Research Plan

Health and Human Services (HHS) Indian Health Service (IHS) IHS Health Information Technology (HIT) Modernization Project - Human Centered Design (HCD)

Background

The Indian Health Service utilizes the Resource and Patient Management Systems (RPMS) as the core Health Information Technology (IT) Electronic Healthcare Record (EHR) system. RPMS was ahead of its time in the 1980s, adapted specifically for the AI/AN population with forward-thinking features like population health. However, the IHS is chronically underfunded and it has proven unable to maintain a modern code base leading to issues in staffing, maintenance, security, interoperability, and extensibility.

The goal of the HHS IHS HIT Modernization Project is to use a Human-Centered Design approach to provide insights into the technology needs and goals of American Indian and Alaska Native healthcare facilities to inform future investments in infrastructure and software. We will identify the core concepts and functional needs of a modern HIT system and develop use cases that can be tested in the field and used to evaluate possible solutions.

The HCD team will conduct interviews and workshops in the field to get a deeper, more comprehensive understanding of the IHS facility staff and patient's needs for HIT from end to end. Based on our findings and team engagement, we will outline requirements for the next generation of Health IT at IHS.

Our team will embed within the greater team to build these artifacts collaboratively, and put in place a system wherein they can be continually updated and referenced. By handoff, these artifacts will be “owned” internally, and a clear and validated vision for HIT modernization will result.

We will enable the department goal of setting up a bidding competition with a series of problems that describe the general and prioritized needs of I/T/U by identifying specific user journeys that test key functional needs, thus creating a rubric by which to evaluate bidders.

Goals

We will conduct activities to understand overall processes at I/T/U facilities and identify areas where technology is used or needed, with the goal of defining needs and goals for Health IT.

- We will help the federal government and Congress understand these needs and challenges.
- We will create a rubric by which to evaluate bidders.

This project is NOT focused on how staff use RPMS or other Health IT tools, but rather on their activities in general, and how they can be supported by technology.

Research Questions

- Identify process, needs, goals, and pain points of different staff members at I/T/U facilities;
- Articulate how IHS staff interacts with different areas and departments, and how they use technology to get their job done;
- Identify how I/T/U staff's success is measured, and what affects it;
- Illustrate what makes I/T/U staff's process, needs and goals unique in comparison with non-IHS health facilities.

Method(s)

&Partners will utilize multiple methods for gathering information that will best inform the anticipated design decisions. The project lead will work with all team members to ensure they understand the methodologies and what is needed to complete the research.

1-on-1 Interviews

Goal: To understand I/T/U staff's common tasks, workflows, processes and interactions with team members and technology to help us add context to the requirements for Health IT modernization.

- In-person interviews at site visits; 45-1 hour; May include shadowing and roleplay (e.g., patient experience) as needed
- Remote interviews; 45-1 hour; Scheduled with listening session participants if they agree to be reached out to in the sign-up sheet
- Interviews will be recorded if participants allow.
- Information shared will be anonymized.
- No protected health information (PHI) will be recorded.

Small Workshops

Goal: To understand processes, workflows, and interactions with team members and technology which will help us add context to the requirements for Health IT modernization.

- 3-5 clinical providers who work together from different roles and disciplines (in person)
- Build a journey map/service blueprint together based on agreed-upon scenarios

Subject Matter Expert (SME) Interviews

SMEs interviews will include Ruben Hernandez (Family Medicine at IU), Theresa Cullen, Howard Hays, Vince Berkeley (Phoenix Area standardization of care, out of Sakaton WRTC), Dede, and SMEs at VA, other health systems (healthcare for other remote populations and ethnicities), compared with VA use cases (if relevant).

Journey Mapping Workshop

Goal: Incorporate existing insights from the various engagements with stakeholders into a journey map that will be iterated on after 1:1 interviews and other activities. Leverage the intelligence gathered at past site visits as well as the team's personal experience providing healthcare in the IHS system. It will be one of the inputs that will help us define requirements for HIT Modernization and validate what we learned from interviews. This work will give us a headstart on journey maps that will continue to be iterated through the end of the HCD portion of this project. 2 hours long.

