Goals and Reality in the Compacting of the Cherokee Indian Hospital: Evaluating the Process of Change

By

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Abstract

Objective: (1) To describe and analyze the process of “compacting,” or moving control of health systems from the Indian Health Service to American Indian and Alaska Native (AIAN) tribes, and the stimuli that drove it; (2) To evaluate the obstacles and advantages to compacting; (3) To determine whether compacting has the capacity to contribute to improved quality of care and better health outcomes of AIAN people; (4) To illustrate these processes via a preliminary case study of the compacting of the Cherokee Indian Hospital of the Eastern Band of the Cherokee Indians, in Cherokee, North Carolina.

Design: Primary analysis of legislation and other primary source documents and in-depth interviews with key informants.

Source of Study Data: Public documents in the form of legislation, regulation, and administrative policies; key informant interviews of health policymakers in the Cherokee Indian Hospital conducted by the author.

Findings: Successful compacting requires an intricate, multistage process of preparation and high levels of assistance and cooperation. The goal of compacting is not accompanied by the level of resources necessary to make compacting a straightforward matter of transfer of federal funds to tribes. Successful compacting, at present, is probably only possible for wealthier tribes with independent revenue streams that can be diverted to tribal health system support, such as gaming revenues.

Conclusions: Tribal health care likely cannot escape the challenges of existing in a public-private hybrid that dominate the larger U.S. health care system, despite the clear federal treaty obligation to provide for AIAN health. Compact ing, as an important part of the larger trend to tribal self-governance, is the best strategy for improving the quality of care and health outcomes for AIANs, since tribes know their members’ needs best. Compacting in the absence of adequate resources, including money and administrative capacity, is likely doomed to failure. With such resources, however, compacting will improve the health and health care of AIANs.
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Overview: historical and political paths to compacting

I, a sickly child, had no difficulty obtaining the care I needed from the Cherokee Indian Hospital in Cherokee, North Carolina; contract health services, for example, referred me to a cardiologist when my EKG showed an abnormal heart rhythm. During most of my childhood, the hospital was owned and operated by the Indian Health Service (IHS). IHS offers health care to 1.4 million American Indians and Alaskan Natives (AIANs) from 500 federally recognized tribes in 35 states.¹ The Indian Health Service is an agency within the Department of Health and Human Services whose goal is to “assure that comprehensive, culturally acceptable, personal and public health services are available and accessible to American Indians and Alaskan Natives”.² Although I received good care from the IHS facility in Cherokee, IHS health services have usually suffered from inadequate funding, limited facilities, and workforce shortages. In addition, IHS’s top-down provision of services to AIANs perpetuates a state of affairs that, many argue, does not support tribal autonomy or facilitate tribes’ capacity to govern their own affairs; nor may it be the best way to promote quality of care and good health outcomes for AIANs.

Currently, tribes are taking more control of IHS programs and facilities. The Indian Self-Determination and Education Assistance Act (Public Law 93-638) of 1975 allows tribes to manage health programs of their choosing. The Act mandated that IHS provide the tribe with assets to support this transition. The
Act also gave tribes the power to overhaul health programs to combine services or contract with other providers. Many IHS facilities function as managed care components of a larger IHS system that includes more than 59,000 hospital admissions and 8 million ambulatory care visits each year. At present, as a result of the Self-Determination Act, over half of IHS facilities and programs are now administered by tribes.

Tribes and the federal government use the term “compacting” when a tribe assumes administrative responsibility for a facility previously managed by the IHS. Compacting enables a tribe to use IHS appropriations according to the needs of that individual community. Tribes can also use revenue from other sources (e.g. casinos) under compacting, something that had not been possible under the old style of IHS administration. One of this paper’s major findings is that a significant force pushing the IHS and the tribes toward compacting is chronic inadequate funding of IHS by Congress.

Other forces driving more tribes to compact include a desire for increased self-governance; decreased administrative costs for area headquarters’ offices and IHS, and therefore more budgeting allocations directly to tribes for various programs; and increased quality of care for tribes. Compacting also presents potential problems for data collection; the creation of a new public-private hybrid health system; and transparent reporting of performance measures. This paper examines the compacting of the Cherokee Indian Hospital by the Eastern Band of Cherokee Indians, which took place in 2003, within the broader context of how compacts will affect the future of the Indian Health Service.
The Eastern Band of Cherokee Indians

A brief history of the Removal, citizenship status, and land ownership of the Eastern Band of Cherokee Indians (EBCI) will provide evidence of the difficulties this tribe has endured in its relationship to the state and federal governments. This history makes clear the EBCI developed distrust of government and desired to become self-governing.

The EBCI is a tribe located on approximately 56,000 acres, known as the Qualla Boundary, in Western North Carolina.5 Approximately 13,400 people are members of the EBCI, and 60 percent of them reside on the reservation.6 The members have descended from the few who defied what is known as the “Removal” in 1838 and stayed in the Appalachian mountains that had always been their home.

The Removal is often referred to as the “Trail of Tears” because it forced several thousand tribal members to march to Oklahoma. The Removal was the result of a treaty that exchanged lands in the West for those in the East. The EBCI never agreed to this treaty, and even had support from whites who believed the treaty was ridiculous, but the government overruled the wishes of tribal members and leadership. Soldiers then forced the tribe at gunpoint to leave. Approximately one-quarter of the tribe died during the journey, mostly from disease. Those who walked the Trail of Tears established the Cherokee Nation in Tahlequah, Oklahoma. Those who remained behind, defying the treaty, became the Eastern Band of Cherokee Indians. The EBCI tribal government, inaugurated in 1870, consists of a Chief and Vice Chief, who each serve four-year terms, and twelve council members who serve two-year terms. The council members represent the reservation communities of Birdtown, Painttown, Wolftown, Yellow Hill, Big Cove, and Snowbird. Elections
are by popular vote. I am an enrolled member of this tribe, and grew up on the Qualla Boundary.

The citizenship status of the EBCI created many disputes about what relationship the federal government and states had with the tribe, and whether tribe members were citizens of the United States. The case of US v. D.L. Boyd in 1897 designated EBCI as being under “direct jurisdiction of the federal government” but the case did not resolve citizenship questions; nor did the federal government adequately define the citizenship status of tribal members. EBCI members were encouraged to serve in World War I in order to obtain citizenship, despite many Native Americans’ lack of interest in such foreign affairs.

The May 18, 1917 draft should not have applied to AIANs, since state and federal governments could not agree that they were citizens. This did not prevent many officials from telling tribal members that the draft applied to them. A large number of EBCI members served after seeing the many posters and flyers encouraging them to demonstrate their patriotism. EBCIs were relatively complacent about military service compared to other tribes, who rioted over the draft. EBCI men may have felt that they had to enroll in the draft because Cherokee citizenship in the U.S. was again under consideration at this time. After the conclusion of World War I, and after several more elections in which EBCI members were targeted by county politicians to exploit their voting power, Congress passed the Indian Citizenship Act on June 2, 1920.

Land ownership has been another enduring dispute in Cherokee history, and land ownership also affected the citizenship debate. Politicians and even
several tribal members wanted allotment, meaning the division of tribal land into parcels intended to individualize land ownership for AIANs, even though it had proven to be tragic for other tribes. The tribe also tried to complete a new roll of members, as a stipulation of an allotment bill of 1924 - a bill that caused total confusion. The allotment bill caused EBCI to be removed from county property tax lists; the fact that EBCI did not pay property taxes infuriated many officials of the county containing the Qualla Boundary, who attempted to tax members anyway. At the same time, officials in surrounding counties continued to obstruct EBCI’s voting rights, despite the Indian Citizenship Act. The unceasing dispute between the federal, state, and local governments over Native Americans’ rights can be considered evidence of governments’ paternalistic approach to the tribes. The citizenship and land ownership struggles make clear that the EBCI faced considerable challenges merely to be treated as citizens, much less as individuals capable of, and entitled to, self-governance, and the struggles form a backdrop for any analysis of the provision of health services to AIANs.

Health status of the EBCI

Historically, government physicians who have worked at the Cherokee Indian Hospital or who have visited periodically have documented the health status of the EBCI. This section presents a summary of the health status of the EBCI and the history of alternative healing therapies used by the tribe and ends with a brief discussion of the reservation’s first tribal hospital.

