Indian Health Service

Program Evaluation Services

Community Health Representatives Evaluation Final Report

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Executive Summary

The Indian Health Service (IHS) provides culturally appropriate health care to approximately 2.6 million American Indians and Alaska Natives (AI/AN) from 573 federally recognized tribes.[1] The Community Health Representative (CHR) Program, an important component of health care provision, is IHS-funded and tribally contracted. CHRs are frontline, tribal health workers who provide health promotion and disease prevention services in their communities.

This report presents findings from a mixed-method evaluation of the IHS CHR program conducted by a contractor on behalf of IHS. This comprehensive evaluation of the CHR program documents observations of program activity including impact in tribal communities and examines recommendations. The evaluation included four components: a literature review and overview of congressional testimony, key informant interviews, focus group discussions, and a survey.

The evaluation respondents (IHS leadership, CHRs, CHR program directors, IHS Area CHR Representatives, public health nurses, and environmental health officers) perceive the CHR program to have a positive impact on tribal communities' health, despite complex challenges. Overall, respondents perceive CHRs as trusted members of tribal communities who connect their communities with health care and public health in a way that no other health care provider can. For example, CHRs draw on their tribal membership and familiarity with Native languages, customs, and traditions to deliver a unique health care provider role. However, confusion about the CHR role and inconsistent access to electronic health records and computers, and challenges with billing for CHR services may limit proper measurement of CHRs' impact.

Evaluation respondents expressed their perception of the CHR program as critical to the provision of culturally appropriate health care. This connection to culturally appropriate care aligns with the IHS FY 2019-2023 Strategic Plan's first strategic goal: "*To ensure that comprehensive, culturally appropriate personal and public health services are available and accessible to American Indian and Alaska Native people.*"[2] Without their membership in and understanding of tribal culture and shared life experience with their patients, CHRs could not gain access to the community settings where they provide care or develop the relationships with patients that, in turn, build trust.

Several key findings emerged across the evaluation components in relation to the project's research questions.

- The trust that CHRs establish with patients through shared life experience and culture is perceived as central to the CHR program's positive impact, rather than formal education and standardized trainings.
- Through their health education, translation, and transportation services, CHRs are perceived as improving patients' understanding of medical instructions.
- CHRs are described as vital members of primary care teams.
- Given the remote and rural nature of many tribal communities, CHR transportation services are essential for access to health care.
- CHRs monitor high-risk patients, which prevents serious conditions and complications and reduces emergency room visits and hospitalizations among their patients.

[1] Indian Health Service. (2019). About IHS. Retrieved from https://www.ihs.gov/aboutihs/
[2] IHS. (2019). *Indian Health Service: Strategic Plan: FY 2019-2023.* Retrieved from https://www.ihs.gov/sites/strategicplan/themes/responsive2017/display_objects/documents/IHS_Strategic_Plan_FY%202019-2023.pdf

- Confusion about the CHR role among tribal health and IHS administrators may limit impact measurement of the program.
- The inability to bill Medicaid for stand-alone CHR services in most states may impede the perceived impact and impact measurement of the CHR program.
- Decreases in CHR reporting are due to challenges with computer and electronic health records access, tribes moving off the IHS Resource and Patient Management System, and unrequired reporting by tribally operated programs, and not due to a decrease in CHR services.

Introduction

This report presents findings from a mixed-method evaluation of the Indian Health Service (IHS) Community Health Representative (CHR) Program conducted by a contractor on behalf of IHS. This first-ever comprehensive evaluation of the CHR program illustrates the perceived impact of CHR program activities in tribal communities.

The evaluation included four components: (1) a literature review and a review of testimony related to the CHR program; (2) key informant interviews with IHS headquarters and area leadership; (3) focus groups with CHR program directors, IHS Area CHR Representatives, public health nurses, and environmental health officers; and (4) a survey of CHRs. These components assessed the perceived impact of the CHR program held by evaluation respondents. The evaluation components were designed to address the research questions presented in Table 1. Multiple evaluation components were used to triangulate findings and offer unique perspectives on the research questions. Some evaluation components did not answer all research questions. Table 1 outlines the evaluation components aimed to address the research questions.

Table 1. Evaluation Research Questions and Components

Evaluation Research Question	Literature Review and Testimony Search	Key Informant Interviews	Focus Groups	CHR Survey
1. What is the overall impact of CHR services in tribal communities?	✓	✓	✓	✓
2. In what ways or circumstances do CHRs assist in improving clinical and health outcomes?	✓	✓	✓	✓
3. Do CHRs improve access to care? If so, in what way?		✓	✓	✓
4. How do CHRs reduce health care costs?	✓	✓	✓	
5. How do CHRs provide culturally appropriate care?	✓		✓	✓
6. Why has reporting decreased? Is this an actual decline in CHR services or is it a lack of access to the IHS electronic health records (EHRs) due to tribes using other software?	✓	✓	✓	

Evaluation Research Question	Literature Review and Testimony Search	Key Informant Interviews	Focus Groups	CHR Survey
7. In which ways do tribal communities value the CHR program?[3]	**NA**	**NA**	**NA**	**NA**

As part of the evaluation, several documents were created that discuss findings from the different evaluation components. Table 2 briefly summarizes these documents.

Table 2. Summary of Evaluation Documents

Document	Summary
Literature review	An analysis of peer-reviewed literature, gray literature, and internal IHS documents relevant to the CHR program from 2006–2018
Testimony overview	A summary of testimony related to the CHR program from the past 10 years
Review and analysis of existing CHR data reports	A review of three secondary data reports provided by IHS
Key informant interview summary	A summary of the findings from five key informant interviews KAI conducted with three leadership at headquarters and two area leadership
Focus group overview	A write-up of the findings from three focus groups with individuals who have in-depth knowledge of the CHR program – (1) CHR program directors from tribally operated programs, (2) IHS Area CHR Representatives, and (3) public health nurses and environmental health officers who work with CHRs

This evaluation report details the CHR program's background, the evaluation methodology, and the evaluation findings. Finally, the conclusion summarizes the report followed by appendices with important study documents.

