# DIGITAL STORYTELLING: IMPLICATIONS FOR HEALTH RESEARCH AND POLICY

## A POLICY BRIEF

Based on research conducted through the *Changing Climate*, *Changing Health*, *Changing Stories* project in Rigolet, Nunatsiavut, Labrador, Canada (2009-2012)



Kassandra Hamilton<sup>1</sup>, Ashlee Cunsolo Willox<sup>2</sup>, Sherilee Harper<sup>3</sup>, the 'My Word': Storytelling and Digital Media Lab<sup>4</sup>, and the Rigolet Inuit Community Government<sup>4</sup>

 $<sup>^4</sup>Rigolet, Nunatsia vut, Canada, charlotte.wolfrey@nunatsia vut.com; \\ my.word.rigolet@gmail.com$ 













<sup>&</sup>lt;sup>1</sup>Master's Student, Global Health Program, McMaster University, Hamilton, Ontario, kassandra\_hamilton@yahoo.com

<sup>&</sup>lt;sup>2</sup>Postdoctoral Research Fellow, Department of Geography, McGill University, Montreal, Quebec, ashlee.cunsolo@mail.mcgill.ca

<sup>&</sup>lt;sup>3</sup>PhD Candidate, Department of Population Medicine, University of Guelph, harpers@uoguelph.ca



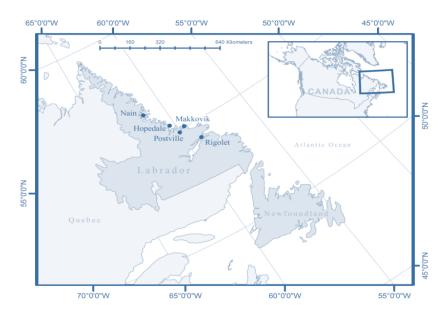
#### **EXECUTIVE SUMMARY**

Newly-emerging digital technologies are expanding the data-gathering and communication strategies available to health researchers. In particular, digital storytelling—the process of uniting audio, photographs, video, and music to create a three-to-five minute first-person digital narrative—is showing strong promise as an effective and engaging research method, capable not only of creating locally-relevant narratives, but also of developing culturally-appropriate health communication platforms.

This report outlines the value of digital storytelling as a participatory health data-gathering method that can also be used as a health communication strategy, particularly for Indigenous communities in Canada, such as the Inuit. Building from findings and experience emergent from the *Changing Climate*, *Changing Health*, *Changing Stories* project, a multi-year, community-led, participatory project conducted in Rigolet, Nunatsiavut, Labrador (Figure 1) from 2009 to 2012, digital storytelling was used as:

- 1. A method to gather data around climate change observations and climate-health challenges from a first-person perspective;
- 2. A strategy to expand and complement other health research methods; and
- 3. A platform for creating health communication messages containing local voices and experiences in a culturally-meaningful format.

This report will discuss recommendations based on the challenges and success of using digital storytelling, pulling from a case study based on climate-health research, and the resulting impacts for the community, researchers, and policy makers. The potential uses for digital storytelling in other health sectors will also be discussed.

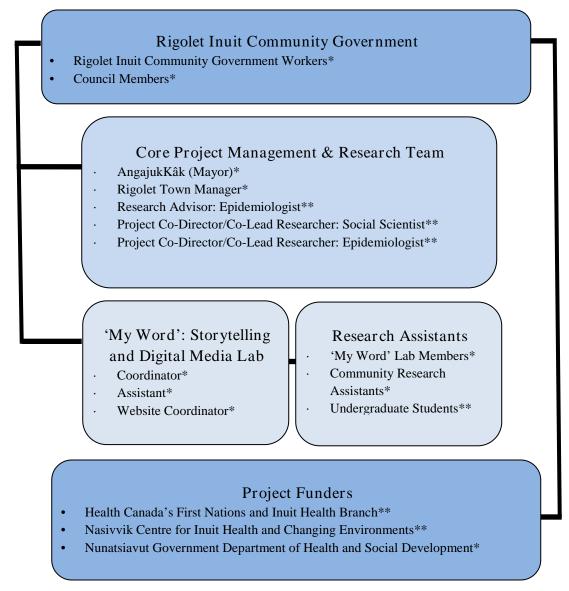


**Figure 1:** A map depicting Rigolet, Nunatsiavut, Labrador, Canada, along with the other four communities in Nunatsiavut, Nain, Hopedale, Postville, and Makkovik.