In 1914, untreated waste water from the Cherokee Boarding School ran straight into the Oconoluftee River. This situation may seem unsanitary, but this level of plumbing actually exceeded that of most homes in the area that
lacked even outhouses. The absence of a sewage treatment infrastructure in
the reservation's early years is illustrative of the sources of many tribal health
problems.\textsuperscript{5}

The EBCI, as do many tribes, has a strong history of alternative forms of
medicine. Several taboos associated with "white" medicine still existed in the
1920's, after the 1918 influenza pandemic had killed 21 million worldwide,
including many EBCI members. One belief was that physicians purposely gave
diseases to AIANs. Traditional medicine flourished amidst beliefs that magic
and conjuring were better to use for any illness. Most physicians commenting
on EBCI health in the early part of the twentieth century said that they didn't
see those AIANs who used traditional medicine unless it was unsuccessful,
suggesting that some EBCI were willing to try "white medicine", at least when
traditional methods failed or when death was the only other option. This
health care discord was built on the enduring conflict between AIANs and
whites, especially white professionals, who wanted "progress." The AIANs, in
contrast, wanted to preserve their traditions and be left alone by outsiders who
wanted to change traditional ways. Many of those outsiders wanted to
eliminate any practice by conjurers.\textsuperscript{5}

Beyond the borders of the Qualla Boundary, American medicine as a
whole was undergoing a dramatic consolidation, with physicians achieving
unprecedented levels of autonomy and control over admission to their ranks.
In the latter decades of the nineteenth century, the American Medical
Association (AMA) and other entities began virtually recreating medical
education, establishing something like uniform standards for the first time.
Entry to medical school, and the medical school curriculum, became more
consistent, leading to a more homogeneous group of physicians. Around 1900, the medical profession went to war with patent medicine makers to prevent them from being able to market their products. In 1905, the AMA created the Council on Pharmacy and Chemistry to have the authority to assess the effectiveness and safety of drugs. Physicians also felt very confident about their profession, after several advances in medicine had been made. The bacteria responsible for several deadly diseases had been isolated, vaccines for diphtheria and tetanus existed, and new diagnostic tools like the stethoscope enabled physicians to increase their ability to accurately diagnose disease.7

American allopathic medicine used this combination of strong new confidence in what it could accomplish and new authority to control admission to its ranks, to pressure other practitioners, or the “sectarian groups” who practiced what we would now call alternative forms of medicine that set them apart from the medical establishment.7 Conjurers and healers of the EBCI would have been considered “sectarians,” and it is not therefore surprising that visiting physicians wanted to put an end to their practices, particularly given the health problems these white physicians saw on the reservation.

The EBCI’s most common health problems in the first decade of the twentieth century included measles, tuberculosis, malnutrition, and “female problems.”5 By 1923, health improvements had already begun to come about. Walter S. Stevens, after conducting a medical inspection, found high prevalence only of hookworm, pellagra, and goiter, illnesses that are more treatable and have less severe sequelae than do the aforementioned diseases. A 24-bed government hospital staffed by one physician, one nurse, and an assistant had been operational in Cherokee for years. The physician, Dr.
Russell D. Holt, had gained the trust of the EBCI after working there for 26 years. The hospital admitted 251 patients in 1922-1923 and discharged 250. This remarkable apparent hospital mortality rate is somewhat was deceptive, since most EBCI members feeling close to death preferred to live out their final days at home rather than even go to the hospital, but this first hospital served some important EBCI needs.5

The federal government decided to close the Cherokee Hospital on June 30, 1954. The Chief at the time, Osley Bird Saunooke, persuaded officials to give him a one-year extension to try to find a “private sponsor-preferably a religious denomination,” but when the year was up the U.S. Public Health Service (PHS) assumed control of the hospital in what the PHS and the EBCI thought would be a temporary arrangement.5 From this time, the Indian Health Service became the most important factor affecting Native American health care for many years.

History of the Indian Health Service: the road to compacting
The Indian Health Service (IHS) offers health care to 1.4 million AIANs from 500 federally recognized tribes in 35 states.1 In order to understand how compacting developed, we must understand how the IHS has been the locus of interaction between the tribes and the US government for health care delivery. As more and more Europeans settlers claimed lands without regard for prior tribal territorial claims, and forced movements of Native Americans from their ancestral homes, the U.S. Government attempted some amelioration through the creation of treaties with the tribes, the enforcement of which the government delegated to the U.S. Army. The Army sometimes ignored the treaties and often changed tribal borders; nonetheless, the treaties
represented the first effort by the federal government to protect Native Americans. The treaties retained their legal validity even though they were not being upheld. The provision of health care was a part of the treaty agreements and the Army was also charged with delivering this care, an assignment it often neglected to complete. 8

The Bureau of Indian Affairs (BIA) was created as a government response to the Army’s inability or unwillingness to execute treaties but the BIA, like the Army, also failed to deliver adequate health services, and its health care responsibilities were transferred to the Public Health Service in 1954, which responded by creating the Indian Health Service in 1955. The Snyder Act of 1920 had legislated that Congress would provide a budget and occasional monetary support for AIANs, giving the new IHS a legislative foundation for appropriation of revenues to implement its responsibilities. 9 Initially, IHS funding was almost nonexistent; despite this, the US Public Health Service was nonetheless able to provide what was considered quality health care during the 1920's. 8 This good quality health care meant improving the health status of AIANs to the point that they achieved average lifespan and health status equal to that of white populations.

**Indian Health Service today**

Many people assume that the IHS is an entitlement program, similar to Medicare and Medicaid. This is not the case; health care delivered by the IHS is the fulfillment of a federal treaty obligation, and the budget for IHS is appropriated as a form of block grant, with Fiscal Year 2005 appropriations of three billion dollars. 2 This sum is not enough to meet obligations. The IHS perpetually suffers from inadequate funding, impairing its ability to realize its
mission. Its current per capita expenditure is $2,100, compared to an average per capita expenditure on health care of $5,298 for the U.S. population as a whole.\textsuperscript{10} The IHS is currently funded to meet only 60 percent of estimated need for services.\textsuperscript{11} Although IHS does not charge its users for services, it is considered a “residual” payer; that is, a user must exhaust all other sources of payment, including insurance, before IHS begins to cover health care costs.\textsuperscript{12} Approximately one in five AIANs is covered by Medicaid (17 percent), compared to 5 percent of whites who are Medicaid clients.\textsuperscript{13} Approximately half of AIANs have employee-based or private insurance, a number much lower than the 83 percent of whites who have such coverage. Unfortunately, one-third of AIANs have no insurance, leaving them virtually entirely dependent on meager IHS resources to cover most of the services they receive.\textsuperscript{13} Many IHS facilities function as managed care components of a larger IHS system that includes more than 59,000 hospital admissions and 8 million ambulatory care visits each year.\textsuperscript{2}

IHS coverage is capitated and, as a result, in the IHS system care is often postponed or overlooked. The IHS capitation for contracted services must cover everything from simple x-rays or diagnostic tests to specialist visits that are not available at the local clinic or hospital.\textsuperscript{14} Contract health services (CHS) are often difficult to acquire via IHS not just because of insufficient funding or geographic remoteness, but because patients must complete a long and wearisome process before becoming eligible for CHS. They are required to go through every other avenue of available assistance, including Medicaid and Medicare, before CHS coverage begins.\textsuperscript{11}
Despite inadequate resources, the IHS has accomplished a great deal in decreasing incidence of preventable diseases. AIANs have benefited from exceptional declines in infectious disease, infant mortality, homicide, and alcohol-related deaths. This progress has not eliminated disparities between AIANs and whites and other populations. In the EBCI, complications from diabetes are three to six times higher than for the white population of the United States. Stroke and heart disease death rates are 25 percent higher for North Carolina American Indians than for non-Hispanic whites. All of the IHS attempts to raise the health status of AIANs have not yet brought them to a par with the larger American population.

Tribes are making improvements since they have begun to compact, or administer their own health care programs, as a part of the larger drive known as “self-determination”. Health care administrators in specific tribes are using their knowledge of the culture to re-design programs and improve facilities. This micromanagement may produce better health outcomes than did one large organization administering programs for all IHS facilities. On the other hand, others believe that self-determination may cause tribes to plunge into a private health care market for which they do not have the resources to thrive, and because this move toward the private sector will inevitably result in the decline of Indian Health Service capacity on many reservations, a failure to thrive in the private market may leave tribes with no recourse.

Development of Native American self-governance

Self-governance legislation succeeded because of the tireless efforts of a few leaders in Congress and the IHS who refused to give up on the idea that tribes can better decide what is best for their people than can the federal
government. Passage of the legislation, however, has by no means ended the debate over whether tribes are truly prepared to handle the responsibility. During the development of the self-governance legislation, even tribal members were unsure of the strength of their appetite for self-governance.

Self-governance (also known as self-determination) for AIANs is a concept that has struggled to exist since federal responsibility for tribal services began. Before any settlers arrived in the United States, Native American tribes were self-governed; that is, all operated as autonomous political systems and were completely self-sufficient. These tribes had been sovereign; the introduction of new ways of life forced them to forfeit their traditions and customs, and were anathema to tribal self-governance. For example, the Dawes Act of 1887 insisted on assimilation, preventing AIANs from using their language, dress, or customs, and divided tribal land into pieces for each family. This approach to assimilation harmed the unity and connectivity of tribes, and health status plummeted and mortality rates rose, as a consequence.

Given the strength of the ideology of assimilation, the idea of self-governance did not re-emerge until the 1950’s, but by the 1970’s, it was encouraged to the point of being forced on tribes, particularly in the administration of their health programs. Regaining power and feeling more united as a community and tribe is desirable in many ways. However, many tribal members and policy-makers question what benefits this new government-to-government relationship will actually produce.

The IHS has had its own self-governance struggles. It survives only because of the combination of extremely hard work and political skills of key
directors, and with the aid of important allies in some presidential administrations. Joseph Jorgensen concludes from comments made by several congressional members that IHS was created by members of Congress who wanted to dismantle the Bureau of Indian Affairs (BIA) and demolish Indian Programs, ultimately denying AIANs any federal provisions. \(^{19}\) The biggest struggle for the IHS occurred during the 1950's, the era of assimilation, when the Eisenhower Administration endorsed the idea of “termination,” or terminating federal responsibility for AIANs and acculturating them to become typical American citizens. \(^{17}\)

Eisenhower and many members of Congress believed that termination was desirable for AIANs, and that the exchange of lands for the loss of federally recognized status was a worthy exchange - an improvement, and the route to becoming more “American.” At the same time, no one in government wanted responsibility for AIAN health- including the Department of Health, Education, and Welfare and the Public Health Service. After all, AIANs were the poorest, least educated, and most unhealthy population in the United States. \(^{17}\)

Native Americans were influenced by their experiences in World War II and after, and by the Civil Rights Movement, and began to press for more control over tribal matters. Many were tired of government decisions being made with no tribal input. \(^{5,16}\) At the same time, the IHS and the perpetuation of a federal obligation to AIANs survived, in part, because Emery Johnson became the new Director of IHS in 1969 and supported self-governance; President Nixon was also an avid supporter of AIAN rights. “We must make it clear that Indians can become independent of federal control without being cut off from federal concern and federal support,” he said. \(^{16}\) Dr. Johnson’s goal
was to place the power of administering health programs in the hands of the tribes. His first step in doing this was training and recruiting Community Health Representatives (CHR) on the reservations, who were chosen and supervised by the tribes themselves.  