Background

Established by Congress in 1968, CHRs are "frontline public health workers who are trusted members of the community with a close understanding of the community, language, and traditions."[4] Originating in the Office for Economic Opportunity to train community health aides in 1968, the CHR program was transferred to IHS in the early 1970s and provided a new and crucial link between tribal communities and health care providers. Indigenous workers who are known within their communities and who

[3] Findings on the perception of CHRs by tribal communities were not addressed, as evaluation respondents included CHRs and other professionals who they work with and for, rather than community members.
[4] Indian Health Service. (No Date). Community Health Representative: About Us. Retrieved from https://www.ihs.gov/chr/aboutus/

understand their language and culture serve as CHRs in different capacities to bridge the gap between health care systems and the communities they serve.

While the program began at IHS in the 1970s, Dr. Annie Dodge Wauneka (the first woman elected to the Navajo Tribal Council) is one of the earliest examples of indigenous workers building bridges between health service providers and tribal communities through her community health work, beginning in the 1950s. Dr. Wauneka worked to eradicate tuberculosis in the Navajo Nation with a community health approach. She, "lived a real reservation life with feet well planted in her home community. She was able to convey the essential points to the community as she, more than any other Navajo, had a comprehensive knowledge of tuberculosis and its treatment."[5] Her work provided a roadmap for indigenous health workers in Indian Country.

CHRs act as liaisons between tribal members and health care providers. They foster greater ownership and involvement of AI/ANs in their health. CHRs also connect available health programs to AI/AN patients and communities, particularly in very rural areas.[6] CHR programs exist in 12 IHS areas and can be supplemented by the Community Health Aides/Practitioners (CHA/Ps), as is the case in the Alaska Area. In addition, CHR programs can operate as either federal or tribally managed programs, with the majority of tribal communities electing to contract with IHS through the Indian Self-Determination Education Assistance Act (ISDEAA) contract and compact program. Today, IHS estimates that more than 1,600 CHRs serve their communities in over 250 tribal locations across the United States.

Based on findings from the literature review and key informant interviews, CHRs have a wide breadth of functions that are tailored to the needs of their communities, and they participate in a variety of trainings. These functions include working as a key member of a care team, from providing transportation to medical appointments and pharmacies, to the interpretation of health information for tribal communities, and acting as a first line of communication on emerging health priorities.

CHRs receive training to conduct basic health screenings in the community (e.g., blood pressure checks at community health fairs) and certification to measure vital signs and blood sugar levels. CHR training typically involves basic and advanced online training.[7] For CHRs with 3 or more years of experience, specialized, onsite training with health brokers is available to expand their knowledge of topics like case management, mental health, and CHR document training. They can also receive training through IHS-funded opportunities, such as Mental Health First Aid (MFHA) training.[8]

Evaluation Methodology

To understand the potential impacts of CHRs on AI/AN health, the contractor conducted a mixed-method evaluation through qualitative methods of a literature review, key informant interviews, and focus group discussions, which prefaced the quantitative methodology of a CHR survey. Each component examined the evaluation's research questions.

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[5] Bergman, A., Grossman, D., Erdrich, A., et al. (1999). A political history of the Indian Health Service. *The Millibank Quarterly, 77*(4), 571-604. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/10656033
[6] Indian Health Service. (2018). *White Paper on IHS Community Health Representatives (CHR) Program.* Office of Clinical and Preventive Services. Division of Behavioral Health.
[7] Indian Health Service. (No Date). Community Health Representative: Education and Training. Retrieved from https://www.ihs.gov/chr/education/
[8] *See Footnote 7.*

IRB and OMB

The contractor received an exemption from the IHS National Institutional Review Boards (NIRB) to conduct the cognitive interviews to test the survey with three CHRs focus groups, and survey. The survey complies with the Paperwork Reduction Act of 1995 and received clearance from the IHS Office of Management and Budget.

Key Informant Interviews

The contractor conducted five key informant interviews with IHS leadership by phone to gain contextual information on the impact of the CHR program from leadership's perspective and to obtain recommendations for focus group participants, the survey's focus, and survey respondents. The interviews were conducted with three leadership staff at IHS headquarters and two at IHS area offices. Nine interview questions were developed, which IHS approved.

Focus Groups

The contractor conducted three focus group discussions with three unique groups who have in-depth knowledge of the CHR program: (1) CHR program directors from tribally operated programs, (2) IHS Area CHR Representatives, and (3) public health nurses and environmental health officers who work with CHRs. The contractor selected these three groups based on recommendations provided by IHS leadership during the key informant interviews. Each focus group included fewer than nine participants and had different questions to comply with the Paperwork Reduction Act. To protect their privacy, the contractor did not disclose the focus group participants' identities or tribal affiliations. The specific IHS Areas are not disclosed for the CHR representatives to ensure confidentiality. Table 3 lists the number of participants and the IHS areas represented in each focus group.

Table 3. Focus Group Participants by Number and IHS Areas

Focus Group	Number of Participants	IHS Areas Represented
CHR program directors	5	Portland and Oklahoma City IHS Areas
Public health nurses and environmental health officers	3	Navajo, California, and Phoenix IHS Areas
IHS Area CHR Representatives	5	5 IHS areas

CHR Survey

Understanding the impact of CHRs within tribal communities was limited to the experiences and perceptions of CHRs, whose responses were analyzed as a proxy for client experience. Survey participants were deemed eligible based on current status as a CHR employee serving within a federal or tribally operated program.

IHS obtained contact information from 10 of the 12 IHS Area CHR Representatives. The Alaska Area and Tucson Area were not included for several reasons. In many Alaska Native villages, Community Health Aides/Practitioners (CHA/Ps) are the main source of primary health care and also conduct some of the health promption/disease prevention work done by CHRs but through a separate program. In addition, the Alaska Area does not have a federal Area CHR representative and the Tucson Area's CHR representative position was vacant, and IHS could not obtain CHR contact information for those areas.

While IHS reports that approximately 1,600 CHRs work in the Unites States,[9] the IHS CHR program was able to provide e-mail addresses for 400 CHRs which included CHR managers. Out of this list, our initial outreach efforts identified 78 invalid email addresses. A total of 322 CHR contacts with valid e-mail addresses were invited to complete the survey.