Literature Review

- AI/AN facilities: What are the most needed healthcare disciplines? Most common types of patients and conditions treated? Conditions with greatest (unmet) needs?
  - Quality measures, Outcomes, Meaningful Use metrics: which ones each of them use, and how they are performing on those.
  - Stats for common types of conditions treated in these facilities
  - Stats for kinds of services they provide, and to how many patients
  - Stats for unmet needs (e.g. services they don't provide but should)
- AI/AN patient demographic and challenges by Community
  - General population stats: tribes, size, rural/urban, income, education, family make-up, etc.
  - Common types of conditions
  - Challenges servicing each community
- Healthcare workflows outside of IHS
- Meaningful Use and Standardization of Care
  - Workflows, process: documentation generated as part of efforts to standardize care. This would help us learn the basics about some of these processes (which may inform our recommendations for processes, or improve upon them based on requirements).
- NUKA, GPRA

Research Roles

Research Lead: Sabrina Fonseca — Oversee the research plan development and execution, the ethical considerations, and the analysis, synthesis, and delivery/presentation of the research findings.

Moderator: Sabrina Fonseca & Arden Klemmer — Conducts interviews and workshops with research participants.

Observer(s)/Notetaker(s): Kate Murphy & Rients van Blanken — Record, with the interviewees permission, the listening session or interview, help anonymize interviewees responses, and document research so that it's accessible by the research team and absent stakeholders.

Timeline

Activities	Team Members
Planning & Study Design (1 week / May 2019) - Plan: building and review with all teams - Interview Guides - Create flyers, comms, etc.	&Partners Site Visits Team Stakeholders
Recruiting and Scheduling (11 weeks / May-July 2019) - Remote interview sign up - Create and share sign-up form on IHS listservs (only groups already connected with the project) - Schedule remote interviews	&Partners Site Visits team
Build Initial Hypothesis and Assumptions (1 week / May 2019) - In-person workshop archetypes and workflows based on past site visits, review and agree upon discovery goals, identify potential interview sources — scheduled to be done during California site visit and Alaska site visit - Identify assumptions and questions - Revise recruitment plan and interview guides	&Partners Site Visits team

Field Discovery, Data Collection, Remote Interviews (11 weeks / May-July 2019)
- 4 site visits:
  - Cherokee NC (5/14-18), California (5/28-31), Alaska (6/10-14), Billings (7/8-12)
  - Ad-hoc interviews
  - Recruitment for remote interviews
- Total 80-90 interviews: 10-12/week (may be fewer depending on what can be built from existing Site Visit work)
  - Recruitment will be key to reaching this number
	&Partners

Synthesis (4 weeks / August 2019) - Top-line synthesis - Collaborative analysis - Collaborative synthesis - Identify Themes, Journeys/Service Blueprints, and Personas/Archetypes	&Partners Stakeholders

- In-person workshop/presentation late July to review and map work so far, prioritize use cases (location to be defined)	
Summary and Outputs (ongoing / May-August 2019) - Weekly project updates - Monthly share-outs of work-in-progress: informal presentation format - In-person Workshop (see above) - Final presentation: Last week of August 2019 - Delivery August 31st 2019	&Partners Stakeholders

Participants and Recruiting

Participants included in the research include I/T/U staff, I/T/U patients, Tribal community leaders, and IHS leadership. Recruiting occurs in two phases. Below is an outline of the I/T/U Staff recruitment plan.

Phase One Tactics: I/T/U Staff

Emerging Sun Email Account: Contact staff who sent emails to Emerging Sun address (shared during site visits) for remote interviews. Emails will be sent by Sabrina as replies to each individual email sent (see Email Sample 1) using the account. Sabrina to look through submissions to select who we want to contact (IT personnel will be excluded).
In-Person Recruitment: Approach individuals during site visits.

- Ad-hoc in-person interviews
- Listening Session Sign-up sheet: Request for sign-ups for remote interviews
  - Sabrina will send emails directly to each person who opted in to be interviewed (see Email Sample 2) using the hitmodernization@emergingsun.com account.

Re-Engage: Recontact people from sites we've already visited for remote interviews.