Tribes were confused by the alternating status of their independence. Some had even supported termination during the Eisenhower Administration, because they believed anything was better than having the BIA make decisions for them, since the BIA had a long-standing record of inadequate health care administration. Others were vehemently opposed to termination, because it violated the promise of federal obligation in treaties that should never be forgotten. Whichever side they took on termination, most Native Americans had an intense distrust of the government and the IHS. The distrust is not surprising, given the most recent experiences under assimilationist policies. Now, people in the government wanted to give them power- an idea that was perplexing and seemed too good to be true. Many AIANs distrusted their own tribal governments to handle this kind of responsibility, believing politics and health care never mix well. Others assumed this new power was embedded in a plan designed for tribal failure.  

Dr. Johnson truly supported the self-governance of tribes, and with the help of his ties to key members of Congress, he was a driver of the passage of the Indian Health Care Improvement Act (PL 94-437) in 1976. The Act required tribes to determine their specific health care needs and design a comprehensive health plan; to the surprise of many, more than 90 percent of tribes completed plans. The Act’s purpose was raising the health care quality and status of Native Americans, but most importantly it was “to encourage the
maximum participation of Indians in the planning and management of those services.\textsuperscript{17} This was a small victory, as it only allowed Native Americans to take part in construction of facilities for safe water, waste disposal, and limited facility management.\textsuperscript{17}

A year before the Indian Health Care Improvement Act became law, the Indian Self-Determination and Education Assistance Act (Public Law 93-638) of 1975 established tribes' ability to manage health programs of their choosing. The act mandated IHS provision of assets to tribes to support this transition. The Act also gave tribes the power to overhaul health programs to combine services or contract with other providers. Over half of IHS facilities and programs are now administered by tribes as a result of these Acts.\textsuperscript{3} These two pieces of legislation, supporting health care improvement and endorsing self-determination, formed the present policy foundation for compacting.

**Compacting: giving substance to self-governance**

Compacts, or the assumption by tribes of the administration of their own health services, are the ultimate goal of self-governance. They allow tribes to be completely in control of their health systems and the funding associated with them. However, compacting also has potential problems, including the use of gambling revenues to supplement the cost of health care for a tribe, inadequate data collection and reporting, and the possible inability of tribes who are not wealthy to compact.

Compacts are similar to contracts, but allow more flexible use of IHS funds. The direct relationship between the federal government and tribal governments cuts administrative costs from intermediary IHS headquarters and
area offices. Compacting also allows tribes to tailor federal money to suit the specific needs of their tribes. Unlike IHS administration, which does not permit the use of outside revenues, compacts authorize tribes to take advantage of any monetary resources available.⁴

However, compacts have many extant and potential problems. One problem confronts those tribes who do not have other sources of monetary support to help them run programs. While many are excited about compacting and its preliminary results showing improving health care on reservations, others are sure this new relationship will cause the downfall of many tribes who do not have gambling revenues to enhance their programs.⁴ Everett Rhoades, the Director of the IHS from 1981 to 1993, believes “a great redistribution or rearrangement is happening, with a shift of resources to the compacted (wealthier) tribes”, and “...a possible ultimate outcome of self-determination and now self-governance will be termination”¹⁷ - to the detriment of tribes without their own unique revenue sources.

Self-governance and compacting are means to functional independence. Compacted tribes can decide for themselves the pressing issues for their tribes and apply the proper resources to resolve these issues. The separation of the tribes into many entities, however, also causes a loss of consistent, comparable data gathered from similarly administered health programs, and, as with other features of compacting, the effects of this loss of health status information will cause the poorest tribes to suffer the most. Self-governance may also help the federal government move closer to transferring IHS responsibilities to the states, via block grants, with the increased risk of termination in many states. Only time, and the improvement in leadership and skills in business, will
determine whether tribes can survive their own “market-based health economy” now thriving in other parts of the US health care system.

Compacting has fragmented the system of care for AIANs. If the government had provided the Indian Health Service with adequate funds from the beginning of its existence, the system of AIAN health care delivery context would be better and stronger, able to enjoy the benefits of centralization - and compacting of health care may not ever have gained momentum; the targets of self-governance may have been elsewhere. The federal government, however, has never made budgets adequate to meet AIAN health care needs. This has forced tribes to abandon some ties to IHS in an attempt to salvage health care for their communities. Though IHS provides support for tribes throughout their transition into compacts, the ultimate success of these new arrangements will depend on the business mentality of tribal leaders.

**Methods**

This research uses a variety of policy analysis techniques, often denoted "qualitative," to explore the likely consequences of compacting. In particular, I have searched the published literature, analyzed primary public and quasi-public source documents, including legislation, IHS documents, and tribal documents, and have conducted in-depth interviews of tribal policymakers. This section concludes with a summary of the legislation that surrounds self-governance and compacting.

**Searching the literature and locating primary documents**
I searched several databases including Cochrane, PubMed (MEDLINE), and Ebsco in addition to using the "Google" search engine to identify documents relevant to my topic. I used the search terms and combinations presented in Figure 1 below.

I eliminated most documents concentrating on specific tribes other than the Eastern Band of Cherokee Indians. These excluded articles covered a variety of the topics discussed here, but since my focus is on compacting with particular reference to my tribe, I did not feel that using several documents from different tribes in other geographical locations would provide generalizability to the EBCI, although such a comparative analysis of compacting in other tribes would certainly be a valuable future area for research. Such an analysis is beyond the scope of the present work but, in a few cases, I have included documents associated with other tribes' compacting when the documents provided insight into the development of self-governance, compacting, gaming, insurance coverage, or access to care. I also excluded documents that did not have legislative or regulatory authority, and documents that were created before 1995 in order to include only the most recent evidence on compacting and the state of the IHS. I attempted to gather information on as many perspectives as possible, and was also interested in obtaining an indication of the degree of public discussion surrounding compacting. To this end, I have included some editorials. Dr. Anne Bullock, Medical Director at Cherokee Indian Hospital, provided the remainder of primary documents I have used for this research. The documents she provided me were specific to the EBCI during the compacting planning and process. A friend provided me with the source on Cherokee history by John Finger.
Figure 1. Search terms for locating primary documents

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<thead>
<tr>
<th>Compacts AND Native American tribes</th>
<th>Gambling revenues AND compacts</th>
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<td>Indian Health Service</td>
<td>Native American access, quality of care</td>
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<td>Self-governance</td>
<td>Third-party payments AND tribes</td>
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<tr>
<td>Self-governance AND tribes</td>
<td>Medicare OR Medicaid OR SCHIP AND tribes</td>
</tr>
<tr>
<td>Indian gaming</td>
<td>Self-determination AND tribes</td>
</tr>
<tr>
<td>Gambling revenues AND tribes</td>
<td>Self-determination OR compacts OR gaming AND legislation</td>
</tr>
</tbody>
</table>

Conducting research with members of a sensitive population

My project involves research on a sensitive population. A sensitive population is a group who may have been exploited by researchers in the past, and for whom researchers must now take special considerations and steps to ensure the protection and integrity of the study population. The EBCI has a tribal Institutional Review Board (IRB) that must approve any research conducted on the reservation, or research using data from the reservation. After tribal IRB approval, the research proposal must go before tribal council. The researcher must be present to answer questions the council members have about the project, and how the information it produces will be used. Of key interest to all tribal parties involved is the assurance that the researcher will provide copies of final research products to the tribe. In the past, researchers
often failed to give the tribe information about research results after having collected data from the tribe. This failure, helped in part to spur the creation of the tribal IRB. The whole approval process may take up to three months, as tribal IRB and council meetings permit. The present research has passed through this process.

After I received IRB approval from UNC-Chapel Hill, I submitted my IRB application to the tribal IRB through Dr. Bullock. I received council approval upon my assurance that I would provide the council with a copy of my final document. I then conducted three open-ended in-depth interviews. I selected the three respondents based on their role in the compacting. I wanted to talk with employees who focused on different areas: community, clinical services, and overall administration. The three respondents representing those domains, respectively, were Jody Adams, Public Relations Officer of the Cherokee Indian Hospital Authority; Dr. Ann Bullock, Medical Director, Eastern Band of Cherokee Indians Health and Medical Division; and Casey Cooper, CEO of the Cherokee Indian Hospital Authority.

