

Digital Storytelling (DST) in Health Research: Amplifying Patient Voices to Improve Person-Centred Care

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Introduction

Digital storytelling (DST) is a qualitative, arts-based research method that integrates narrative and digital media to create engaging and creative ways of exploring complex health issues and communicating research findings.(1) Digital stories are typically short, first-person videos, approximately 3 to 5 minutes in length, that combine a narrated voice with images, video clips, music, and sound.(1, 2) Guided by trained DST facilitators, the methodology provides a structured yet flexible framework that empowers workshop participants with full creative autonomy, enabling them to make decisions about how their story is told and represented in a way that is personally meaningful.

Arts-based methods have been found to be highly engaging for people with lived experience and promoting interaction with researchers and the research process.(3) Arts-based methods have been well established in other fields, but newer to health research.(4) Incorporating arts-based methods such as DST into the health research process encourages deep reflection on health experiences, helping participants to process emotions, make sense of illness or recovery, and share personal insights and learnings in an intentional and meaningful way. These short and impactful stories also offer an opportunity for viewers to engage in reflective learning. DST promotes inclusivity and challenge power dynamics by providing alternative ways of engaging with research topics and empowering underrepresented groups to share their lived experiences. DST can promote and support person-centred care as the stories depict the storytellers' lived experiences, bringing what is important to their health and quality of life.

DST can also be used in patient-oriented research to engage patients as partners in the health research process. The Canadian Institutes of Health Research defines patient-oriented research as research that engages patients as partners, focuses on patient-identified priorities, and improves patient outcomes.(5) Within patient-oriented research, patient partners are engaged at all or as many stages of the research cycle including setting research priorities, informing the research proposal, collaborating in data collection and analysis, and supporting knowledge translation efforts.(5) Patient-oriented research supports learning health systems, through providing research evidence to improve healthcare practice and systems. Digital stories in patient-oriented research spotlight patient priorities, experiences, and recommendations. They can also promote

continuous improvement in healthcare systems by providing an arts-based approach to data collection and analysis.

The Alberta SPOR SUPPORT Unit (AbSPORU) Patient Engagement Team works with research teams to support their patient-oriented research project through capacity building opportunities such as training and workshops in health research methods and digital storytelling.(6) As a patient-oriented research team, our aim is to incorporate digital storytelling in patient-oriented research by engaging patient partners in creating digital stories to support knowledge translation efforts in health research. Therefore, in this paper, we detail the process of how we worked with patient research partners to create their own digital stories and the outcomes of working together in the workshops.

Methods

Below, we described the approach to creating the digital stories, main themes and topics addressed in the digital stories and the outcomes of those workshops.

Our DST workshops were co-facilitated by two team members; (SM), lead patient-researcher, and (SA) research associate. Both have participated in a digital storytelling workshop through the StoryCenter and SM also completed the DST facilitator training offered by the StoryCenter.

Digital Storytelling Method: The 7 Steps

The Digital Storytelling (DST) methodology developed by Joe Lambert, Story Center, USA, is a structured seven-step approach used by DST facilitators to support workshop participants in creating short but impactful digital stories.(2) The seven-step method served as a framework for recognizing and engaging with diverse ways of knowing, understanding, and existing in the world. Its primary objective was to foster reflection, prompting individuals to explore their emotions, express key insights, and craft a concise yet impactful digital media narrative.

The 7 steps to DST methodology are:

1. Owning Your Insights,
2. Owning Your Emotions,
3. Finding the Moment,
4. Seeing Your Story,
5. Hearing Your Story,

6. Assembling Your Story, and
7. Sharing Your Story.

The initial three steps were pivotal in this process as they encouraged deep introspection and were the starting point for crafting a script. Workshop participants were encouraged to reflect on the emotions experienced during a specific event, identify the lessons learned, and pinpoint the transformative moment in their healthcare experience where a change occurred, whether initiated by themselves or external forces. Storytellers shared their stories during a guided story circle which is meant to help each storyteller in moving their story forward. These reflections were then translated into a written script ranging from 200-400 words. The visual aspect of storytelling involved selecting images and short video clips that best convey the story, emphasizing the principle of less is more to prevent an overload of visuals resembling a slideshow. The recorded voice of each storyteller enhanced the authenticity, uniqueness, emotional tone, and connection of the digital story. The final steps were a creative process that involved the storytellers assembling all elements into a video editing software program. Each digital story produced through this method was inherently unique, highlighting endless possibilities for creativity and personal expression. Using the seven-step approach guided each storyteller in having full autonomy to create their story in the way that they would like it to be told.

In our projects, the DST workshops were delivered online, or hybrid. However, they can be delivered in-person only.

