Towards a Framework for the Development, Implementation, and Sustainability of eHealth Interventions in Indigenous Communities

Kian Madjedi, HBA[1], Rukhsaar Daya, BHSc[2]

[1]Northern Ontario School of Medicine
[2]Faculty of Health Sciences, McMaster University

ABSTRACT

eHealth technology, an umbrella term including telemedicine, telehealth, and mobile health interventions (among others), has recently begun expanding its reach into Indigenous communities. With this new "migration" comes the need for special consideration of the factors that contribute to "successful" adoption, integration, and sustainability of such eHealth technologies in Indigenous communities. While existing frameworks are typically helpful orientations to guide eHealth implementation, they commonly lack elements that give specific consideration to the important nuances and special considerations when piloting eHealth initiatives in these unique and diverse community and cultural contexts. There is thus a need to expand, adapt, or design new eHealth adoption and implementation frameworks that help guide the piloting and use of health technologies in respectful, ethical, and community-centered ways in Indigenous communities. This paper suggests subjective considerations for the preliminary development of a generic eHealth technology adoption and implementation framework in Indigenous communities. Considerations are divided into three main sections: Development and Adoption; Implementation; and Sustainability, with relevant discussion of the centrality of community engagement, inclusivity, and respect.

RÉSUMÉ

La cybersanté est une expression utilisée en médecine pour regrouper différentes technologies telles que la télémédecine, la télésanté, et les interventions de santé mobile. Avec une mise en œuvre graduelle de la cybersanté dans les communautés autochtones, il y a des considérations spéciales et des facteurs spécifiques à prendre en compte pour assurer une intégration efficace et durable de ces technologies. Certaines infrastructures existent déjà pour faciliter l'utilisation de la cybersanté. Toutefois, il est important que l'utilisation de ces technologies soit éthique, respectueuse des différences culturelles autochtones, et en fonction des besoins des communautés autochtones. Cet article suggère des éléments à considérer dans le développement préliminaire d'une approche médicale axée sur la cybersanté et dans la mise en oeuvre d'infrastructure dans les communautés autochtones. Les considérations sont divisées en trois sections : le développement et l'adoption; la mise en œuvre; et la durabilité, avec une discussion sur l'engagement communautaire, l'inclusion, et le respect mutuel.

INTRODUCTION

eHealth technology, an umbrella term including (but not limited to) telemedicine, telehealth, and mobile health interventions, has recently begun expanding its reach into Indigenous communities [1]. With its potential to support increased access to health services in rural, remote, and isolated communities, eHealth initiatives are occupying an increasingly relevant and important place in the spectrum of secondary and tertiary prevention services in Indigenous communities [1]. The diverse initiatives that have been implemented to date range from teleophthalmology-based retinal screening programs, to the use of health promoting short messaging services (SMS) for individuals living with hypertension [4].

With this relatively new "migration" of eHealth technologies into Indigenous contexts comes the need for special consideration of the factors that contribute to their "successful" adoption, integration, and sustainability in these community contexts. Existing frameworks of eHealth technology adoption and implementation tend to focus on best practices for piloting eHealth in urban communities, with an emphasis on quality, efficiency, and cost [2,5]. While these frameworks are typically helpful in guiding eHealth implementation, they commonly lack elements that

give specific consideration to context-specific nuances. There is thus a need to expand, adapt, or design new eHealth adoption and implementation frameworks that help guide the piloting and use of health technologies in respectful, ethical, and community-centered ways.

This commentary suggests subjective considerations in the preliminary development of a generic eHealth technology adoption and implementation framework in Indigenous communities. Considerations are divided into three main sections: Development and Adoption; Implementation; and Sustainability, with the themes of community engagement, respect, and equity cutting across all three considerations.

DEVELOPMENT AND ADOPTION

The importance of contextual inquiry

van Gemert-Pijnen et al. (2011) identify that introducing any eHealth technology into the healthcare system requires careful coordination and communication with health care professionals, patients, and technicians—a process they term "contextual inquiry" [2]. This process is an important but often overlooked consideration in developing and piloting eHealth technology. Specifically, contextual inquiry refers to the process of "information gathering" from the intended users and environment in which the technology will be implemented [2]. In an Indigenous context, there is an even more pronounced need to recognize that eHealth technology development and adoption is a participatory process.

The importance of contextual inquiry in the planning stages of eHealth innovation emphasizes the need for a process of "participatory development" grounded in community engagement [1]. Successful initiatives with Indigenous communities commonly come as the result of working in partnership with the members of the community to develop or provide an eHealth service that addresses a need that the community has identified for itself [3]. It is especially important that the values and opinions of all those involved are taken into consideration and respected throughout the process [3]. It is key to work in partnership with the community from the first day to ensure eHealth technology development begins (and remains) in line with community-directed needs and priorities.