Scientific rigor in qualitative research

Throughout my data collection I adhered to the principles of qualitative research collection as described by King, Keohane, and Verba in “Designing Social Inquiry: Scientific inference in Qualitative Research”. One of the principles is to keep and recount the full data collection process. I have described my search terms and how I have gathered all forms of data in an attempt to fulfill this principle. Another principle is to use many different ways to gather data from several sources, or to gather “observable implications”.20
This gathering data from several sources is, in essence, the concept behind the theory of triangulating research. If data from several different sources converge, they validate one another and strengthen the synthesized findings to which they contribute. One should also take care to use valid and reliable data collection techniques. Figure 1 shows the breadth of the search terms I used to uncover primary documents. I used the same interview script for each in-depth interview respondent, following established principles of in-depth interviewing.\textsuperscript{21} The interview script is presented as an Appendix at the end of this paper.

Even with the most careful use of both methods -- analysis of primary documents and in-depth interviewing -- we cannot always be certain that we have avoided "omitted variable bias".\textsuperscript{20} It is possible that my interview questions, selection of respondents, or literature search omitted a key "control variable" that would affect any cause and effect association I attempted to make.\textsuperscript{20} By searching broadly rather than narrowly, however, I am less likely to have missed a key variable in the causal pathway.

The data collection process should also be replicable. I believe that this presentation of my research methods would enable another researcher to replicate my processes and collect the same data, from which he or she could draw the same, if not very similar, conclusions. Replicability, however, remains the most difficult of the qualitative research principles to assure, as many different and unexpected obstacles may prevent someone else from having access to the same materials I have used.\textsuperscript{20} Also, any other researcher would need to be able to interview the same people, which assumes that those people would always be available and would answer another researcher's
questions in ways substantially similar to their responses to the questions I asked. This is a stringent assumption. Nonetheless, if my conclusions are valid, and if I have presented my methods clearly enough, a replication of the research should produce findings similar to those I have drawn. In fact, I welcome additional research on this topic.

On the following page, Figure 2 presents a summary of critical legislative and regulatory developments that set the path on which tribes and the IHS walked toward compacting. In the sections to follow, I present an analysis of compacting in the EBCI.
Figure 2. Chronology of legislation and development of self-governance

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>1824</td>
<td>Bureau of Indian Affairs created and located in War Dept.</td>
</tr>
<tr>
<td>1887</td>
<td>Dawes Act forced assimilation of AIANs</td>
</tr>
<tr>
<td>1920</td>
<td>Indian Citizenship Act declares AIANs to be citizens of the United States</td>
</tr>
<tr>
<td>1920</td>
<td>Snyder Act appropriates a budget for AIAN health care.</td>
</tr>
<tr>
<td>1920</td>
<td>BIA transferred to Dept of the Interior and charged with responsibility for Native health</td>
</tr>
<tr>
<td>1949</td>
<td>Public Health Service assumes responsibility for AIAN health care from the BIA</td>
</tr>
<tr>
<td>1954</td>
<td>Indian Health Service created</td>
</tr>
<tr>
<td>1975</td>
<td>Indian Self-Determination and Education Assistance Act (ISDEAA), Public Law (PL) 93-638 allows tribes to manage their own health programs</td>
</tr>
<tr>
<td>1976</td>
<td>Indian Health Care Improvement Act, PL 94-437 mandates that tribes should determine their own needs and encourages maximum participation in the management of health care</td>
</tr>
<tr>
<td>1994</td>
<td>Permanent Self-Governance Legislation, PL 103-413 established permanence of self-governance in tribes</td>
</tr>
<tr>
<td>2000</td>
<td>Tribal Self-Governance Amendments of 2000, PL: laid out the specific tasks and responsibilities of IHS and tribes in carrying out self-governance</td>
</tr>
</tbody>
</table>

SOURCES: 3, 9, 22, 23
The decision to compact

The following four sections describe and analyze the process of compacting specifically for the EBCI. This first section describes why compacting was seen by the tribe to be the best option to improve the health care system and outlines the steps the tribe took to make this decision.

The EBCI experienced budgetary shortfalls that had left the tribe on the point of making drastic cuts in health services; in the circumstances, they had been searching for any alternatives that would change or delay that outcome. Compacting was an option that, at a glance, seemed to be favorable. The tribe had a casino and other gaming revenue that could provide additional funding, and the ability to use tribal shares and provide care specific to EBCI needs were very appealing aspects of compacting. Also, as mentioned by Casey Cooper, the tribe had been exercising their 638 rights (638 referring to the ISDEAA legislation) in the form of a Title I contract and already managed many services such as housekeeping and the Community Health Representatives program. He estimates they were managing approximately $3 million of the services, and had done so for years. Therefore, self-determination was not a completely new concept to the tribe.

Aside from financial issues, several other factors accelerated the tribe’s perception that it needed a new system of health services delivery. Patient satisfaction had declined, staff turnover had increased, better technology was needed, and the very health status of the tribe was changing. In particular, increases in the incidence of chronic disease clearly required a change in the scope of care delivered and resources used to improve chronic disease management and strengthen preventive care.
Determining feasibility

The tribe then had to determine whether compacting would be feasible in terms of finances, staff, resources, and community and council support. They also had to examine what the relevant legislation permits and requires for a tribe to compact.

The governing legislation mandates permits a tribe to compact if it meets three criteria:

- The tribe must demonstrate financial stability over three consecutive years. That is, they cannot have a history of any uncorrected significant and material audit exceptions in the required annual audit of contracts or funding agreements.
- A tribe must also have completed the planning phase as stated in §137, which requires budgetary and legal research, as well as internal tribal government planning and organizational preparation relating to administration of programs.
- Finally, the tribe must have passed a resolution to compact, and the council and Chief must agree to the resolution.

The EBCI first created a core committee charged with determining the feasibility of a compact. They had to examine the current system and decide if adequate systems were in place to make the transition to a tribally run facility. The tribe would be responsible for payroll and would acquire a mountain of financial responsibility it had never had before.
One of the most difficult tasks was to create five-year forecasts with and without compacting as a measure of whether compacting was economically desirable. The committee determined that compacting would postpone the drastic financial shortfall from 2003 to 2007. One of the ways this financial boost would take place is through using tribal shares. Indian Health Service has an extensive book that describes the programs, services, functions, and activities (PSFAs) the organization provides and oversees for tribes. Each of these PSFAs has a dollar amount or “share” attached to it. Though some of the PSFAs are inherently Federal and cannot have their shares used for other programs, several of the PSFA shares can be controlled by tribes for programs of their own choosing. Many of these shares had resided at the headquarters level and, upon compacting, would be transferred to the tribe for local services.

Doing research on the available shares as well as the legislation and rights under compacting was an extensive process, Casey Cooper explained in his interview. The legislation on self-governance is fairly specific on the question of what information about IHS and PSFAs is available for tribes to use in this research.

Even more beneficial than the general mandate in the legislation is its requirement that the IHS as an agency must support self-governance and all tribes who wish to participate in it. Ironically, the agency must support a concept and actions the effect of which will be to take money away from the agency at the national headquarters level. The law requires the IHS to encourage self-governance and assist the tribes in gaining self-governing skills in a process that will diminish or eliminate the need for many IHS jobs. All
respondents noted the awkwardness of this situation. Jody Adams remarked about the suspicions present among Cherokee representatives who met with IHS employees. She said "sometimes we left thinking that it was just, 'that's what they are supposed to say to us'." However, she also said that they (IHS employees) were helpful and offered to assist as much as possible.

Casey Cooper also mentioned that, in particular, the Nashville area office is extremely helpful: "The agency lead negotiator is one of the best advocates in the nation," he said. This is extremely important, as "there are other areas in the nation where there is still a lot of agency resistance to self-governance and it makes it very difficult for those tribes, and very contentious." Mr. Cooper emphasized how crucial it is to have someone who really comprehends self-governance and supports its implementation.

Certainly, bureaucratic obstructionism has slowed or halted the implementation of other policies, and such would be the case with compacting if all IHS employees resisted the policy change.

Apart from the question of IHS resistance to implementation of self-governance is the question of the funds available to help tribes prepare to compact. Each year a specific amount is available to as many as 50 tribes who decide to compact. When large tribes choose to compact, their budgets consume a considerable share of the funds, limiting the number of smaller tribes who can begin the process. The EBCI is a large tribe, but it is smaller than are some others, meaning that it might come out quite well or quite poorly in the compacting budget exercise. As Dr. Bullock noted, the Navajo tribe was considering a compact at the same time that the EBCI had begun to consider compacting. The 2000 census reported 298,215 Navajos in the US,
with 173,987 of those members living on the reservation. If the Navajos, with a population about 20 times that of the EBCI, had compacted at the same time as did the EBCI, the money available to assist the EBCI would have been proportionately much smaller than what they did in fact receive. Section 1000.52 of the Federal code regulations for self-governance states that tribes are awarded advanced planning grants based on need, completeness of the grant application, and the percentage of tribal resources comprising the total resources covered by the last audit. Section 1000.47 states that these grants are not competitive but, if there are insufficient funds, then priority is first given to those tribes that have been selected from an applicant pool to negotiate a Funding Agreement. So, an element of chance and timing also affects a tribe’s successful initiation of the compacting process.

Community support

The EBCI conducted all of the budgetary and legal research required to compact. After determining that compacting the hospital would be the best option to improve quality of care and deal with the budgetary shortfall, they also wanted to make sure they had community support. Those involved with researching the compact addressed both the community and hospital employee concerns. All three of my interview respondents named community and employee resistance as one of the most important challenges in the compacting process.

To get the community’s perspective, Jody Adams and others conducted several community group meetings in churches and other locales to educate the community about compacting. They asked tribal members what they knew about compacting and what their concerns were, and then informed them of
what the predictions were for the future of the hospital with and without compacting. Casey Cooper said that they also held a "...series of town hall meetings, if you will, where we had televised meetings in the council chambers and hired a completely independent moderator to put forth questions that were coming from the community and then answer them the best that we could."