#### CHANGING CLIMATE, CHANGING HEALTH, CHANGING STORIES PROJECT

The Changing Climate, Changing Health, Changing Stories project brought together a transdisciplinary team of Indigenous and non-Indigenous researchers to study the impacts of climate change on the physical, mental, emotional health and well-being for the community of Rigolet, Nunatsiavut through community-engaged participatory methods (Harper et al., 2012; Figure 2). Based in Rigolet, Nunatsiavut, and led by the Rigolet Inuit Community Government, this project piloted the use of digital storytelling as a data-gathering method, a health-communication platform, and a community-led research process.



<sup>\*</sup>Represents Rigolet, Nunatsiavut, and/or Inuit members

**Figure 2:** An Overview of the *Changing Climate, Changing Health, Changing Stories* Project Team and associated funders (2009-Present) (Cunsolo Willox et al., 2012).

<sup>\*\*</sup>Represents non-Rigolet and non-Indigenous members



#### DIGITAL STORYTELLING: POTENTIALS FOR HEALTH RESEARCH

Newly-emerging digital technologies are expanding the data-gathering and communication strategies available to health researchers. In particular, digital storytelling is showing strong promise as an effective and engaging research method, capable of not only creating locally-relevant narratives, but also of developing culturally-appropriate health communication platforms.

As a process and a participatory research method premised on community engagement and narratives, digital storytelling allows participants to create three-to-five minute first-person digital narratives, illustrated with video clips, photographs, artwork, music, and text. Conducted by trained digital storytelling facilitators, participants create these stories within a week-long workshop, which provides them with all needed skills and technologies to create the digital stories. These workshops also emphasize participant engagement and sharing of narratives to hone the stories while simultaneously increasing group cohesions (Cunsolo Willox et al., 2012b, Gubrium, 2009; Lambert, 2006).

Digital storytelling not only adds value through its use as a reflective tool for personal, professional, organizational and community development (Freidus & Hlubinka), it also provides an excellent medium for promoting health and for disseminating health information (Wyatt & Hauenstein, 2008; Drew et al, 2010). Going further, digital storytelling can also encourage the sharing of information between regions in a short period of time, and promote awareness about what is happening in a community, from a community perspective.

Finally, digital storytelling has the potential to help to mitigate social inequities in health research by involving those concerned directly in the research process, and by providing a platform for individuals and communities to tell their own stories, in their own voices (Israel, Eng, Schultz, & Parker, 2005).

# A CASE STUDY: THE CHANGING CLIMATE, CHANGING HEALTH, CHANGING STORIES PROJECT

Through a case study of using digital storytelling as research method through the *Changing Climate*, *Changing Health*, *Changing Stories* project, digital storytelling emerged as a strong community-based, qualitative, research method appropriate for working with Indigenous communities, and resonates with the strong oral story traditions within many of the communities (Cunsolo Willox et al., 2012b; Harper et al. 2012).

The potential of using digital storytelling as a climate-health data collecting strategy is evident in the numerous climate change observations made in the digital stories created in Rigolet. Many observations shared by participants highlighted the complex ways in which these changes were altering socio-cultural activities, and subsequently negatively impacting health and well-being in the community (Table 1).



Table 1: Climate change observations emergent from the digital stories created in Rigolet, Nunatsiavut (2009-2011), and the perceived impacts on health and well-being.

Climate Change Observations from the Digital Stories	Social and Cultural Implications of Climate Change from the Stories	Potential Health Impacts of Climate Change from the Stories
Changes in Climate, Ice, Snow, and Water Patterns		
<ul> <li>Alterations in precipitation patterns</li> <li>Decrease in water levels of brooks and ponds</li> <li>Decrease in snow and ice quality, stability, and extent</li> <li>Warmer seasonal temperatures</li> <li>Shorter winter season</li> </ul>	<ul> <li>Disruption to ability to travel safely on the land</li> <li>Decrease in access to fishing and hunting</li> <li>Decreased access to cabins due to lack of snow and ice</li> <li>Change in overall lifestyle due to changes in land access</li> <li>Loss of intergenerational knowledge transmission opportunities</li> </ul>	<ul> <li>Decrease in physical activity</li> <li>Decrease in ability to access wild meat and country foods</li> <li>Decrease in quality of mental health due to being unable to travel on the land and hunt, fish, forage, and trap</li> <li>Change in emotional health due to change of lifestyle</li> <li>Increase in mental and emotional stress around future of cultural activities and knowledge transmission</li> </ul>
Changes in Hunting, Fishing, and Food Security		
<ul> <li>Animal migration patterns, behaviour, and overall health are changing</li> <li>Decrease in availability of fish due to warming waters</li> <li>Decreased access to travel and hunting grounds due to lack of snow and unstable ice</li> </ul>	<ul> <li>Decreased ability to hunt, fish, and trap</li> <li>Lost revenue from decreased hunting and fishing</li> <li>Change in cultural patterns of land-based activities</li> <li>Loss of intergenerational knowledge transmission opportunities</li> </ul>	<ul> <li>Decrease in physical activity</li> <li>Decrease in nutritional intake from inability to access country foods</li> <li>Increase in diabetes and obesity due to increase in salt and preservatives in store-bought food and decreased wild meat consumption</li> <li>Decrease in quality of mental health due to increased stress and anxiety levels over lost revenue, food security, and cultural connections</li> <li>Increase in mental and emotional stress around future of cultural activities and knowledge transmission</li> </ul>
Changes in Foraging and Access to Medicinal Plants		
Decrease in abundance of vegetation used for food or medicinal purposes		<ul> <li>Decrease in physical health due to loss of medicinal plants</li> <li>Decrease in quality of mental health state as cultural activities become less accessible</li> <li>Increased mental and emotional stress around future of cultural activities and knowledge transmission</li> </ul>