Table 4 presents several survey rates that describe the level of participation and eligibility status for CHRs invited to participate in the survey. Of the 322 CHRs invited to participate in the survey, 174 completed surveys through SurveyMonkey, a web-based survey platform. After cleaning the data generated from the 174 submitted responses, we observed that three respondents opted out of the survey by declining to provide the informed consent, 31 respondents indicated they were not current CHRs and were thus not eligible to complete the survey, and 25 respondents submitted completely blank surveys. These 59 cases were removed from the dataset. The resulting valid sample size for this study was 115. All reported survey statistics are based on these 115 respondents.

Table 4. Survey Outcome Rates

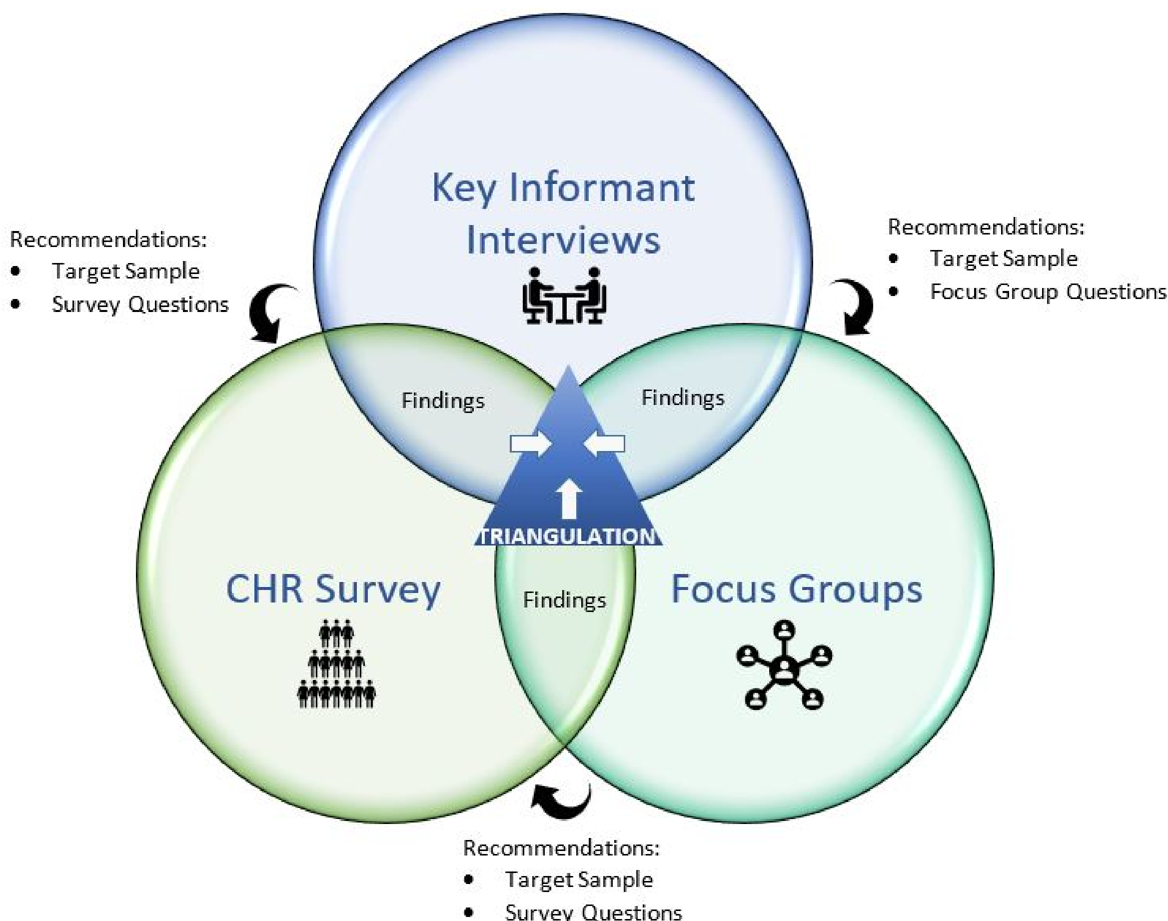
Rate	Definition[10]	Value (%)
Return Rate	$\frac{\#\ Surveys\ Returned}{\#\ Deliverable\ Surveys} = \frac{174}{322}$	54.0%
Eligibility Rate	$\frac{\#\ Respondents\ Confirmed\ Eligible}{\#\ Respondents\ Confirmed\ Eligible\ or\ Ineligible} = \frac{115}{(115+31)}$	78.8%
Response Rate	$\frac{\#\ Eligible\ Usable\ Surveys}{\#\ Estimated\ Eligible\ Respondents^{11}} = \frac{115}{(115+117+2+20)}$	45.3%

Data Source Triangulation

The contractor analyzed and compared findings from the literature review, key informant interviews, focus groups, and survey to identify themes about the perceived impact of the CHR program among the evaluation respondents. This method of data collection allows for data source triangulation, in which the researchers collected data through multiple methods and sources to validate it and "gain multiple perspectives" of the CHR program.[12] Figure 1 on the following page shows the triangulation process, how the methodologies informed the target populations and instrument questions, and the relationships of the findings. The literature review informed the key informant interviews, focus groups, and survey to provide important contextual information.