One way to achieve these goals would be to conduct focus groups with community members and leaders to discuss the health needs of the community, and the ways in which eHealth might be able to effectively meet such needs [1]. In particular, those individuals identified as elders in the community should be approached for their input and perspectives on the project. It is of vital importance for the planning stages of programs (health-

related or otherwise) in Indigenous communities to include, from the onset, real and meaningful engagement with elders and inclusion of their perspectives into the design of the project. One key strategy to assist in this relationship-building involves re-framing communities as "co-researchers" with whom the health technology developers are actively working hand-in-hand, rather than seeing communities as "targeted populations" upon whom the technology will simply be passively implemented [3].

In this sense, contextual inquiry during the planning stages of an eHealth initiative moves well beyond a simple "needs assessment" and embraces the full spectrum of relationship-building, community engagement, and participatory action that is so fundamental to research and the development of relationships with Indigenous communities.

Community buy-in and obtaining ongoing permission

Achieving community buy-in is a crucial step in working to pilot or implement any health-related initiative in an Indigenous community [3]. The process of community engagement should include extensive community consultations and the willingness to work collaboratively with partners at the local level [3]. There is a strong need for frequent consultation and to obtain ongoing permission from both political and health leaders in the community [3]. Identifying locally-based individuals who will support the initiative ("local champions") is also critically important to the long-term success of the initiative [5]. With this permission comes the responsibility of generating awareness to ensure members of the larger community are fully aware and generally supportive of the methods and processes that will potentially be implemented in their community [1].

Recognizing existing technological infrastructure

Recognition of the existing technological infrastructure in the community is a critical consideration in rolling out an eHealth initiative [5]. Access to reliable, high-speed wireless signals or broadband may be limited in some communities, leading to the dilemma wherein communities that may perhaps be best suited for the eHealth initiative in question are not necessarily able to participate [5]. Engaging existing telemedicine providers or leaders in the region who have established connections with communities may allow for the use of existing resources, and can also provide a more locally-informed perspective on the resources and feasibility of implementing the initiative [5].

Engaging local health human resources

Evaluating a community's eHealth "readiness" must include positive and respectful engagement with local site coordinators and health workers who will play a central role in the daily function-

ing of the initiative [1,5]. Recognizing *who* will be involved at the frontlines of the project, *what* they believe about the project, and *how* they believe it can be made more relevant and useful to the community is an important step in the development stage that should not be overlooked. Preliminary considerations here might also include developing and delivering specific educational or training sessions for community health workers, and providing access to ongoing technical and financial support.

Identifying multiple funding avenues and contingency planning

The depth and longevity of eHealth initiatives are, in reality, often dictated by financial constraints [3,5]. It is crucial to be aware of the availability of long-term financial support for these projects during the planning stages. Ensuring that potential funding partners recognize and appreciate that the project itself may be required to adapt in response to changing community priorities (and that, as a result, the implementation process may potentially take longer than originally anticipated) is critical.

IMPLEMENTATION

Implementation includes the "enabling and reinforcing activities" as well as the mobilization of resources for the training, education, and use of the technology in daily practice [2]. In an Indigenous context, this might include ensuring ongoing financial and educational support for the community workers who are helping to roll out the initiative; maintaining the relationships that have been built with community members and leaders; and ensuring that there is fair and equitable access to the eHealth service itself.

Providing ongoing support for health workers

Once the initiative has been put in place in the community, it is important to ensure that there are established provisions for open channels of communication with frontline health workers involved in the daily functions of the initiative. This might include establishing and maintaining a dedicated forum for ensuring the perspectives and concerns of the frontline staff are heard.

Making provisions for equitable access

In line with the principles of justice and respect that guide Indigenous community-based health research, there is a need to ensure reasonable and equitable access to the eHealth service among members of the community, especially if the service being researched or piloted is already evidence-based [3]. In order to avoid the paternalistic approach that has marked research relationships with Indigenous communities in the past, implementing a new technology should be done while striving to ensure equitable access in the target population [3]. This provision should

be made both out of respect for equity, and to avoid generating tension between members of the community, or animosity towards the intervention itself.

In the case of piloting evidence-based, health promotion eHealth initiatives, this could be as simple as ensuring the control group receives a lower level of intervention rather than no intervention at all [6]. While this approach may sacrifice internal validity, there are strong precedents for the use of such a method in Indigenous communities [6]. Researchers are encouraged to explore the possible use of the Pragmatic Randomized Control Trial, which trades internal validity for external validity and is commonly seen as flexible and community-supportive for Indigenous health research [6]. This approach is worth considering but is only one of numerous ways of ensuring research or piloting of technology in Indigenous communities is done with a particular emphasis on respect and equity of access.