**Note:** These changes were also resonant with the findings from the interviews, focus groups, and surveys conducted in Rigolet as part of the *Changing Climate, Changing Health, Changing Stories* project (Cunsolo Willox et al., 2012, b; Harper et al., 2012; Ostapchuk et al., under review; Petrasek MacDonald et al., 2012).



For example, in the digital story created in Rigolet, My Dad Taught Me Well (2010, 2:32), the narrator linked decreased snow and ice conditions with an inability to hunt country food and subsequently, an increased reliance on store-bought food: "Hunting has changed," he stated as pictures of trout and caribou meat, juxtaposed with store-bought food appear on the screen, "it is not so plentiful. Eating healthy is hard to do these days. The stuff from the store is so expensive, and there is so much salt in there and preservatives, it's not good for us. It's time for us to be eating our own traditional foods, so we can take care of our bodies." This digital story illustrates the ways in which changes in climate and land conditions are disrupting food security and decreasing the quality of nutritional intake for the Rigolet community.

Similarly, in the digital story, <u>Have we Waited too Long</u>? (2010, 3:42), the narrator explained that a decrease in snow and ice has affected all aspects of Inuit culture: hunting, fishing, trapping, foraging, traveling, and intergenerational knowledge translation. In addition to physical health impacts from these changes, this story also emphasizes the mental and emotional impacts, such as fear, anxiety, worry and concern about the climate changes in the community. "I worry that my children will not get to do all the things that I found so exciting," she shared, illustrating her words with pictures of her children learning on the land from their grandparents. "Will they be able to pass our traditions onto their children?...Not only is our weather changing, but our whole way of life is changing along with it." Going further, the narrator questioned: "Is it too late for us to preserve our way of life? Or has too much already changed?" This fear for the loss of intergenerational knowledge-sharing opportunities, combined with anxiety about the potential loss of cultural activities, communicates the nuanced and interrelated connections among climate change, physical health, and mental health.

While this research has been conducted in a Canadian Inuit context, the use of digital storytelling in community based health research as a data-gathering strategy, a communication platform, and way to expand and enhance adaptive capacities is broadly applicable to researchers working on climate-health and participatory research in other communities and regions in Canada and globally.

#### **DIGITAL STORYTELLING: POLICY POTENTIALS**

Digital storytelling is emerging as an innovative community-based participatory research method that increases community members' participation in research on local health issues (Cunsolo Willox et al., 2012b). For example, many participants in the Rigolet case study reported that they thought digital stories could communicate local observations and wisdom effectively not only to researchers, but also to policy makers and government representatives. This was due to the ability of digital storytelling to share local knowledge with policy makers in a way that is personal, engaging, and easily accessible.

Rigolet residents also reported that it was important for policy makers to understand what was happening in the community, from a *community* perspective. In addition, digital stories can be communicated between regions locally, nationally, and globally, in a very short period of time. For these reasons, digital storytelling is gaining attention as a valuable strategy for policy makers to use as a tool for community health promotion (Cunsolo Willox et al., 2012b; Gubrium, 2009).

<sup>&</sup>lt;sup>1</sup>While there were a number of digital stories created in Rigolet discussing the impacts of climate change on health, only two examples from exemplary and complementary stories are highlighted in this report. For more stories, visit <a href="www.rigolet.ca">www.rigolet.ca</a>.