[9] *See Footnote 4.*
[10] Outcome rates for the CHR survey were formed using guidelines from the American Association of Public Opinion Research. https://www.aapor.org/AAPOR_Main/media/publications/Standard-Definitions20169theditionfinal.pdf
[11] Eligibility status is unknown for CHRs who were invited to complete the survey but did not answer the screening questions. Thus, to calculate the response rate, it was necessary to estimate the total number of CHRs who were invited and eligible to complete the survey. This quantity was estimated as the sum of two parts: (1) the number of CHRs confirmed to be eligible and (2) the product of the eligibility rate observed for CHRs who completed screening times the number of CHRs with unknown eligibility status.
[12] Carter, et al. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum. 41*(5), 545-547. doi:10.1188/14.ONF.545-547

Figure 1. Mixed Method Triangulation Process



Evaluation Findings

The evaluation of the CHR program yielded rich qualitative and quantitative data on the program's perceived impact. Overall, the evaluation participants perceive the CHR program to have a positive, noticeable impact on the health of tribal communities. **Approximately 67% of the CHR survey participants rated the impact of CHRs' work on the health of tribal communities as a 5** on a scale from 1–5, with 5 having the most positive impact. During the key informant interviews, **IHS leadership described the program as "irreplaceable,"** and **focus group participants described CHRs as the link to public health and health care across Indian Country,** connecting patients with a wide array of health and human services. The data from the evaluation offered an informative perspective of the CHR program, but the survey data were based on a non-representative sample of service providers (further described in the limitations on page 20). The following section provides an overview of the evaluation findings, organized by the research questions, with recommendations.

1. What is the overall impact of the CHR services in tribal communities?

Due to data limitations, the evaluation does not address the actual overall impact of the CHR program. However, it does address the perceived impact of the CHR program held by the evaluation respondents.

Overall, evaluation respondents relayed positive perceptions of the program's impact based on CHRs' abilities to build trusting relationships with patients and serve as the connection to public health and health care in Indian Country. However, confusion regarding the CHRs' role and their broad array of services may hinder their impact in Indian Country. The following findings from the evaluation illustrate the unique and complex nature of the CHR program.

Positive Impact Due to Ability to Build Trust with Patients, beyond CHR Formal Education and Trainings

Several published studies on the CHR program highlight the trust between patients and CHRs as critical to the program's successful provision of culturally appropriate care.[13, 14, 15] For example, in a 2017 qualitative study on the Navajo Nation's CHR program, Navajo CHR study participants shared the importance of building trust through shared culture and traditions for conducting home visits. Gaining entry to a Navajo home and conducting a successful home visit includes the exchange of a traditional Navajo greeting that identifies a person's Navajo clans, hometown, and family name. The author states, "CHRs indicate that revealing their hometowns and sharing their family backgrounds provide contexts for their clients and define turning points in the clients' willingness to trust them." Further, building trust in tribal communities is essential given the mistrust many AI/ANs have of medical providers due to the impact of historical trauma and history of abuse and mistrust they experienced with western medicine.[16]

Because there is a dearth of CHR program-specific research, broad literature on community health workers (CHWs) were examined [17]. Based on the available literature on CHWs, the trust of the communities served is what makes CHWs unique and valuable, rather than formal education and standardized trainings.[18] Throughout the evaluation, respondents emphasized the importance of trust and shared life experiences for the CHR role.

Trust was a prominent theme in the survey responses related to the perceived impact of the CHR program. **Approximately 67 percent (66.7%) of the CHR survey respondents felt they have a high impact on AI/AN health.** CHR survey respondents further described their impact as tied to building trust with clients. For example, a CHR survey respondent from the Bemidji Area shared, **"Many of our clients may not trust the people coming to see them. If a CHR takes the program representative, it is a different story altogether. [CHRs] work tirelessly to achieve trust with our clients."** Throughout the survey, respondents wrote the word *trust* 44 times in their open-ended responses.

During the focus groups, the public health nurses and environmental health officers explained that working with CHRs is critical for the success of their work in Indian Country. They said CHRs have established the relationships and trust with tribal community members needed to work directly with

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[13] *See Footnote* ***Error! Bookmark not defined.***.

[14] Mullany, B., Barlow, A., Neault, N., Billy, T., Jones, T. …Walkup, J. (2012). The family spirit trial for American Indian teen mothers and their children: CBPR rationale, design, methods and baseline characteristics. *Society for Prevention Research, 13*(5), 504-518. doi:10.1007/s11121-012-0277-2

[15] Barlow, A., Mullany, B., Neault, N., Compton, S., Carter, A. ... Walkup, J. (2012). Effect of paraprofessional home-visiting intervention on American Indian teen mothers and infants' behavioral risks: A randomized controlled trial. *American Journal of Psychiatry, 170*(1), 83-93. https://doi.org/10.1176/appi.ajp.2012.12010121

[16] *See Footnote 14.*

[17] The American Public Health Association's Community Health Workers section defines a CHW as "A frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery." Retrieved from https://www.apha.org/apha-communities/member-sections/community-health-workers

[18] Malcarney, M., Pittman, P., Quigley, L., Horton, K., & Seiler, N. (2017). The changing roles of community health workers. *Health Serv Res, 52*(1), 360-382. doi:10.1111/1475-6773.1265710.1111/1475-6773.12657

families and in their homes. A California Area environmental health officer explained, **"[CHRs] might come with me to do a home investigation, because I wouldn't be allowed in that area of the community without having a local person. And I think that having them as a partner and bridging that gap, especially culturally—[as] I wear a uniform, so I sometimes stand out. And having a local person there is calming if I'm working directly with families. I think that's really helped my work positively."** The CHRs offer a trusted face and foster a more receptive attitude toward public health interventions and other professionals in Indian Country.

Establishing trust with patients through shared culture and life experience was repeatedly noted as an important factor in the CHR program's perceived positive impact, while training and education were not. For example, **93 percent of CHR survey respondents indicated that they feel more effective in providing services as a CHR because they understand tribal culture.**

The Link to Public Health and Health Care in Indian Country

Throughout the evaluation, participants described CHRs as essential to connecting tribal communities to public health and health care. A Navajo Area CHR survey respondent explained, **"The impact is enormous as the CHR program is like the hub for the local community health services. It provides support, collaboration, and carries out the tasks to serve the community."** CHRs function as this link due to their deep ties in and understanding of tribal communities.

Focus group participants described the CHRs' ability to link patients to public health efforts across IHS. A Navajo Area environmental health officer explained, **"I think that they do add a lot to many programs across IHS, whether or not they know it or are aware of it. They link a lot of programs together."** The direct line of communication that CHRs provide between tribal members and health care providers is essential. An IHS area staff key informant stated, **"CHRs become our first line of communication between [the health care community] and the tribal community… The tribal leadership doesn't necessarily give us the messages that we need to have from the local folks and the CHRs are able to do that."**

Confusion About the CHR Role and Its Broad Scope

The CHR program serves as the largest tribally contracted and compacted program within IHS. More than 95% of CHR programs are directly operated by tribes, as authorized by the Indian Self-Determination Education Assistance Act. Thus, CHR program priorities and activities are often community specific and can change according to emerging needs.