Why was the community concerned? A perceived majority felt that there was not anything in particular wrong with the existing system of health care delivery and therefore wondered why the tribe wanted control of the hospital. The biggest concern emerging from the meetings was that a political body would be responsible for the functionality of the hospital. Many community members did not know what a compact was, and explaining these concepts in the appropriate manner was very delicate. Casey Cooper said that if compacting is "...oversimplified it stimulates a lot of unnecessary fears and concerns in people." Community members also feared that compacting would diminish the responsibility of the federal government for their health care. Casey Cooper also stressed that "it was really difficult to get the community to understand that self-governance doesn't relieve the government and it doesn't eliminate their accountability to those treaty obligations, it just provides it in a different method. Rather than providing that accountability or paying those treaty debts through service, they're paying it monetarily through financial resources, and then the management is up to the local tribe." He called the meetings a very open forum of information flow: "there was nothing held back, there was nothing hidden, it was really important to just roll it out when it was available."
Employee unease had a different source. They felt their jobs were on the line, and felt that they had much more of a vested interest in what happened to the hospital and to their positions. The tribe hired an independent facilitator to conduct focus groups with the employees. Their anonymity was protected in these meetings, and all responses were recorded and collected into a large document distributed to all who were responsible for planning the compact. As Casey Cooper noted, this document helped “...so that we could just address [employee concerns] and so they could be assured that their concerns were affirmed, that leadership heard them, and then there were a lot of conditions applied to the self-governance process to help resolve some of their fears.” He gives as an example “the federal employees said they feared an unfair personnel system, one that wouldn’t provide the same level of rights they had, rights to due process, rights to appeals. They feared that they would lose credit for their services or that their retirement would be in jeopardy.” The compacting committee then prepared a “whole list of recommendations that were endorsed by tribal council to help address each of those fears.”

The employee focus groups transcript shows that, indeed, the main concerns were political influence and job security. Dr. Bullock understood this concern completely. She was recruited in 2000 to be the medical director of the Health and Medical Division of the Eastern Band of Cherokee Indians. She had many years of Federal service under her belt. She wanted to remain a “Fed”, as she puts it, throughout the compact. Casey Cooper granted her wish and created an Intergovernmental Personnel Agreement (IPA) for her. The IPA allows the employee to work at a non-Federal government institution but
retain all of his/her benefits, as the government pays the hospital for that employee’s salary/benefits. She describes her desire to stay a Federal employee as “...you get enough years toward a pension, and a lot of sick hours built up, and you want to keep them.” The breadth of federal employees’ concerns about their federal employment credit and their concern about becoming tribal employees led the compacting committee to structure a choice: employees could stay in federal employ, enter into a hybrid arrangement via devices like the IPA, or become a tribal employee. For those with years of Federal service, there is clearly a benefit to staying Federal, as described by Dr. Bullock. For others, the excellent benefits package offered to tribal employees may be more attractive. The goal of the compacting is to increase the number of tribal employees over the years, and that is occurring. This goal exists because a compacted tribe is trying to cut ties to the Federal government; having more tribal employees supports this transition.

The EBCI had resources at hand; the histories of compacts in other tribes enabled the EBCI to see how these personnel questions had been resolved elsewhere. The EBCI obtained statistics from these tribes on percentages of employees who decided to stay Federal or switch, and the attrition they experienced up to five years after compacting. This information also helped the EBCI to reassure employees that indeed this system had been accomplished in other places.

By the time the issue of compacting went before council, everyone was well-informed. Council members had been invited to serve on the compacting exploration committees, and were well aware of or had participated in community meetings. The exploration core committee had thoroughly
conducted research on all areas of the compact including PSFA shares, core competency of hospital employees, financial forecasts, and employee and community concerns (as well as how to address them). When resolution 739 passed, the process of compacting could begin.

Planning phase

The planning phase of the compact consisted of demonstrating eligibility, showing the tribal resolution, and completing the planning requirements. The planning report, according to section 1000.20 of the Code of Federal Regulations for self-governance, must describe each of the following:

- The programs the tribe wants to negotiate to include in the compact;
- Planning activities for the programs;
- Benefits derived from planning activities;
- Processes the tribe will use to resolve complaints by service recipients;
- Organizational planning the tribe has completed in anticipation of implementing tribal self-governance;
- Indications of whether the tribe’s planning efforts have revealed that its current organization is adequate to assume programs under tribal self-governance.

Several hospital committees from various departments met on a regular basis to plan how the compact would take place. Casey Cooper became the lead negotiator for the EBCI in negotiating what shares the tribe would control. The ultimate goal in everyone’s planning was to design a system of implementation that would cause no break in clinical services. Essentially, if the goal were reached, the patients would see no immediate difference in
health care delivery on the first day of compacting. Each department
determined its short- and long-term needs to help determine financial
estimates for compacting. More definitive policies and procedures were
formed to govern performance and evaluation measures as well as job
descriptions. Jody Adams and others continued to educate both the community
and hospital employees about the compacting process.

Negotiation

The negotiation phase consisted of developing the proposed compact,
itemizing the shares the tribe would control, and negotiating with the IHS (and
BIA) to finalize a Compact and Funding Agreement.

The annual funding agreement (AFA) as defined by § 100.81 of the
governing CFR is a “legally binding and mutually enforceable written
agreement negotiated and entered into annually between a self-governance
tribe/consortium and BIA”.

The AFA specifies the funding that will be retained by BIA for Federal programs, those shares that could not be used by tribes; the funding that will be transferred to tribes; and the funding to be retained by the BIA because the tribe is leaving such funding to BIA administration. Residual funds are those necessary to carry out functions only BIA employees could do given that all tribes assumed responsibilities for all BIA programs the Act opens to tribal assumption.

The two phases of AFA negotiation are the information phase and the
negotiation phase. The tribe is not required to go through the information
phase; should it do so, the tribe would have to submit a letter of interest that
demonstrates interest in negotiating a program to be included in the AFA. The
letter must also describe several other aspects of the program including a
description of the program's cultural or geographical significance to the tribe, requests for available program funds, and the technical assistance to be provided by the Bureau. The actual negotiation process involves a discussion of tribal legal or program concerns and the options for program amounts.25

The most difficult part of negotiation for Casey Cooper was determining contract support costs. These are the "administrative or the indirect costs associated with management." Each tribe must try to estimate how much money it will need to cover those contract support costs. If the tribe negotiates an amount that turns out to be below what it needs, the tribe will not have enough administrative support, or it will have to cut direct care services to make up the administrative shortfall. Each year Mr. Cooper participates in the revision of the AFA, and reviews the "services we will provide, the services that we will buy back from them, and the cost associated with each of those." Negotiators also discuss the funding associated with different services no matter whether the tribe provides them or they remain a government provision.

One of the main services the EBCI decided to buy back was use of the Resource Patient Management System (RPMS), an extensive data collection system that integrates clinical and administrative data. Several parts of the system are based on the Department of Veteran Affairs (VA) VistA software.35 The RPMS contains over 50 integrated software applications, and allows the Cherokee Indian Hospital data to be accessed on a national level by IHS. It is an expensive data system, and is often not affordable to the smaller tribes that compact. As Casey Cooper noted, having the RPMS would not be a high priority for tribes with workforce constraints. If, he said, a tribe has "... access to a
family practice doc two days a week and you’re trying to get all your enrolled members who need visits seen in the two days that he’s available, the last thing on your mind is all that intensive data collection.”

**Implementing the compact**

Implementation refers to the actual transition from IHS administration to tribal control of the hospital. The implementation of the compact went smoothly for the EBCI in September of 2003. Respondents attribute this smooth transition to the excellent preparation and organization of all parties involved. Casey Cooper said “as far as the clinical side and the patient care, I think it went very smooth.” The difficulties in implementation were in the functionality of the accounting and finance divisions, departments that had been virtually non-existent before, and had to be built almost from the ground up. Administrative and support services “had to be developed and had to evolve, and as they were evolving there were obvious limitations on the system.” The clinical services transition was flawless, Cooper said, because “there were good systems in place and it was not vulnerable really to the attrition or to the change in management because the systems were so formalized.”

All three respondents feel that compacting has greatly benefited the EBCI. Compacting postponed a drastic budgetary shortfall and freed shares to be used to administer programs the tribe needs. The employees can now feel more of a sense of ownership of the hospital. Jody Adams noted that before compacting the IHS “…just gave you that pocket of money and they …dictated the services we would provide, they dictated if we could paint a room, if we
could remodel...the money came from them, it was really that paternalistic type of management...”. She emphasized that now “...we ask the community what they want and then we try to implement that.” Dr. Bullock supported the self-governance: “…I believe Indian people can and should, when the infrastructure...is there, when the local expertise is there, when the pieces are in place to do it, tribes should do it.”

Respondents also noted the financial benefits of compacting. Tribes can use supplemental revenue sources under a compact, and can therefore get additional funding from gaming revenue, foundations, and donations. Dr. Bullock noted the hospital’s ability to acquire a CT scanner and the flexibility in how to allocate funding. Because she is deeply involved in diabetes programs at a national level, she advocates for the cutting-edge diabetes program in Cherokee, including a complete complementary medicine program with acupuncture, massage, and yoga. A meditation garden is under construction now.