#### DIGITAL STORYTELLING: CHALLENGES FOR RESEARCH AND POLICY

There are certain challenges associated with incorporating digital storytelling as a health method to inform research and policy. From the experiences of the *Changing Climate*, *Changing Health*, *Changing Stories* project, these

- While digital storytelling allows a health platform to be moved into a public arena, for some Rigolet
  community members, there was concern about having the digital stories available on the internet for
  public use and public consumption, for fear of perpetuating stereotypes about the community. It is
  important that participants and communities are directly and continually involved in discussions around
  usage and sharing of stories (Cunsolo Willox et al., 2012b).
- Using digital stories as health data can be challenging because not all researchers and policy makers will be comfortable with analyzing or understanding the stories, themselves, as data. Furthermore, many individuals want numbers, and it is difficult to measure, in quantitative terms, data from digital stories, or how digital stories may impact health policy (Wang & Pies, 2004). That said, from the experience of this project, digital stories provide an excellent narrative complement to other forms of research, and can share rich and personal details about the larger research questions being examined (Cunsolo Willox et al., 2012b).
- Applying for institutional review board (IRB) approval for conducting a digital storytelling workshop can
  potentially be challenging, as the method is not known to all reviewers because digital storytelling is a
  relatively new, qualitative method of recording health data (Gubrium, 2009). Again, from the experiences
  of this project, once an understanding of the digital storytelling method emerges, there is support and
  appreciation for this approach.

#### RECOMMENDATIONS FOR RESEARCHERS AND POLICY MAKERS

Based on experiences with the *Changing Climate, Changing Health, Changing Stories* project, as well as findings in published literature, the following recommendations emerge when using digital storytelling in health research.

- Before carrying out a digital storytelling project, it is recommended that those involved recognize the
  purpose of their research, identify resources and partners, as well as the audience, and ethics involved. It
  is important to develop a project timeline, a budget, a communication plan, and clear guidelines for the
  research process and community involvement. Participant and community involvement at all stages of the
  research process is imperative for success, support, and community buy-in.
- Since there are sometimes differences in the application of digital storytelling methodology (Hergenrather et al., 2009), those who apply a digital storytelling method to their own community-based participatory research are encouraged to carefully document and report the details of their work, and share with others (Castleden et al., 2008). In addition, modifying and altering the digital storytelling process to meet local



contexts and needs is also an important part of the process, and often essential to the final outcome and the quality of the stories (Cunsolo Willox et al., in press).

• The use of digital storytelling to promote health awareness is particularly useful for youth because younger audiences become easily engaged in stories and interactive information, and are already usually very interested in, and engaged with, new media technologies (Wyatt & Hauenstein, 2008; Drew et al, 2010).

#### **CONCLUSION**

It is clear that digital storytelling has many applications as a participatory research method, and an engaging communication platform (Cunsolo Willox et al., in press; c.f. Gubrium, 2009). Its first-person narrative form, the digital format, and the visual nature of the video all connect to create powerful 'digital dialogues' around specific topics and can serve to enhance and expand understanding about local health issues through local voices, experiences, and wisdom (Cunsolo Willox et al., 2011 in press).

"It is important for policy makers to understand [what is happening in our community]. Stories make this click. We have to get the message out there and let everybody know what is going on." Rigolet Resident

Digital storytelling shows promise and potential of both communicating and sharing challenges to diverse audiences nationally and internationally, in a

holistic way, and allows community voices and perspectives to be heard. Digital storytelling serves as a method for community participants to produce something concrete and tangible out of their experiences, thus being a forum for advocacy on issues of concern (Gubrium, 2009). Digital storytelling provides an alternative way to share local knowledge with researchers and policy makers in a way that is personal, engaging, and easily accessible. It has the ability to complement other forms of data-gathering methods with first-person narratives and lived experiences, and to enhance understanding of the complexities of health research. Finally, by virtue of its form and structure, digital storytelling is also an excellent communication platform, and the digital stories produced can also share health information and health messaging with a variety of audiences locally, regionally, nationally, and internationally.

"Digital storytelling informs people how fast climate change is happening and how fast policy makers gotta take action and do something about it." Rigolet Resident Together, these individual stories come together to create a rich tapestry of local experiences and wisdom, and important data and health information that is locally-appropriate and culturally-relevant (Cunsolo Willox et al., in press). As one Rigolet community member suggests, "maybe you can't learn from just one story, but as a collective, all the stories are informative of the community

as a unit and how it is transitioning towards a different type of future. More stories should be told."