Not surprisingly, evaluation respondents indicated that CHRs provide a broad variety of health care and case management services. CHRs most commonly offer transportation assistance and home visiting services. They also coordinate a wide variety of social service programs, like Meals on Wheels, Title IX services, Child Protective Services, tribal education department and school programs, diabetes education, and injury prevention efforts.

However, focus group participants and survey respondents reported that administrators of tribal health and IHS programs do not always realize the breadth of CHR services and do not understand the CHR's role. A Portland Area CHR program director focus group participant explained, **"I do feel like there's a misunderstanding of the role of the CHR. A lot of people feel like it's just for transport."** Similarly, a California Area CHR survey respondent wrote, **"The CEO, administration, and supervisors don't**

understand the CHR's role and what we do on a daily basis. We wear lots of different hats and we're spread thin by having so many roles."

Based on literature review findings, confusion about their scope of services is also a problem for CHWs. In a report on findings from the 2016 CHW Common Indicator Summit, the authors describe the broad array of services that CHWs offer as a strength and weakness. CHWs are effective because they provide a wide variety of health services that meet the diverse and unique needs of the communities they serve; however, it is also challenging to measure these activities in a way that can be aggregated. A dearth of long-term longitudinal studies on CHWs also may contribute to confusion about the role and the establishment of an evidence base to strengthen it.[19] The authors suggest establishing a common set of evaluation indicators for CHW programs, which the Michigan Community Health Worker Alliance is developing with the intention of creating a tool that can be used by CHW programs nationwide.[20]

Inability to Bill and Receive Reimbursement from Medicaid for CHR Services in Some States May Hinder Perceived Impact

Health care services documented in the billing process can be a source of information for describing impact. However, Medicaid reimbursement for CHRs and CHWs is complicated and varies widely by state**.** In fact, evaluation respondents identified the inability to bill Medicaid for CHR services in several states as a challenge. Approximately 22 states allow some level of Medicaid funding for CHW services, including CHRs.[21] During one of the focus groups, an area CHR Representative explained, **"I think the CHR program is challenged by how health care is changing… Health care is becoming more medically focused, while the CHR program is community focused… For the most part, when I talk to tribal directors or service unit directors about the CHR program, we're always in dialogue about billing and billing for services."**

Limited reimbursement for CHRs may also hinder measurement of CHR activities, as reimbursement provides an incentive for reporting. A key informant from IHS headquarters explained, **"If states don't allow reimbursement for CHR activity, there's no business case for [CHRs] to enter that data. The only value would be in reporting that activity. In some states, CHRs can bill for services, their Medicaid program allows that. So, then you've got an incentive for documentation and the electronic medical record in generation of a bill."**

Recommendations

The following recommendations may help strengthen the impact of the CHR program. They address the confusion about the CHR role and challenges related to billing and establishing an evidence base.

- Clarify the role of IHS CHRs and create a standardized job description.
- Develop a common evaluation indicator for the CHR program. The Michigan Community Health Worker Alliance's Common Indicators Project may provide useful guidance.[22]

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[19] Kiefer, E., Palmisano, G., Wang, P., Garcia, L., Maes, K. … Wiggins, N. (2016). *Community Health Worker Common Indicator Summit: Executive Summary of Proceedings.* Retrieved from http://oregonconsensus.org/wp-content/uploads/2013/10/Executive-Summary_Community-Health-Worker-Common-Indicator-Summit_Final.pdf

[20] Michigan Community Health Worker Alliance. (2018). Common Indicators Project. https://www.michwa.org/common-indicators-project-2/

[21] These states are Colorado, Idaho, Kansas, Louisiana, Maine, Massachusetts, Michigan, Minnesota, Missouri, New Jersey, New York, North Dakota, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, Utah, Vermont, Washington, West Virginia, and Wisconsin.
National Academy for State Health Policy. (2018). State Community Health Worker Models. https://nashp.org/state-community-health-worker-models/

[22] *See Footnote 19.*

- Conduct a longitudinal study that examines the impact of the CHR program to help establish an evidence base for the program.
- Provide education on the CHR role to tribal health and IHS administrators, and other stakeholders.
- Promote Medicaid reimbursement for CHR services.
- Promote a business model that supports documentation and incentive for reporting.

2. In what ways or circumstances do CHRs assist in improving clinical and health outcomes?

CHRs are often part of a multi-disciplinary medical team and can collaborate with medical providers, public health nurses, behavioral health staff, and members of the tribal health education and health promotion and disease prevention team. Improved clinical and health outcomes for the CHR program fall under two components: (1) their ability to improve patient understanding of medical instructions and (2) their integral role in primary care.

CHRs Are Perceived to Improve Patient Understanding of Medical Instructions

Survey respondents and key informants described CHRs as serving a role in improved understanding of medical instructions in tribal communities. CHRs provide health education to patients, which allows patients to more accurately follow directions from doctors and pharmacists. CHRs often speak Native languages, so they can translate and describe directions in layman's terms. Approximately 53 percent (**52.8%) of the CHR survey respondents report that they "Help patients understand the terms used by their medical providers and feel empowered to ask questions."**

Patients are also more comfortable getting guidance on their health and medical instructions from a trusted community member in their homes. A key informant from IHS headquarters stated, **"[CHRs] can provide additional education to the patient in their home environment, and they can do things like follow up with patients to make sure that medications are being taken correctly."** The assistance CHRs provide with medical instructions may contribute to improved medication adherence in tribal communities.