Phase Two: I/T/U Staff

Additional round of recruitment based on gaps in our interviews. Groups from the second round may be overwhelmed by requests for participation in other projects, hence why we won't reach out to them initially.
IHS Professional Groups: Email blast for remote interviews

- Howard conducted listening sessions with some professional groups, we might be able to contact them again. They are likely to be super users. Groups include:

- Informatics (clinical application coordinators) group from Great Plains Area – mostly not users in the direct line of care, but there are a couple from that call who might be willing to talk further;
- Health Information Management consultants – these were mostly Area-level HIM people (but some from sites) involved in policy-making; probably not the best group for your purposes but there are folks in that group who could point us to people in the HIM world locally;
- Pharmacy Professional Specialty Group – these are pharmacists at sites, typically super-users, so may have some of the selection bias.
- Nursing groups
- Dental program

Listserv

IHS Listserv Call for Participation: Email blast for remote interviews

- Start with listserv of people interested in the project—it's unlikely we'll obtain permission from IHS to blast all of their employees. Contact: Jason Hairston - jhairston@pistisllc.com

Ethics Considerations

A number of ethical considerations gover this research, including:

- Knowing that approaching Tribal members directly for interviews would be considered a breach of trust between the Tribal leadership and HHS, we will work with patient advocacy to recruit them. They will put us in touch with Tribal leaders who also offer valuable data.
- De-identify and anonymize all data collected from interviews when we log it to protect privacy and the information shared with us.
- Raw qualitative data is accessible only to those performing synthesis and analysis.
- Use consent forms and information sheets in patient and Tribal leader interviews (not with healthcare workers because those are protected by existing relationships with HHS AFAIK).
- Workshop the synthesis with end users (IHS healthcare employees, patients and patient advocates) to make sure the findings correctly reflect cultural and technical nuances of this unique environment.
- Cite and ensure adherence to the code of conduct in all participant communications and meetings.
- Determine what data is collected and why, how it is used or shared, how it is stored and secured, and how long it is kept.
- Determine whether and how users are notified about how personal information is collected and used.
- Ensure the security of sensitive and confidential data.

Expected Outcomes

Outputs may change to adapt to what's most appropriate for the projects needs and learnings from interviews

Journey Maps/Service Blueprints: "Happy path" maps based on overall and unique needs of the population. Does not include edge cases or BMP workflows. Account for interactions between multiple touchpoints (provider-provider,

provider-admin, patient-provider, etc.). 5-8 service blueprints to account for many different common situations grounded in the patient experience, providers' experience, and organizational goals. 5-7 journey maps (simplified, "happy path" process flows) to account for simpler needs and goals (e.g. leadership)

Personas/Archetypes: High level descriptions based on attributes, aptitudes and attitudes; ~20-25 archetypes to account for the different roles in the organization

Use Cases: List of high level features written from the user's standpoint ("As a [user] I want to [do something] so that I can [accomplish something]"); will be extracted based on Journey Map, Service Blueprint, and Persona/Archetype work; may be prioritized based on team input.

Interview Protocol & Sample

The following sample interview protocol shows the introduction, sample questions, and closing for a **patient interview**.

Audience	Questions
Introduction	● **This will take about an hour.** Does that still work for you? ● **I am part of a team gathering information on how the use of technology can improve healthcare delivery American Indian and Alaskan Native healthcare facilities across the US.** We are interviewing staff at hospitals, community leaders and members, IHS staff, and more. We are also speaking with people like you who use IHS, tribal and urban facilities to understand their experience, needs and goals for getting healthcare for themselves and their family. We want to map all the different roles and what they do as a set of stories. This will help decision-makers in government who are not familiar with your healthcare system understand the needs and hopefully capture more money for AI/AN communities. ● **We are here to learn from you, not to evaluate you.** The more you are able to share from your own personal experience and points of view, the more we will learn. We understand that health can be hard to talk about sometimes. It's ok if you don't have all the answers, or if you're not sure about something. If there's anything I ask that makes you uncomfortable or that you don't want to answer for any reason, that's ok, just let me know and we'll move on. We look forward to learning from anything you share with us. ● **I am not a tribal member.** We are speaking with folks from many different communities and trying our best to learn about all the different healthcare and cultural aspects, but there's so much still to learn. I will ask some questions that will sound basic because I don't want to make assumptions about your personal experience, so we appreciate your patience. ● **This is a confidential conversation.** Everything we discuss will be anonymized and not identifiable. A report will come out of this, but nothing you share with us will be mapped back to you, the healthcare facility in your community, your state or Area. The more candid you are with us, the more we can learn from you. ● **Is it ok if we record?** It'll be used for internal notetaking purposes. It's ok if the answer is no, we'll just write notes.