Though large financial issues loom in the future, the funding that comes from smaller grants, donations, and other sources of revenue is being used for several changes to the hospital. Jody Adams emphasized the need to assure that the hospital has as many culturally appropriate features as possible. She said “I want people to know when they walk in the door, when they drive up the driveway, that it’s a Cherokee Indian Hospital, not just another hospital.”

Current challenges for compacting

Compacting creates several concerns about data collection, reporting requirements, the ability of tribes to function in the private sector, and the use of supplemental revenue from gaming.
Extensive data collection by compacting tribes can demonstrate the degree to which the health system has or has not improved under tribal administration, and data collection can provide continuing information useful to those seeking ways to close gaps in health care and access between AIANs and other groups in society. One question, however, is whether thorough data collection requirements interfere with tribal sovereignty. Reporting these data is obviously helpful, but to what system of reporting should tribes adhere? Compacting tribes are responsible for administering their contract care services and negotiating with outside providers, an entry into the private health services sector tribes have not taken before. Will tribes unfamiliar with the private sector have the resources and skills to negotiate with outside parties?

Because of the overall structure of the Indian Health Service, tribes are increasingly relying on third-party sources of funding. Also, compacting tribes must be able to negotiate and contract for services with outside providers. The structure of these health systems is now that of a public-private hybrid, and whether this structure will be more beneficial than was the old system is uncertain.

Tribes can use gaming revenues to support the cost of their compacted health care systems. The EBCI has both a casino and a bingo hall that provide revenue for everything from the police department and language retention programs to individual tribal members' income. From the time the casino doors opened, people have debated whether gaming is a stable or ethically appropriate use of funding for a hospital. Employees of the Cherokee Hospital were concerned that should the casino close, their hospital would also have to close.28 Many are concerned that gaming revenues gained as a result of the
gambling addictions and loss of income from others are not without ethical questions as a funding source for a hospital system.

The next sections explore these challenges in more detail.

Data collection and reporting requirements

Sovereignty questions surrounding data collection emerge from the Indian Self-Determination and Education Assistance Act (ISDEAA) of 1975 (PL 93-638) and its provision allowing tribes to compact with the Government at the same time that it prevents the Indian Health Service from forcing tribes to conduct outcomes or performance measurement. Any reporting, then, is required only as a result of what is negotiated in the compacting process after the tribe has proven economic feasibility and assumed administration of a program.

According to §137.200 of the Amendments of 2000 to the ISDEAA, each compact must have a stipulation that obligates a tribe to report some measure of health status and services delivered. However, it is stated clearly that these bare data requirements are intended to impose a light burden on tribes, and are in no way intended to be used for quality assessment or monitoring. Tribes can include their own standards and requirements for data reporting as they see fit. This section also states that tribes are never required to report any confidential information regarding employee salary or identifying patient information. Examples of data reported may include sets of existing information such as demographics or workload. Tribes and IHS must agree upon reporting requirements no less than 60 days prior to the initiation of compacting negotiation.
The Secretary of DHHS is required to submit a report of the level of need being funded, or a lack thereof, for each tribe with compacts. However, the Secretary is not allowed to "impose any reporting requirements on participating Indian tribes or tribal organizations to complete these reports...". This report, due no later than January 1st of each year, consists mainly of cost-benefit analysis. The report is intended to describe level of need and funding according only to budgetary requirements. No mandatory report is submitted to the Committee on Indian Affairs of the Senate or the Committee on Resources of the House of Representative to detail health outcomes or performance.

Tribes are encouraged to take part in the reporting system used by the Department of Health and Human Services. This system is set forth by the Government Performance and Results Act (GPRA) of 1993, and GPRA requires that IHS uses these standards in its own reporting. GPRA requires submission of an annual performance plan, report, and a strategic plan that lists goals and how they will be achieved by the program over the next five years. The annual performance plan enables the organization to form both an appropriate set of performance indicators and the associated funding needed meet those goals. However, the issue of designating these goals is tightly bound to political influence and is associated with the amount of funding Congress appropriates. Proposing to meet an unrealistic set of performance indicators may cause a program to lose funding. Presenting goals of reaching very minimal indicators could cause Congress to decrease funding. Therefore, the GPRA standards are not necessarily that easy to adopt. IHS has implemented these standards
because GPRA places “the same planning and evaluation processes that good public health programs have used for years”.  

For an organized federal bureaucracy like the IHS, using GPRA standards is fairly convenient. The centralized data collection system allows IHS to meet GPRA standards regularly. Tribes would have a great deal more difficulty collecting these data in these ways. Tribes are not required to provide GPRA data, but several do so as a way of demonstrating their willingness to be accountable for what the tribe has done. Of Tribally Operated Health Programs (TOHPs), or programs operating under compacts, 68 percent report GPRA standards (the three criteria described in addition to seventeen performance indicators), which represents 85 percent of the total population of TOHP patients. Many tribal leaders have used the system to educate themselves about how funding operates on a public health scale. The Cherokee Indian Hospital Authority adheres to GPRA standards, and it may be easier for them to do this because they retained the RPMS computer data collection system discussed on p.27 above.

The federal bureaucracy believes that GPRA is the best way for tribes to report performance and, thus, the Tribal Self-Governance Amendments of 2000 include a stipulation that IHS will provide any support needed for a tribe to adopt data collecting procedures to report these performance measurements. These resources include software, hardware, technical assistance, training, and costs of reporting. As I have noted, legislative mandates prevent extensive required reporting, in order to avoid violating tribal sovereignty, but consistent data collection and reporting do have potential quality, effectiveness, and economic benefits for tribal health programs. IHS encouragement and support
of tribal use of GPRA procedures is a way of helping tribes who wish to report do so.

Requiring a program to be accredited through either the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) or the Accreditation Association of Ambulatory Health Care, Inc. (AAAHC) is another means of ensuring that a compacted tribe is meeting performance indicators. Requiring accreditation must be agreed upon in the negotiation of the compact between the tribe and the Federal Government. At this point, 54 percent of TOHPs are accredited; this percentage represents 77 percent of total health program users. There are no data on what percentage of these accredited programs also provide GPRA data but, increasingly, public and private entities are trying to harmonize quality and outcomes data collection, and this is likely to be the case with tribal reporting as well over time. Of note, there is no penalty for failing to become accredited. Despite the requirement for accreditation in some compacts, PL 93-638 prohibits any recourse being taken against tribes that do not meet negotiated performance measures unless there is “imminent endangerment of the public health caused by an act or omission of the Indian tribe...” or “gross mismanagement with respect to funds transferred to a tribe by a compact...” (Section 507 25 USC 458aaa-6). The Cherokee Indian Hospital Authority most recently achieved their JCAHO accreditation in 2006.

Tribes have several options for reporting performance measures. This decentralization of data collection makes it difficult to compare program information, or draw an overall evaluation, from different compacted tribes. Program evaluation would benefit from agreement by the compacting tribes to
use a single reporting system, accompanied by the resources to do it. For example, the IHS could choose accreditation to be the means through which all tribes would report performance data. With one preferred system available, fewer tribes would face reporting confusion, and more could go through the accreditation process with the assistance of IHS. Or, perhaps IHS should encourage all compacting tribes to become accredited AND comply with GPRA standards. This option seems less feasible given the budget shortfalls IHS already experiences.

The goals of the compacted programs are to provide comprehensive and culturally competent care that is accessible to the population. Determining whether goals are met inherently involves performance measurement of some kind. Tribal leaders, during the negotiation phases, may not get enough assistance and education about what reporting requirements to institute in their compacts. How is reporting the data helping those tribes who do submit to GPRA standards? In a report evaluating the effectiveness of TOHPs, tribes wanted the IHS to do more with the data, suggesting that resistance to reporting comes, at least in part, from a belief that nothing will be done with the data. Although IHS conducts conference calls with tribes to discuss results of data analysis and develop competitive grants, tribes only receive this support if they ask for it.\(^{36}\) We have no data on the typical response time for IHS to contact a tribe who has asked for assistance. However, Jody Adams did mention that “sometimes it was hard to get the help, but the offer was there and I think that was always helpful.” Tribes should be informed of the purpose of data collection and involved in the results and uses of reporting. Tribes should also be fully aware of the ramifications of reporting, i.e., that
they will not be penalized for any results of performance measurements, but that the results can be used by the tribe in many ways.

IHS has a goal of collecting reporting data on 90 percent of the population served by TOHPs by 2008. The general evidence from those tribes who report extensive data show that TOHPs are better at providing a wider range of services suited to a tribe's specific needs than was the old system.\textsuperscript{36} The collection of data on access, patient satisfaction, and quality of care is essential to demonstrating the effectiveness of a program. Unfortunately, none of the reporting systems address the collection of patient satisfaction data in a way that addresses the cultural needs specific to tribal populations.

Tribal sovereignty represents the rights of tribes to have the power to make decisions regarding the health and safety of their citizens. Tribes should be able to govern themselves and preserve their cultures through organized bodies of persons who ensure a protected reservation on which to exercise this self-determination.\textsuperscript{38} We do not as yet know why remaining compacted tribes do not attempt to be accredited or use GPRA measures; we do not know the degree to which tribal leaders feel reporting requirements violate their sovereignty. Since some tribes have very minimal reporting requirements, and all tribes negotiate what reporting they will participate in, it is unlikely they feel that their sovereignty is in jeopardy from more thorough reporting, but IHS will need to use resources to determine why all tribes do not participate in rigorous performance measurement. Once tribes are educated on the benefits of data collection and reporting, they will better understand why both are necessary and can be done without violating sovereignty. With the greatest
understanding of and desire for reporting, however, tribes without the
resources to measure performance cannot do it.

