents

Several of the subjective responses from providers describing how PDAs can be useful in clinical situations included the following:

- Up-to-date information is indispensable
- Less guesswork
- Less time needed to review medications
- Less time away from patients to look up information
- Drug dosing calculations quicker
- More efficient and accurate patient care
- More confident in caring for patients

Several of the comments from providers related to the utility of PDAs in non-clinical situations included the following:

- Schedule was more organized and accurate
- Better patient tracking capabilities
- Ease of access to names, addresses and telephone num bers for referals

We collected a great deal of data from the 54 providers who responded to the survey. The following represent several of the interesting general statistics.

- The number of patients seen per week by the providers who responded to the survey was between 10 and 150+, a very wide range. On average the number of patients seen per week was 89.
- The number of prescriptions per week ranged from between 1 to 24 prescriptions (26%) to 75-150 prescriptions per week (20%); 20% wrote no prescriptions.
- There was a fairly even distribution in the types of applications used and commented on by those responding. Most providers using the Palm system used the m105, m125, or m505; for the Handspring applications, most providers used the Deluxe, Pro, and Prism.
- A wide variety of provider specialties were represented in the survey:
  - Cardiology (1)
  - Emergency Medicine (3)
  - Neurology (1)
  - Orthopedics (2)
  - Psychiatry (2)
  - General Surgery (3)
  - Family Practice (19)
  - Internal Medicine (5)
  - OB/GYN (2)
  - Pediatrics (9)
  - Radiology (1)
  - And other specialties
- 42% of the respondents using PDAs were in the age range of 40-49, whereas the second largest group was those age 50-59 years old group (28%).

- The majority of providers responding to the survey had been practicing over one year, with the greatest percent (39%) practicing 11-20 years.
- Most of the respondents were from rural IHS hospitals or clinics, with the next largest groups being from rural IHS health centers, and tribal hospitals or clinics.
- There was a wide distribution in usage of the PDA, from "multiple times per day" (34%), "now and then throughout the day" (29%), "constantly" (21%), to "sporadic access" for the remainder.

The following is a summary of the key sections of the survey results from the 54 respondents. A second follow-up survey is planned later this year to see just how completely people have incorporated the PDA into their lifestyle after they have had more time to gain experience and skills and explore more of the PDA functions.

PDA Applications

The following are the respondents' descriptions of the ways they use their devices, in descending order of frequency:

- Address book and contact information (18%)
- Calendar and appointments (16%)
- Drug information look-up and drug interaction (14%)
- Dosing calculations (12%)
- Formulary look-up (11%)
- Treatment algorithms (10%)
- Scattered responses such as e-prescribing, patient records, charge/procedure capture, patient and text references, and task list.

It is interesting to note the two most common uses of the PDA are the same as those claimed by the majority of lay individuals using PDAs across the United States. Most of our respondents were pleased with the PDA, and a good majority did not have problems learning how to use the applications. The primary problems were difficulty with set-up, Internet connectivity issues, technical support at their facility, and "too time consuming." Overall, the average time for data input was 1-2 minutes; delays occurred when using handwriting recognition such as "graffiti" or entering higher volumes of data.

Clinical Drug Applications for the PDA

The following is a summary of the usage of various drug applications for the PDA:

- ePocrates Rx (45%)
- ePocrates QID (22%)
- "Other" (12%)
- Other drug applications such as ePocrates Formulary, Sars formulary, Dr. Drug, etc.

Most of the providers responding used one of these applications more than twice a day (60%).

Clinical Non-drug Software Applications

Twenty-seven percent of respondents said they used no other clinical applications besides the drug applications. The most frequently used non-drug applications were the Five Minute Clinical Consultant (22%) and PregCalc (17%). There were scattered responses among ACLS protocol, mini-mental status exam, MedCalc, MedMath, Shots 2002, Heart Rate Calc, Five Minute Peds, and diets for various conditions.

Those who used clinical non-drug software used it either more than twice a day or a few times a week.

Non-clinical Software

Sixty-one percent of respondents did not use any non-clinical applications. Those who did used such applications as QuickSheet, Quicken, Spellman, various dictionaries, patient tracker, Word-To-Go and others. Those who used these described a variable rate of usage, from more than twice a day to a few times per week. It appeared that most of these providers either preferred their own computer system for non-clinical software such as word processing, spreadsheets, accounting packages, and others or were more interested in loading clinical reference material onto their PDA.