CHRs Are Integral to Primary Care

According to survey respondents, CHRs are integral to primary and follow-up care in tribal communities. In their response, a Navajo Area CHR stated, **"The primary [care] doctors rely on the CHRs for health updates, follow-ups, and consultation to extend the healthcare for patients. We serve as an extension of the hospitals and clinics."** Approximately 53 percent **(53.3%) of the CHR survey respondents indicated that their role as a CHR helps provide accessible health care to the people in their communities by providing transportation for clients and facilitating communication between the medical providers on behalf of the clients.** Survey results also suggest a role for CHRs in patient follow-up care. Approximately 66% **(65.7%) of CHR survey respondents reported that CHRs are the next provider that a patient sees after receiving medical care (e.g., following a doctor's office visit, surgery, or emergency room visit).**

Literature review research suggests that the integration of CHWs into a primary care team contributes to positive outcomes, including improved follow-up primary care post-hospitalization. A 2014 randomized control trial of a patient-centered CHW program among adults with a low-socioeconomic

status found that intervention patients were more likely to obtain timely post-hospital care.[23] CHWs connected patients with primary care providers and accompanied patients to their first primary care appointments, as needed. A 2013 parallel randomized trial assessing the integration of CHWs into primary care teams for patients with chronic diseases (e.g., hypertension, diabetes, heart failure), found that, after 1 year, patients who worked with CHWs met more health goals (like not using tobacco) than those who did not work with CHWs.[24]

Recommendations

While evaluation respondents relayed compelling information about the CHR program's role in improving clinical and health outcomes, more research is needed to understand this role. The following are recommendations to bolster this understanding.

- Promote improved reporting of CHR services (including improved access to community electronic health record data systems) to better determine the impact on clinical and health outcomes.
- Conduct a study or evaluation of the CHR program focused on the clinical and health outcomes.
- Conduct a longitudinal study on the CHR program to help establish an evidence base for the program.

3. Do CHRs improve access to care? If so, what way?

CHRs appear to improve access to care in tribal communities. Approximately 53 percent (53.3%) of CHR survey respondents reported that their role as a CHR allows for "completely accessible" health care for the people in their community. Transportation services and home visits are key components of improved access. These services are critical for access to care in remote, rural tribal communities, particularly for tribal elders.

CHR Transportation Services are Essential for Access to Care

Throughout the evaluation, participants stressed the importance of the transportation services provided by CHRs. According to the most recent available U.S. Census Bureau data (2010), approximately 20% of the AI/AN population (1,069,411 AI/ANs) lives in "federal American Indian reservations and/or off-reservation trust lands, Oklahoma tribal statistical areas, tribal designated statistical areas, state American Indian reservations, and state designated American Indian statistical areas."[25] Many of these areas are remote, which challenges access to care, and many individuals in tribal communities rely on CHRs for transportation to their medical appointments and to deliver or obtain medications. An IHS headquarters key informant stated, **"If it were not for that transportation, I think many patients would simply miss their appointment [or] rely on family and friend's schedules to get them to the doctor's visits… The importance of patient transportation cannot be overstated."**

CHR survey respondent feedback also described the dire need for these transportation services. A Great Plains Area CHR survey respondent explained, **"Without the CHR program there will be no**

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[23] Kangovi, S., Mitra, N., Grande, D., White, M., McCollum, S. … Long, J. (2014). Patient-centered community health worker intervention to improve posthospital outcomes: A randomized clinical trial. *JAMA Internal Medicine, 174*(4), 535-543. doi:10.1001/jamainternmed.2013.14327
[24] Adair, R., Wholey, D., Christianson, J., White, K., Britt., H., & Lee, S. (2013). Improving chronic disease care by adding laypersons to the primary care team. *Annals of Internal Medicine, 159*(3), 176–184. doi:10.7326/0003-4819-159-3-201308060-00007
[25] U.S. Census Bureau. (2012). *The American Indian and Alaska Native Population:2010.* Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf

transportation for our relatives to seek medical attention or get medication… More deaths would be happening due to inability to get to treatments."

CHR Home Visits Provide Critical Access to Care for Tribal Elders

The success of the CHR home visiting program for American Indian teen mothers is well documented by several studies.[26, 27] In 2016, CHRs conducted 340,270 home visits for health-related needs.[28] Survey respondents stressed that CHRs' home visits are vital to populations other than teen mothers, especially tribal elders. Based on data from the IHS CHR Data Mart, in FY 2017, the majority of patient visits for the top five chronic diseases included those age 60 and over. A Navajo Area CHR survey respondent explained, **"A lot of our community elders live alone and do not have family support. They depend on the CHR program."** As part of these home visits, CHRs provide emotional support and help elders cope with loneliness. A California Area CHR survey respondent explained, "**Many of our elders really do not have a lot of support and guidance from family. I have 3–4 very sad and lonely elderly clients. I have one client that I spend 2–3 hours with every other week for a home visit… Our visits are plentiful, and we get a lot accomplished."**

Recommendations

Limited transportation is a barrier to health care access and is a long standing and well documented problem in tribal communities, and CHR home visiting programs are effective, evidence-based interventions. The following are recommendations based on these facts.

- Continue to support CHR transportation services.
- Continue to support CHR home visiting programs.
- Improve reporting of services provided in home visits.
- Conduct a longitudinal study on the CHR program to better understand the impact of CHR transportation and home visiting services.

4. How do CHRs reduce health care costs?

Patient monitoring programs are an important factor in driving better outcomes for patients. CHRs may contribute to reductions in health care costs by monitoring high-risk patients. This monitoring may lead to preventive care and a reduction in hospitalizations and emergency room visits.

Monitoring High-Risk Patients Decreases Emergency Room Visits and Hospitalizations

The CHRs' focus on prevention and monitoring high risk patients was a theme throughout the evaluation. In 2016, 70 percent of services provided by CHRs were related to chronic disease management, with the majority of those services involving patient screening, referring patients for medical follow up, and other case management activities.[29] This focus may contribute to reduced health

[26] *See Footnotes 15 and 16.*
[27] Barlow, A., Mullany, B., Neault, N., Goklish, N., Billy, T. ... Walkup, J. (2014). Paraprofessional-delivered home-visiting intervention for American Indian teen mothers and children: 3-year outcomes from a randomized controlled trial. *American Journal of Psychiatry,* 1–9. doi: 10.1176/appi.ajp.2014.14030332
[28] IHS. (2017). *Fiscal Year 2018: Indian Health Service, Justification of Estimates for Appropriations Committees. CJ-115.* Retrieved from https://www.ihs.gov/sites/budgetformulation/themes/responsive2017/display_objects/documents/FY2018CongressionalJustification.pdf
[29] *See Footnote 28.*

care costs through decreased hospitalizations and emergency room visits. Literature exists more broadly on CHW cost reduction and may be relevant to CHRs.