The public-private hybrid

The budget for IHS continues to fall short of providing adequate care for
all AIANs. As a result of inadequate funding, facilities and programs must
accept more payments from third-party sources. Also, tribes are increasingly
depending on Medicaid, State Children’s Health Insurance Plan (SCHIP), and
various forms of private insurance. The combination of inadequate funding,
more third-party payments, and higher insurance use has culminated in a
transition of IHS from a purely public program to a public-private hybrid
(indeed, more closely mirroring the larger American health care system).

Another reason for this shift is increased demand for a broader range of IHS
services. Especially with many tribes contracting or compacting to administer
their own health programs, Indian Health Service is playing a smaller role each
year in the overall assistance to these programs. Several changes in the
current health system need to be made to accommodate these shifts within IHS.

One of the simplest and most effective ways to ensure health care coverage of
AIANs is through changes to Medicaid and SCHIP.

The current state of insurance coverage. Unfortunately, though IHS
does increase access to care for those AIANs who are in close proximity to an
IHS facility, just under half of low-income, uninsured AIANs have access to
these facilities. These low-income persons also have lower rates of private
coverage. AIANs in general have lower rates of employer coverage and higher
rates of public coverage than is true of the population as a whole. The overall
The uninsured rate for AIANs is 35 percent, three times the 12 percent rate for whites. In absolute numbers, AIANs are a small percentage of Medicaid recipients; they make up 0.9 percent of all Medicaid recipients, and their services account for only 0.6 percent of Medicaid expenditures. But proportionately speaking, AIANs, with lower incomes, are more likely to be eligible for Medicaid coverage. Approximately one in five AIANs is covered by Medicaid (17 percent), compared to 5 percent of whites who are Medicaid clients; in absolute numbers. Extensive literature tells us that those with insurance have better overall health and health outcomes than do those without health insurance.

Third-party payments and the need for services. Casey Cooper noted that, because IHS is funded at only 60 percent of need, many tribes are attempting to cover the 40 percent shortfall through third-party reimbursement. Because these tribes have such “... a high percentage of patients with no payer source, ...you really don’t make up the shortfall through third-party reimbursement. Fifty to 60 percent of your visits are non-reimbursable.” Nonetheless, tribes will have to continue to seek third-party sources of revenue. Several factors inexorably drive the shift to the private sector.

First, originally, IHS facilities were built and equipped to provide acute care without any long-term or inpatient capabilities. AIANs now expect tribes and IHS facilities to provide all types of care, especially preventive services. When the facilities do not have the resources or equipment to provide these types of care, they either contract with other providers who can offer those services, or look for alternative funding sources to enable them to do so.
Tribes who administer their own programs run into unique problems in attempting to provide services their tribes need. Providers who agree to provide contract care through IHS or tribal facilities have to complete a substantial amount of additional paperwork. This is an added burden on the already extremely busy clinician, and leads fewer physicians to be willing to contract with tribes. Some self-governing tribes are concerned that shifting more responsibility to them will somehow lessen federal responsibility. As I have noted, as tribes gain more administrative power, some AIANs worry that this is the federal government’s way of slowly phasing out its obligation to provide quality health care for them. Others support the increasing role tribes have in designating health care because this role represents tribal sovereignty and self-governance. Extensive legislation in place prevents the federal government from relinquishing its responsibility to AIANs, but this may not eliminate the tribes’ challenge of finding and contracting for new services.

**Medicaid.** Medicaid insurance covers children, pregnant women, the disabled, elderly, and those who have limited income. AIANs’ high rate of poverty is what makes so many of them eligible for Medicaid. This is not a desirable situation, but with no other source of assistance for many of these people, Medicaid is the only option for coverage. Medicaid is a federal-state hybrid, making its recipients in any given state vulnerable to that state’s cuts or changes to service, potentially meaning that AIAN Medicaid recipients may not receive the uniform benefits that the federal obligation to provide AIAN care would seem to require. Several protective measures could be implemented to ensure Medicaid coverage for AIANs that is not subject to
state-designated changes. These measures would result in a small overall effect in the total budget of Medicaid and would guarantee the Federal trust responsibility to AIANs.

Unfortunately, Congress is calling for several cuts in Medicaid that, if they are passed, will total $11 billion dollars in savings over the next five years.\(^4^2\) In the past year, every state has adopted one or more strategies to contain costs. These range from decreased eligibility or benefits, to cuts in services offered. This allows states to spend less, but also causes them to lose Federal funds usually appropriated to them through the Federal Medical Assistance Percentage (FMAP).\(^4^1\) The average percentage of Medicaid paid by the federal government per state is between 50 and 83 percent. For services provided to AIANs, this percentage is 100 percent, because care for this population is strictly a federal responsibility. However, as states make reductions to contain costs, these cuts nonetheless affect AIANs, because services that a state withholds from everyone on Medicaid are also withheld from that state’s AIAN population.\(^4^2\) To eliminate this possible failure of the obligation to provide care, AIANs should be exempt from any kind of state reductions in either eligibility or benefits.

Moreover, the 100 percent federal coverage of Medicaid services applies only to services that are provided directly to AIANs through IHS facilities. Referral or contract services are not presently covered by federal Medicaid reimbursement. Full federal Medicaid coverage needs to be extended to both referral and contract services. This extension, coupled with the exemption from service cuts, would still miss those AIANs who get care from a non-IHS provider and are not provided any contract or referral care, but it would
increase the provision of care to the rest of the population a great deal.\textsuperscript{41} Many states exempt AIANs from having to pay premiums, deductibles, co-payments, or cost sharing.\textsuperscript{42} These should apply to all AIANs in all states. These changes would not generally affect state budgets.

Many AIANs are also concerned that cost containment for Medicaid will cause services to be cut for AIANs, who make up such a small part of expenditure for Medicaid overall. They fear they will be forgotten and subject to large losses compared to those endured by the rest of the population.\textsuperscript{42} These fears may originate from the history of AIANs being overlooked in national government and health policy matters. Countless examples throughout history of political authorities making decisions regarding AIAN citizenship and rights without allowing AIANs to express their views on the matters fuel this distrust. Until recently, decisions about AIAN health care were made without their input.

Lack of awareness also affects implementation of the Medicaid changes for AIANs. Many of the commission members who make Medicaid policy changes do not know about Indian programs or the trust responsibility the Federal Government has to AIANs.\textsuperscript{42} Part of the advantage of IHS programs is that the system was built specifically to serve AIANs. All staff who work with these programs should be educated about the special relationship between tribal governments and the federal government, and how this relationship affects health care and insurance coverage. Such education is not necessarily extended to Medicaid staffers.

Another important component of education and increasing awareness is consideration of the cultural needs and beliefs of a population. AIANs may
have different views of long-term care of family members than does the larger population, for example. The individual IHS facilities have done very well with forming programs specific to tribes, by providing specific education for family members in how to provide long-term care for family members that suits their cultural beliefs. Also, the approach to mental health is often viewed very differently by tribes than the general population. Many tribes believe certain mental illnesses are not illnesses at all, or that the treatment should consist more of tribal practices and treatments than medication. A new conglomeration of programs entitled “Circle of Care” now has sixteen locations and provides behavioral health care appropriate to tribes.42

Future changes in health insurance policy. What is being done to broaden the current extent of insurance coverage? The Centers for Medicare and Medicaid Services (CMS) is the Federal agency that oversees Medicare, Medicaid, and SCHIP. In 2003, CMS contracted for a Tribal Technical Advisory Group to acknowledge the sovereignty of tribes by consulting with them regarding any possible changes in policy for these programs.42 The group is made up of 15 members of different tribes who are elected leaders from 12 Area Offices of IHS as well as representatives of National AIAN organizations. The CMS is currently creating a “formal consultation policy”.43

This advisory group will be able to provide input from an AIAN perspective; its goals are to make the changes, some of which are described above, to ensure consistent coverage of AIANs. It is important that the federal responsibility continue by means of Medicaid and SCHIP, because of the substantial number of AIANs who are in the low-income group. Medicaid supplies approximately 20 percent of the IHS budget, but less than 0.5 percent
of Medicaid’s budget is spent on AIAN health and services.\textsuperscript{42} Since services for Medicaid provided to AIANs only account for a minuscule amount of the total Medicaid budget, it is unlikely that implementing the new recommendations would significantly affect the budget.\textsuperscript{12}

The shift of IHS into the private sector results from several factors that originate in the paths taken by the U.S. health care system as a whole. The advancement of services and rising emphasis on preventive services leave the Indian Health Service constantly striving not only to catch up to the quality of health care in the rest of the U.S., but to make sure this care is provided to everyone who is eligible. Increasing the third-party payments is necessary to provide services not offered in IHS facilities. All AIANs are relying more on insurance to supplement what IHS cannot pay due to budget shortfalls. Until Congress appropriates amounts sufficient for IHS to provide services to all AIANs, making changes to Medicaid and SCHIP to accommodate a high percentage of AIANs is a small and incremental, but feasible step in improving care for this population.