Positive and Negative Comments

The following table is a summary of the pros and cons of PDAs according to the respondents, in descending order of importance.

Positive Comments	Negative Comments
Availability and accessibility of data anywhere, improving clinical decision- making, and improving patient flow	Screen to small
Quicker access to drug information when writing a prescription	Battery life too short
Access to other data, such as addresses, telephone numbers, schedules	Awkward to use
Portability	Not enough storage capacity
	Transmission difficulties
	Too slow
	Quality and readability of screen
	Another item to carry
	Graffiti hard to enter
	Acceptance by facility and clinic
	Training on use and technical support
	Prior knowledge of software pro grams available over the Internet

Even though the list of negative comments is longer than the positive list, the frequency of positive comments was greater, and more importance was ascribed to them.

Future Wish List

There are several capabilities that the respondents would like to see added to the PDA. They are:

- Immediate download of lab results onto the PDA, especially for critically ill patients.
- Voice activated dictation and transcription.
- Wireless paging.
- Real-time connectivity with other providers, and with main and satellite clinics.
- Direct interface of patient clinical data and procedure and charge information into the electronic medical record.
- Telemedicine accessibility.
- e-Prescribing.

Summary

PDA technology is hugely popular in the USA, both inside and outside of medicine. There are innumerable medical software programs that are now available. However, even in the academic medical setting, there is not yet convincing evidence that the technology delivers the improved patient outcomes or improved patient care that it promises.

Despite this, most users in our pilot project quickly adapted to using this technology and would not consider giving it up without a protest. Instead, these "consumers" are demanding more (see the wish list above), although these are applications that the technology may or may not support in the near future. ePocrates is clearly the favorite tool both inside and outside of I/T/U settings, and one can hope that its use will lead to fewer medication errors.

At the initiation of our project, it was unclear how many of the providers had prior knowledge of the capabilities of the PDA or the number of or types of software applications that can be downloaded from the Internet. If this information had been readily available at the time the PDA was purchased or distributed by ITSC, perhaps a different usage pattern would have resulted. As time goes on and providers become more acustomed to using PDAs, it is our collective feeling that providers will increase their use of clinical and non-clinical software applications.

This certainly appears to be a technology that can offer significant benefits without a large initial investment. Providers have shown initial excitement and appear to be satisfied. It appears to be useful now, and by building on their early skills and experience, providers should be able to use PDAs for more advanced interactions within the next several years as the technology advances.

Hope and Truth Telling

The following article is the second in an ongoing series in support of the development of a unified approach to palliative care services for American Indians and Alaska Natives. Each will present brief, concise facts and information for providers of palliative care.

Judith A. Kitzes, MD, MPH, Soros Foundation, Project on Death In America Faculty Scholar, University of New Mexico Health Science Center, School of Medicine, Albuquerque, New Mexico

- ☐ *Hope is an expectation greater than zero of achieving a goal.*
- ☐ *Doctors generally underestimate what a patient already knows.*
- ☐ *The provider patient relationship is founded on trust and nurtured by honesty.*[1]

One of the most difficult things for physicians to do is to give bad news. Delivering bad news is a learned skill and art, and it always respects the cultural background of the recipient. Truth telling within the cultural context requires active listening, and responds to the lead of the individual patient and family. However, even when it is done well, providers are often afraid that by telling someone the truth about her or his diagnosis, they will take away hope. Are we that powerful?

Brody writes, "Hope means different things to different people, and different things to the same person as he or she moves through stages of illness."[2] Physicians play a valuable role in helping individual patients define their hopes and fears. Hope may mean a pain free day, a sense of security, love and nonabandonment, or a ceremony or event to attend in the near future. Factors that increase hope include feeling valued, meaningful relationships, reminiscence, appropriate light-heartedness or humor, realistic goals, and pain and symptom relief.

Strategies to begin a dialogue about hope and goals include the following:

1. Familiarize yourself with the skill and art of breaking bad news.[3]
2. Ask, "What does hope mean to you?"
3. Ask, "What are your hopes for the future?" and"Do you have specific concerns or fears?"
4. Give factual explanations of the disease process and realistic reassurances of pain and symptom management and nonabandonment.