For CHWs, cost reductions appear to result from fewer emergency room visits, lower hospitalization rates, and lower readmission rates for complex patients, as reported in a study of CHWs in New Mexico by Molina Healthcare who noted a cost savings of $1,522,722.[30] Results from a 2013 report, which included a review of 14 studies on CHW programs, also found that most programs reported a net cost savings, largely due to reductions in urgent care use and hospitalization.[31]

CHRs identify and monitor higher-risk patients and help them receive care through home visits, which is further supported by their in-depth knowledge of the communities they serve. A Portland Area focus group participant explained, **"We have higher risk patients that the CHRs visit on a regular basis. So, they might actually see something before it is even at a provider level and be able to encourage the patient to see a doctor."** An Oklahoma City Area focus group participant further explained, "**They'll [patients] tell the [CHRs] things they won't tell the doctors, and we'll kind of gently remind them, you know, 'You said this.' We'll catch it before they'll actually have to have emergency medical care or anything like that."**

Recommendation

The evaluation did not include a cost-benefit analysis of the CHR program, and the findings are based on literature on CHWs and findings from the focus groups. The following is a recommendation to improve data on health care costs related to the CHR program.

- Conduct a cost-benefit analysis of the CHR program to determine associated health care costs.

5. How do CHRs provide culturally appropriate care?

CHRs provide culturally appropriate care through their membership in and extensive knowledge of tribal communities.

CHRs' In-depth Knowledge of Tribal Culture Is Invaluable for Providing Care and Developing Relationships with Patients

A patient visit within a health care system should accomplish: (1) a positive interaction between the provider and patient, (2) determine the patient's ailment, and (3) provide proper treatment.[32] Cultural and language barriers can impact the outcome of a patient-provider interaction. Within the IHS health care system, many facilities experience difficulty in recruiting and retaining health care professionals, and they often recruit providers through contract positions or time-limited service obligation and loan repayment programs. In addition, nationally, the number of registered nurse graduates and percent of AI/AN medical students have declined in recent years.[33]

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[30] Massachusetts Department of Public Health. (2015). *Achieving the Triple Aim: Success with Community Health Workers.* Retrieved from https://www.mass.gov/files/documents/2016/07/xb/achieving-the-triple-aim.pdf

[31] The Institute for Clinical and Economic Review. (2013). *Community Health Workers: A Review of Program Evolution, Evidence of Effectiveness and Value, and Status of Workforce Development in New England. Final Report – July 2013.* The New England Comparative Effectiveness Advisory Council Public Meeting – June 28, 2013. Retrieved from http://www.healthreform.ct.gov/ohri/lib/ohri/1._CHW-Final-Report-07-26-MASTER.pdf

[32] Patient Engagement HIT. (2017). *Cultural Barriers Limit Immigrant Patient-Provider Interactions.* Retrieved from https://patientengagementhit.com/news/cultural-barriers-limit-immigrant-patient-provider-interactions

[33] AARP. (2018). Prospective Native American health care providers declining in number. *Health Conditions & Treatments.* Retrieved from https://www.aarp.org/health/conditions-treatments/info-2018/prospective-native-american-health-providers.html

CHRs may lessen challenges related to the shortage of AI/AN health care providers, as they can help providers who are less familiar with tribal communities to navigate cultural and language barriers. CHRs have made a perceived, positive impact by building trust with patients and are considered essential to connecting tribal communities to public health and health care.

CHRs provide culturally appropriate care through their community membership, fluency in tribal languages, and deep understanding of the community. These factors are critical to building relationships and trust with patients. A California Area CHR survey respondent explained, **"Understanding tribal culture is key to having that relationship with our patients. They can talk to you about certain things such as ceremonies, language, native foods, or people that we both know."**

CHRs' in-depth understanding of the communities they serve also helps ensure that individuals from outside the community interact with tribal members with respect and competence. During the focus groups, a Phoenix Area public health nurse stated, **"[CHRs] can also orient new providers that are there in the field or that even don't know that much about a community. We got to be very respectful in working with our tribal community partners."** Also, **93 percent of CHR survey respondents indicated that they feel more effective in providing services as a CHR because they understand tribal culture.**

Recommendation

Although the CHRs' provision of culturally appropriate care is essential to the program, more research is needed to better understand how CHRs effectively engage with tribal communities. The following are recommendations towards this effort.

- Conduct a comparative or longitudinal study on the CHR program to better understand the provision of culturally acceptable care.
- Conduct a survey of community members related to the CHR program, which includes an assessment of culturally appropriate care.

6. Why has CHR reporting decreased? Is this an actual decline in CHR services or is it a lack of access to the IHS electronic health records (EHRs) due to tribes using other software?

CHR services are reported from the local health care facility to the IHS national reporting system, the National Data Warehouse (NDW). Aggregate CHR services are captured in a specific database, called the CHR DataMart, which supports agency reporting requirements of the CHR program. Importantly, CHR data reported into the CHR DataMart is used to report on IHS Government Performance and Reporting Act (GPRA) measures. GPRA measures are reported in budget formulation and congressional justification documents to reflect the scope of services provided by the CHRs.

Decreases in CHR reporting appear to be the result of challenges with computer and EHR access, tribes moving off the IHS Resource and Patient Management System (RPMS), and inconsistent reporting by tribally operated programs.

Challenges with Tribes Moving off the IHS RPMS, Computer and EHR Access, and Unrequired Reporting

A decrease in the reporting of CHR activities is an area of concern for IHS. Based on the evaluation findings, it is the result of complex issues. Many tribally operated programs are moving off the IHS

RPMS. Additionally, CHRs have inconsistent access to EHRs, RPMS, and computers. Further, CHRs tend to receive insufficient education on reporting, and not all CHRs are required to obtain this education.