SUSTAINABILITY

Recognizing the diversity of Indigenous communities

When implementing eHealth initiatives in Indigenous communities, it is crucial to recognize that no two communities are exactly alike. Communities even within the same geographic region may differ substantially in terms of health care resources, infrastructure, and community support for the initiative. A common saying in Indigenous health research circles bears repeating here: "If you have been to one Indigenous community, you have been to one Indigenous community."

Recognizing potential difficulties across "scaling-up"

It is important to understand that eHealth initiatives that are successful in theory (or even in practice) in the urban communities in which they are typically conceived may not necessarily enjoy the same success in diverse Indigenous communities. eHealth sustainability planning should recognize that successful research and development relationships with Indigenous communities require longer term commitments grounded in respect for the communities' approaches and timelines [1]. This underscores the particular attention that needs to be paid to consistent engagement with frontline healthcare providers, and to work with leaders to maintain support for the project, especially when there are changes in community governance (which can occur more frequently than in non-Indigenous communities).

Appreciating subjectivity in measures of result demonstrability

It is important to recognize that "success" in the eHealth initiative may be measured differently by the implementation team and the community itself. While pilot studies of the eHealth

initiative may not necessarily show statistical or strong clinical significance, it may have been perceived as successful from a subjective, qualitative perspective at the community level. Appreciating and making space for formal or informal qualitative evaluation of the perspectives of the community adopters, stakeholders, and patients is an important consideration in the evaluation of such eHealth initiatives [1,5]. With this evaluation should come the recognition that result demonstrability may be a more fluid concept in Indigenous communities.

An openness to ongoing community-directed change

Recognizing that in many cases the initiative may shift its original focus or goals in response to changing community needs or desires is an important consideration when planning for long-term sustainability. Setting up events and leading open and honest presentations that keep the community abreast of the program's updates and findings are both a form of respect and a necessity in ongoing community engagement. Frequent site visits from members of the non-locally based research team generally conveys respect for the community, and should take place on an ongoing basis.

CONCLUSION

eHealth technologies are well positioned to improve access to preventative medicine services in Indigenous communities, and have already made substantial headway thereto in recent years.

Every stage of the development, implementation, and sustainability of such initiatives should occur in partnership with the communities in which they are aimed, and should be grounded in the principles of equitable access and respect.

REFERENCES

1. Maar, M, Seymour, A, Sanderson, B, Boesch, L. Reaching agreement for an Aboriginal eHealth research agenda: the Aboriginal Telehealth Knowledge Circle consensus method. Rural Remote Health. 2010;10:1299.
2. van Gemert-Pijnen J, Nijland N, van Limburg M, et al. A holistic framework to improve the uptake and impact of eHealth technologies. J Med Internet Res. 2011;13(4):e111
3. Chilisa, B. Indigenous research methodologies. University of Botswana: SAGE Publishing; (2012).
4. Ng M, Nathoo, N, Rudinsky, C, Tennant, M. Improving access to eye care: teleophthalmology in Alberta, Canada. J Diabetes Sci Technol. 2009;3(2):289–296.
5. Mutitt S, Vingeault R, Loewen L. Integrating telehealth into Aboriginal healthcare: the Canadian experience. Int J Circumpolar Health. 2004; 63(4):401–414.
6. Saini M, Quinn A. A systematic review of Randomized Controlled Trials of health related issues within an Aboriginal context. National Collaborating Centre for Aboriginal Health. Available from: http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/94/RCT_EN_web.pdf.

Table 1. Towards a preliminary framework of eHealth adoption, implementation, and sustainability in an Indigenous community context.

Development	Implementation	Evaluation & Sustainability
• Community engagement, consultation and buy-in • Ongoing engagement with local community champions • Working in partnership to develop eHealth initiatives that address self-determined needs of community • Community-centred contextual inquiry • Recognize limitations of existing technology infrastructure and health human resources • Obtaining community, political and health sector leadership permission • The importance of respect, reciprocity and rapport in relationship-building • Shift from targeted interventions to co-researcher partnered relationships	• Maximize opportunity for all community members to access service • Recognize the diversity of communities and perspectives • Ensure access to ongoing support for front-line personnel • Ongoing engagement with culturally-safe practices	• Recognize "result demonstrability" is a fluid concept • Recognize difference in significance from a statistical and community-based service perspective • Appreciate that timelines are typically longer when working with Indigenous communities • Maximize contingency planning for funding • Recognize necessity of adapting to shifting community needs and priorities