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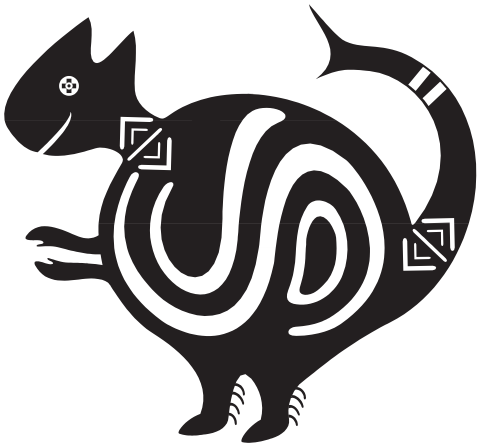


NCME VIDEOTAPES AVAILABLE

Health care professionals employed by Indian health programs may borrow videotapes produced by the Network for Continuing Medical Education (NCME) by contacting the IHS Clinical Support Center, Two Renaissance Square, Suite 780, 40 North Central Avenue, Phoenix, Arizona 85004.

These tapes offer Category 1 or Category 2 credit towards the AMA Physician's Recognition Award. These CME credits can be earned by viewing the tape(s) and submitting the appropriate documentation directly to the NCME.

To increase awareness of this service, new tapes are listed in The IHS Provider *on a regular basis.*

NCME #803

Rural medicine, Today and Tomorrow *(60 minutes)* As the landscape of America has changed over the past decades, so has the face of rural medicine. Today's rural medicine practitioner must overcome numerous cultural, demographic, logistical, and financial challenges to build a successful practice. Yet the rural environment also offers rewards, among them the opportunity to pursue a more diverse practice and to have closer relationships with patients and their families. Several initiatives, including Medicare/Medicaid programs, are under way that are designed to reduce the financial disparity between urban- and rural-based practices, and technologic advances are improving the physician's ability to deliver quality care. Dr. Stowers reviews the challenges facing rural practitioners today, and demonstrates how telemedicine is improving the physician's ability to deliver quality care. Dr. Stowers reviews the challenges facing rural practitioners today, demonstrates how telemedicine is improving patient access to care and physician access to specialists, and, with his colleagues, offers insights into the future of rural medicine.

NCME #804

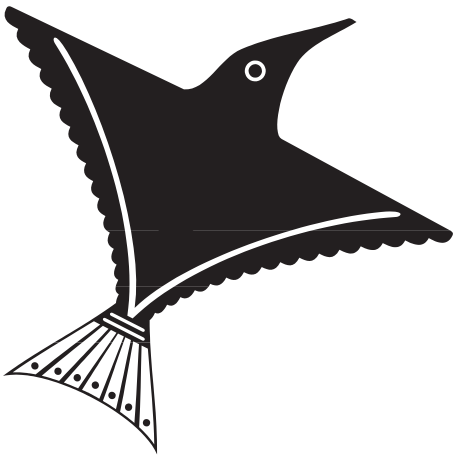
An Update in Neoplastic Diseases: Renal Cell Carcinoma, Testicular Cancer, and Tumors of the Central Nervous System *(50 minutes)* The primary care physician has important roles to play in the patient-oriented management of neoplastic diseases. He or she may be required to recognize any potential cancer – not only the ones that are most common or have the highest mortality – and will be called on to provide information, support, and medical follow-through to patients and their families. In this program, two leading experts share their experience and insight in the diagnosis and management of both highly curable and highly lethal cancers.

Resource Directory for Older People Offered by NIA and AoA

The new Resource Directory for Older People is a comprehensive listing of services and organizations compiled by the National Institute on Aging (NIA) and the Administration on Aging (AoA). The directory contains listings for more than 250 public and private organizations; each organization is briefly described, with mailing addresses, phone numbers, and Internet and e-mail addresses listed. State agencies on aging and ombudsman programs are listed in the appendices.

The directory is particularly useful to health and legal professionals, social service providers, librarians, researchers, and others with an interest in aging. It is also available online at the NIA and AoA websites at *www.nia.nih.gov/resource* and *www.aoa.gov/directory.*

A single copy is available free of charge by calling the NIA Information Center at (800) 222- 2225 or (800) 222-4225 (TTY). A nominal fee to cover shipping and handling will be charged for multiple copies as follows; 2 - 50 copies: $5 per copy; 51+ copies: $3 per copy.



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