Evaluation respondents report that CHRs are often unable to access computers and reliable internet when they are in tribal communities, which impedes CHRs' ability to report their activities. An IHS area focus group participant explained, **"[A] challenge is just computer access. CHRs in my area use IHS computers to enter their visits, but if they're out in the field, they may not have access to a computer or internet. So, sometimes they have to come travel many miles just to get back to the main office to enter their visit."**

Evaluation respondents also report that the movement of IHS programs from RPMS to non-RPMS systems contributes to lower CHR data submission. One IHS area focus group participant explained, **"We have a lot of programs moving off RPMS and going onto a non-RPMS system, which aren't allowed to contribute to the DataMart in the same fashion that it had been in the past… If they're not using RPMS, it's really difficult for me to see what's happening in their program."**

Also, reporting is not always required by tribally operated CHR programs. Participants in all three focus groups highlighted that optional reporting contributed to an overall decrease in CHR data collection. An Oklahoma City Area CHR program director explained, **"Well, it would be nice if [reporting] would be made a requirement. If it was a requirement, I think it would get done more consistently."**

Finally, focus group participants associated a shift from in-person to online training on EHRs for CHRs with reporting challenges. An IHS Area CHR Representative explained, **"As far as reporting through EHR, there's a disconnect there, and there's a lot of education that needs to be done… And I think that because we don't have training like we used to—face-to-face training on documentation and coding—we're not seeing the data and we're not really seeing what our CHRs do or can do, because they're not aware of how to document."**

Recommendations

The following are recommendations related to improving reporting through better data and technology access.

- Reestablish in-person EHR training for CHRs.
- Improve CHR access to EHR systems.
- Address challenges related to equipment access for all CHR programs.
- Improve training for exporting local facility data, especially non-RPMS into the NDW.
- Improve communication of the benefits of reporting CHR activities into the NDW to all CHR programs (federal and tribal).

Limitations

Several limitations emerged throughout the evaluation. For the survey, the experiences and perceptions of CHRs were analyzed as a proxy for client experience. The IHS contractor chose CHRs as the survey respondents, rather than CHR clients, based on recommendations from IHS leadership. IHS leadership noted that research with CHR clients requires obtaining tribal IRB approval from multiple tribes and approval to access patient records to identify CHR clients, which are costly and time-intensive

challenges.[34] Further, research on patient experience and its association with outcomes is mixed at best.[35]

The survey results only represent the perceptions of participating CHRs. Because the survey respondents are a non-random sample of CHRs, the data presented does not reflect feedback from all CHRs in the broader population. Only CHRs on the contact lists shared by IHS were invited to take the survey. Further, because the CHR contact lists had limited information and national benchmarks describing the CHR population were not available, it was not possible to construct weights that would support generalization to the broader CHR population.

The qualitative coding of open-end responses was somewhat subjective and created imputed data.[36] Due to the small survey sample size, it was only possible to conduct exploratory descriptive analyses; we did not conduct hypothesis testing or attempt multivariable models to examine relationships between survey outcomes. Finally, the data collection period was limited to 6 weeks and three outreach efforts, as indicated in the OMB authorization, which contributed to the low sample size of 115 survey respondents.

Conclusion

The CHRs appear to be highly respected and valued by IHS leadership, CHRs, CHR program directors, IHS Area CHR Representatives, public health nurses, and environmental health officers. Evaluation respondents described CHRs as the link between public health efforts and community members across Indian Country. During the focus groups, a Phoenix Area public health nurse explained, **"I value the CHR program, especially regarding moving forth with our national initiatives that are coming out of Indian Health Service. I look to them to help us assist and to really help with cross training out in the field with health educators, PHNs [public health nurses], and EHOs [environmental health officers]. They just really work collaboratively with all disciplines."** Throughout the evaluation, respondents (including CHRs, key informants, and focus group participants) described CHRs as the "eyes and ears" of the public health and medical community in Indian Country.

Evaluation respondents perceive the CHR role as unique and irreplaceable. They emphasized the understanding of and connection with tribal culture among CHRs. During the focus groups, an IHS Area CHR Representative explained, **"I think it's very beneficial that CHRs are from the community because they know everyone, and patients can relate to them and discuss tribal issues that are occurring in the community."** The CHRs' ability to navigate tribal communities and link health care and tribal culture may reflect IHS' commitment to the provision of culturally appropriate care.

Although the evaluation results presented an overall positive perspective of the CHR program, they also presented challenges that may influence the program's perceived impact. These challenges include confusion about the CHRs' role, the broad scope of CHR services, the inability to bill Medicaid for CHR

[34] Anhang Price, R., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., … Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical Care Research and Review, 71*(5), 522–554. http://doi.org/10.1177/1077558714541480

[35] Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open, 3*(1), e001570.

[36] Driscoll, D., Appiah-Yeboah, A., Salib, P., and Rupert, D. (2007). Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology (University of Georgia), 3*(1). Retrieved from https://digitalcommons.unl.edu/cgi/viewcontent.cgi?article=1012&context=icwdmeea

services in many states, limited access to technology, and inconsistent reporting of CHR services. The following recommendations to help mitigate these challenges emerged from the evaluation findings.

- Clarify the role of CHRs and create a standardized job description.
- Provide education on the CHR role to tribal health and IHS administrators.
- Articulate the number of active CHRs operating nationwide.
- Conduct a longitudinal study on the CHR program.
- Conduct a survey of community members related to the CHR program.
- Reestablish in-person EHR training for CHRs.
- Develop common evaluation indicators for the CHR program. The Michigan Community Health Worker Alliance's Common Indicators Project may provide useful guidance.[37]
- Promote improved reporting of CHR services.
- As part of reporting, improve CHR access to EHR systems to better determine the impact on clinical and health outcomes.
- Conduct a cost-benefit analysis of the CHR program to determine associated health care costs.
- Continue to support CHR transportation services.
- Continue to support CHR home visiting programs
- Continue to support and fund the CHR program.

[37] *See Footnote 19.*