	● **Do you have any questions before we start?**
Warm Up	Tell us a bit about yourself so we get to know you better. Where you live, who you live with, how you spend your days… ● Do you care for a loved one's health? If so, who? What are your responsibilities with their health? ○ Does anyone else help care for them? What are their responsibilities? ● Does anyone help you with your healthcare?
Healthcare	Thank you! Let's get a bit into your experience getting the healthcare you need. ● What do you do first when you have a question or concern about your health that you need answers for? ○ Who did you speak with? Did you check online? ● For what reasons do you go to a clinic? How often? ● Think about the last time you or a loved one got sick. ○ What did you do first? ○ Did you go to a clinic? What made you decide it was time to go? ○ Walk me through step by step, how you scheduled the appointment, how you got to the facility, who went with you, things you needed to do to check-in, what happened before you saw the provider, when the provider came in, what happened after you saw the provider… The more detail, the better. ○ What kind of planning did you have to do for this visit? ○ What worked well? What didn't? ○ After seeing the provider, did you have any questions or issues about what was happening next? ■ If so, how did you go about answering those questions or solving those issues? ■ *[if caring for a senior]* Was there anything you or them needed help understanding? How did you go about it? ○ Was there anything different about seeing a provider this time, compared to other times? ● Did you ever have any more complex health issues to deal with? ○ Same questions as question above ● Did you ever have to deal with payment matters? If so, can you tell me more about it? ● Did you ever have to get your health records for any reason? How did you go about it? ● Think about your interactions with the facility and the staff. What are those experiences like for you in general? ○ What works well? What doesn't work well?

Traditional Medicine	● If you're comfortable talking about it, can you share how you use cultural practices in your healthcare and healing, if you use them? ○ Where do cultural healing practices fit into the way you receive or take your healthcare? In what situations do you feel more comfortable consulting with a cultural healing practitioner instead of visiting a hospital or a clinic? ○ What kinds of cultural practices do you typically use for healthcare? ■ Sweat lodge?
Technology and Information Habits	● Do you have internet access? ○ What device do you use for the internet? How is your access? ○ [if mobile] What apps do you use the most?
Final questions	● Think about the healthcare facility or facilities you go to. ○ What would it look like in an ideal world? ○ What are they great at? ○ Where are they falling short? ○ What would they need to do to improve?
Wrap Up	● Thanks for your time! ● Do you have anything you want to share before we finish? ● Is it ok if we reach out to you again if we have any questions?

Summary of Research Findings

The themes below, as well as others not listed here, emerged as essential aspects to consider for Health IT Modernization:

- **Interoperability**: The ability for different facilities, providers, and healthcare systems to exchange information with each other is key to resolve many of the challenges in I/T/U facilities.
- **EHR**: The source of all patient health information should aid the clinical and support staff's workflows, and not be a nuisance. It should adapt to various workflows (facilities distribute tasks differently based on staff capabilities). At the same time, it should provide some consistency necessary for reporting and public health efforts. The rurality of many of these locations should be considered—many providers and care support team members will need asynchronous access to EHR.
- **Telehealth**: It doesn't replace in-person encounters, but it can compensate for many of the staffing issues, particularly in rural facilities. A modern Health IT system needs to support this tool through seamless EHR access to Care Teams, the ability to transmit data to medical devices, and high-resolution video.
- **Patient Registration**: The eligibility requirements based on tribal membership, descendancy, and others are unique in and across I/T/U facilities. Flexible rules, a comprehensive, unique set of demographic data points that help set eligibility levels is an essential requirement.
- **Patient Portal**: Patients and caregivers want easy access to a central repository of all their Patient Health Records. It should be easy to understand and actionable. Tools like scheduling and reminders can help Care Support teams

and Administration staff with struggles around no-shows and contacting patients. Communication tools can help them reach their providers, get screenings as needed without seeing a provider, and even enroll in healthcare insurance and programs.

- **Billing**: Correctly billing a wide variety of payers can help ensure claims are paid on time, and the patient is never charged. Facilities also need accounting tools that estimate Accounts Receivable even if they haven't billed yet.
- **Referrals**: A streamlined, efficient, fast system needs to be in place to resolve these challenges. Health IT modernization may also be an opportunity to redesign the entire workflow around Purchased Referred Care and identify improvement possibilities in the overall process.
- **Cradle-to-Grave Records Legacy**: RPMS has a large amount of medical records from patients who spent their whole lives going to the same facility; records integrity must be maintained during the Health IT Modernization effort.