**Gaming revenues**

Gaming revenues contribute a significant amount of funding to health systems of tribes across the nation. However, revenue-sharing by states endangers the future of this funding stream. The National Indian Gaming Association, created in 1985 as a not-for-profit organization made up of 168 tribes, had as their mission to “protect and preserve the general welfare of tribes striving for self-sufficiency through gaming enterprises in Indian Country”.\textsuperscript{44} The Indian Gaming Regulatory Act of 1998 (25 USC 2701-21) permitted tribes to form compacts with states to build and operate casinos.
During the first decade of gambling the revenues increased from $212 million to $7 billion. Today, approximately 200 tribes operate over 320 gaming enterprises; the annual revenues from these facilities total $14 billion.45

The Cherokee Harrah’s casino opened in 1997, and has over 3,000 employees. The five-year-old gambling agreement between the EBCI and the state of North Carolina mandates that the tribe provide $5 million per year in gaming revenues to foundations that are not related to gambling economic development.46 For example, the tribe has used this money to help fund the Cherokee Preservation Foundation and Cherokee Historical Association for programs to preserve Cherokee heritage and culture. Also, Harrah’s donated $1.2 million to the Cherokee Hospital to purchase a CT scanner and upgrade some of their systems.47 This scanner will save approximately half of a million dollars in referral services.

The casino has provided not only funding for the hospital and many other services on the reservation, but has created huge employment opportunities that not only increase the economic status of many tribal members, but increase the employee health coverage these members have. The casino provides many health care benefits to tribal members.

Those who are concerned about the use of gambling revenues to support the hospital often, ironically, cite moral arguments from white Protestant religious perspectives as reason for disdain of the revenues. Others are concerned that, if the hospital is primarily dependent on gaming revenues, casino closure would mean hospital closure. It seems virtually impossible that the casino will close in the future, given constant growth and expansion of the casino and associated hotels and persistent talk of bringing in live gaming to
the casino.\textsuperscript{46} However, the hospital's significant dependence on a single funding source is a legitimate concern. Although such dependence on gaming may not be desirable, however, no other option to obtain this level of funding exists, and the fact that the funding goes to provide better services and facilities to tribal members overrides the fact that it originates from gambling in the minds of many.

Perhaps a more significant but less obvious concern is states' increasing and possibly illegal revenue-sharing of reservation gaming revenue. Revenue-sharing refers to states' placement of mandates in gaming compacts demanding that tribes must donate a certain share of their revenue to the state, in what may be a clear contravention of the IGRA, §\textsuperscript{11}, which declares that states cannot force tribes to provide a donation to the state or decline to participate in compact negotiation because a tribe will not provide such a donation.\textsuperscript{48} Such "donations," nonetheless, are occurring, and President Bush has allowed revenue-sharing up to 25 percent in several states since 2001. Casinos across the US had $18 billion in revenue in 2004. Of this, $1.8 billion went to states, and $100 million went to local governments.\textsuperscript{49} States are constantly disputing the IGRA in an attempt to gain more control over regulating gaming and revenue-sharing.

The revenue-sharing is what could really endanger the future of health care systems that rely on this funding. As governors who are desperate for state funding demand more revenue-sharing, tribes lose more of the revenue they depended on not only to provide health care, but to improve the quality of care. The future of casinos or bingo facilities is probably secure; what is not so certain is that tribes will be able to keep the lion's share of the revenues
they generate, as states are likely to see gaming revenues as an increasingly
avtractive way of funding their own budgets without raising taxes. State
venue-sharing is the real threat to the use of gaming revenues to support
IAN health care. Only a reiteration of the federal legislation’s ban on state-
mandated “donations” can prevent tribes from continuing to lose significant
amounts of gaming revenues that might otherwise go to improve health care.

Conclusion

Compacting has allowed tribes to lay claim to the self-governance they
were denied for many years. Tribes know what is best for their communities,
and if they can acquire the skills necessary to run their own health facilities,
they should do so.

The policies that have mandated the existence of self-governance were
meant to increase the independence of tribes. This self-governance should
allow tribes to separate themselves from the paternalism of the federal
government and Indian Health Service. Kunitz, however, argues that the initial
policies paradoxically increased the dependence of AINs on federal assistance,
rather than increasing their independence. Native Americans, he contended,
had the ability to run their own programs, but were being forced to negotiate
with private physicians, for which they were unprepared, and for which they
did not have the money. At the same time that tribes were bearing the higher
casts of health care and other challenges of contracting with private physicians,
IHS was continually suffering budget cuts. President Clinton attempted to
assist tribes by adding an extra $125 million to the Fiscal Year 1995 budget for
IHS, but this amount only decreased the budget cut from 13 percent to 6 percent.\textsuperscript{16} In other words, the worthy goal of compacting is not necessarily accompanied by a transfer of federal funds at a level that would make the goals reachable.

It is clear that tribes would be unrealistic to expect improvement in the future levels of funding provided to Indian Health Service. The trend over time has not been one of trying to provide vast amounts of more funding to IHS to improve Native health care, and the current economic climate is one of cuts to domestic programs rather than increases. Tribes, thus, have no choice but to find and use supplemental revenues from any source they can identify. The problems Kunitz identified a decade ago are still problems for tribes - especially poorer tribes - who wish to compact. Legislation mandates the provision of training and education for tribes to be able to do those very things he mentions, such as negotiating with providers, and it is noteworthy that tribes have accomplished as much as they have, despite not being provided the resources they need in many cases. Tribes have gained the skills they need to implement the administration of their own health care systems. When tribes fail, the fault may lie with the failure of the IHS to provide adequate preparation and assistance. Cherokee represents an example of what to do given a supportive area office with employees who support self-governance.

We should not be aiming for the success of a few tribes. We should have a system in place that spreads revenues from the wealthier tribes to those tribes in remote locations with no hope of supplemental income. Soon, with the dwindling IHS funds, tribes will be competing for money.\textsuperscript{16} Money will first go to tribes with contracts or compacts, and those who are poorer will not
improve. The IHS needs to serve as a system unlike what has been demonstrated in the United States. The AIAN population should not become a divided society with a large proportion of uninsured citizens who cannot obtain quality health care. A proportionate or per capita distribution of gambling revenues and IHS funding to all tribes is one way to ensure the survival of health care for all Native Americans. This division of funds, should revenue-sharing not make this impossible, would help those poor tribes compact successfully. Self-governance should not be an option only for wealthy tribes.

The Eastern Band of Cherokee Indians has been successful in compacting the hospital. They had excellent preparation for adhering to legislative requirements to compact, and for extensive community education. They also hired outside consultants to assist in monitoring the progress of committees and in conducting focus groups to assess concerns of hospital employees. All of these actions supported the ability of the tribe to convey to the community a sincere desire to improve health care and to facilitate the tribe's progress. The EBCI, however, may be an exception to the rule of compacting. This tribe is not only one of the largest in the nation, but does have supplemental revenue through gambling. Not many other tribes have the resources available to the EBCI when they tried to compact. The goal for all tribes and the IHS should be successful compacting for every tribe.

The Cherokee Indian Hospital participates in a national data collection system, and periodically tracks performance measures within their own system. Contributing their data to a national system that monitors the progress in eliminating health disparities for Native Americans is extremely important. As Casey Cooper noted, however, obligating tribes to participate in this data
collection is not always feasible. Smaller tribes with less money and workforce to dedicate to extensive data collection simply cannot do it. It is therefore acceptable to require a less stringent reporting and data collection system for these smaller tribes. However, is it too much to ask for even these smaller tribes to adhere to JCAHO or GPRA standards? I believe it is not, although their ability to become accredited depends on the support they will in fact receive from IHS. The real question, then, lies in how much assistance these tribes are really provided by Indian Health Service.

The Indian Health Service is clearly undergoing a major transformation. It was a centralized bureaucracy controlling the programs, services, functions and activities that took place in almost every tribe across the nation. Now, IHS has not only lost control over half of those tribes and the programs they provide, but it must reduce its own workforce in order to provide more money to tribes. Even though this elimination of administrative costs supports the self-governance and success of individual tribes, it must be difficult for IHS and its employees to support legislation and programs that truncate its own scope and mission. However, that is exactly what IHS must do if tribes are to be able to compact. And it seems that for the most part, the employees of IHS are fulfilling this duty, as illustrated by the civil servants in the Nashville office who worked with the EBCI, and the administrators in Washington. All my respondents noted the support of the national and area headquarters’ offices in promoting the compact of Cherokee. This support is exactly what will be necessary for other tribes to be successful.

How will tribes achieve quality health care for all of their members when Indian Health Service continues to have inadequate support from the
government? According to Casey Cooper, “real success for Indian health systems is for local tribes to really take ownership over these systems... to really take a sense of community ownership over them and to support them so that they become not only the provider of choice for your tribes and your local communities, they also become the investment of choice for the tribes and local community”.
List of References


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Appendix: Interview Script

Thank you again for agreeing to speak with me about the Cherokee Indian Hospital Compacting. Because I respect your time, I’d like to go ahead and get started.

First, What role have you played in the compacting of the hospital? That is, I would like to know what you did, and how you did it.

Second, How would you describe the process of compacting? I’m interested in anything you want to tell me - how would you characterize this process?

Third, I’d like to know about the challenges and obstacles you faced. What parts went better, and what parts were more difficult to get through? How did you handle the challenges and obstacles that you faced?

Fourth, Do you feel that compacting has benefited the patients and employees of the hospital? What have those benefits been? What about drawbacks for patients? Employees?

Fifth, How would you describe IHS involvement in the process? What about now? How would you describe IHS involvement now?

I just have one last question. Would you tell me about your future goals for the hospital? Could you tell me your specific ideas for things that you think would most improve the care the hospital delivers?

Thank you so much! I will be sending you a transcript of this interview, and will ask you for one brief follow-up meeting for any clarification or further questions.