For more information on the digital storytelling process in Rigolet, please contact the 'My Word': Storytelling and Digital Media Lab coordinators, Marilyn Baikie and Inez Shiwak, by email at <a href="mailto:my.word.rigolet@gmail.com">my.word.rigolet@gmail.com</a> or by phone at 1-709-947-3313. Postal address: 'My Word': Storytelling and Digital Media Lab, Rigolet Inuit Community Government, Rigolet, Nunatsiavut, NL, A0P 1P0.

### October, 2012

#### Digital Storytelling: Implications for Health Research & Policy

#### **WORKS CITED**

- Castleden, H., Garvin, T., Huu-ay-aht First Nation. (2009). Modifying Photovoice for community-based participatory Indigenous research. Social Science & Medicine, 66 (6), 1393-1405.
- Chamberlin, J. (2003). If This is Your Land, Where Are Your Stories? Ohio: Pilgrim Press.
- Cunsolo Willox, A., Harper, S., Edge, V., the 'My Word' Lab, and the Rigolet Inuit Community Government. (in press). Storytelling in a Digital Age: Digital Storytelling as an Emerging Narrative Method for Preserving and Promoting Indigenous Oral Wisdom. Qualitative Research.
- Cunsolo Willox, A., Harper, S., Ford, J., Landman, K., Houle, K., Edge, V., and the Rigolet Inuit Community Government (2012). "From this Place and of this Place": Climate Change, Health, and Place in Rigolet, Nunatsiavut, Canada. Social Sciences and Medicine. 75(3), 538-547.
- Cunsolo Willox, A., Harper, S., Edge, V., Landman, K., Houle, K., Ford, J., and the Rigolet Inuit Community Government (2011). 'The Land Enriches the Soul:' On Environmental Change, Affect, and Emotional Health and Well-Being in Nunatsiavut, Canada. Emotion, Space, and Society, special issue on Ecology and Emotion. Doi: 10.1016/j.emospa.2011.08.005.
- Drew, S., Duncan, R., Sawyer, S. (2010). Visual Storytelling: A beneficial but challenging method for health research with young people. Qual. Health Res., 20, 12, 1677-1688.
- Freidus, N., and Hlubinka, M. (2002). Digital Storytelling for Reflective Practice in Community Learners. Siggroup Bull 23:24-26.
- Gray, N., Ore de Boehm, C., Farnsworth, A., and Wolf, D. (2010). Integration of Creative Expression into Community Based Participatory Research and Health Promotion with Native Americans. Fam Community Health, 33, 3, 186-192.
- Gubrium A. (2009). Digital storytelling: an emergent method for health promotion research and practice. Health Promotion Practice 10:186-191.
- Harper, S., Edge, V., Cunsolo Willox, A., and the Rigolet Inuit Community Government. (2012). 'Changing Climate, Changing Health, Changing Stories' Profile: Using an EcoHealth Approach to Explore Impacts of Climate Change on Inuit Health. EcoHealth. 9(1), 89-101.
- Hergenrather, K. C., Rhodes, S.D., Cowan, C.A., Bardhoshi, G., Pula, S. (2009). Photovoice as Comunity-Based Participatory Research: A Qualitative Review. Amer. J. of Health Behavior. 33,6, 686-698.
- Isreal, B., Eng, E., Schulz, A., Parker, E. (2005). Methods in Community-Based Participatory Research for Health. CA: Jossey-Bass.
- Lambert, J. (2006). Digital storytelling: Capturing lives, creating community. Berkeley, CA: Digital Diner Press.
- Minkler, M., & Wallerstein, N. (2002). Community-based participatory research for health. San Francisco: Jossey-Bass.
- Ostapchuk, J., Harpers, S., Cunsolo Willox, A., Edge, V., and the Rigolet Inuit Community Government. Climate Change Impacts on Inuit Health: Community Perceptions from Elders and Seniors in Rigolet, Nunatsiavut, Canada. Under review.
- Parlee B, Berkes F, and the TeetlÕit GwichÕin Renewable Resources Council. (2005). Health of the land, health of the people: a case study on gwich'in berry harvesting in northern Canada. EcoHealth 2: 127–137.
- Petrasek MacDonald, J., Harper, S., Cunsolo Willox, A., and the Rigolet Inuit Community Government. A Necessary Voice: Considering Climate Change through the Lived Experience of Inuit Youth in Rigolet, Nunatsiavut, Canada. Doi: 10.1016/j.gloenvcha.2012.07.010
- Wang, C., and Pies, C. (2004). Family, Maternal, and Child Health Through PhotoVoice. Maternal and Child Health Journal 8: 95-102.
- Wyatt, T. and Hauenstein, E. (2008). Enhancing Children's health Through Digital Story. Computers, Informatics, Nursing 26: 142-148.