Outline of the Online DST Workshop (6-weeks)

Each week included a specific tutorial to support the workshop participants in creating their stories. We also watched examples of different digital stories created from various individuals and reflected on them together. Additional one-on-one office hours were provided to support the workshop participants in the week's task. An overview of how we structured our online digital storytelling workshops is presented in Table 1.

Table 1. Overview of the Online DST Workshop (6-weeks)

| Session Title | Description |
|--|--|
| 6) An introduction to digital storytelling | In this session, the group introduces themselves and provide an overview of the story they are thinking of working on. The facilitators also provide an introduction to what digital storytelling is, the seven steps of digital storytelling, and examples of digital stories. |
| 6) Storycircle #1 and Introducing Video Editing Software | In this session, each person is given an allotted time to share their ideas for their digital story. Some storytellers come to the storycircle with a written excerpt (though that is not required). After each person shares, we have a group feedback session where the other storytellers ask further probing questions or point out aspects of the story that stood out to them. Between sessions 2 and 3, storytellers are asked to draft a script that they will share at the next session. |
| 6) Storycircle #2 and Voice Recording | In this session, each person is given an allotted time to share their draft script for their digital story. Group feedback following each person's script reading allows for refinement of the script. The facilitators also provide tips for voice recording. Between sessions 3 and 4, the storytellers refine their script with the support of the facilitators and record their voice once the script is finalized. |
| 6) Introduction to video editing | In this session, the facilitators provide a tutorial on how to select images, and the basics of video editing on the editing software. At the end of the session, storytellers are prepared to put together a rough cut of their digital story. |
| 6) Advanced Video Editing | In this session, the facilitators provide a tutorial on WeVideo for transitions, motions, adding sound, and titles. Storytellers can also share their initial edits with the group for feedback. |
| 6) Story Screening | In this session, storytellers invite anyone they want to come to the screening of the stories (all storytellers must give permission for others to join the session). The group discuss their final reflections about their stories and process of creating their stories. |

Ethical Guidelines

The digital storytelling workshops were conducted with adherence to ethical considerations.

Storyteller wellbeing was at the forefront, and we obtained consent from workshop participants

at various stages. Consent was an on-going process, and not a one-time activity. The ethical guidelines that underpin our work adhere to both the CIHR Ethics Guidance as well as the Storycenter's ethical guidelines for digital storytelling.(7, 8) These guidelines ensured our workshops were conducted in a safe manner. Ultimately, the digital stories belong to the storytellers, and storytellers make their own decisions regarding their story. We provided feedback with the intent of supporting the storytellers in their process. Following the workshop, we sent an online survey to each participant to ask whether they give consent to be contacted for future opportunities to share their story (educational webinar, conferences, and websites). When an opportunity arose, such as a conference workshop- we reached out to storytellers to plan the workshop together.

Results

DST Workshops: Between 2020 and 2024, our research team held four digital storytelling workshops each focusing on an overarching topic of improving person-centred care from the patients' perspective. In total, we worked with 22 storytellers in crafting their digital stories. The storytellers were adults with lived experience of the specific health research theme aligned with the research teams we partnered with. The first workshop theme, **Quality of Life: From the Patient Perspective** was funded by our research team, the second workshop theme, **GUT FEELINGS** was funded by the IMAGINE SPOR research network , the third workshop theme, **Bias and Stigmatization in Healthcare**, was sponsored by a researcher from Athabasca University and the fourth workshop theme, the **Indigenous Grandmother's Wisdom Network**, was sponsored by a researcher from University of Alberta. The purpose of these workshops were to create digital stories from the perspectives of patients to support research programs and contribute to knowledge translation efforts. Some of the patient partners from our workshops gave permission for their stories to be shared on our Digital Storytelling webpage here: <https://absporu.ca/digital-story-telling/>.

Table 2. Overview of the Workshops

| Workshop Theme | Patient Population | Outcomes |
|--|---------------------------|--|
| Quality of Life from the Patient Perspective | Chronic Conditions | Digital stories that have been presented at international and local conferences through workshops, poster and oral presentations, at other digital storytelling workshops. Some of the stories have also been shared on the AbSPORU website. |
| GUT Feelings (personal stories on the topic of Inflammatory Bowel Disease (IBD) and/or Irritable Bowel Syndrome (IBS), and their struggles with diet and/or mental health) | IBD and IBS | Educational Webinar through the IMAGINE network |
| Bias and Stigmatization in Healthcare | Various health conditions | Educational workshop at a local health research conference |
| Restoring and strengthening traditional family systems | Indigenous Health | Presentations at international conferences |

Workshop 1: Quality of Life from the Patient Perspective

In this workshop, we invited seven patient partners living with chronic conditions, who had previously collaborated with our team in prior projects to participate in a DST workshop. Storytellers were asked to reflect on what quality of life means to them, while navigating chronic conditions. Their narratives highlighted similar themes, including, managing mental health challenges, drawing strength from psychosocial supports such as family and pets, cultivating resilience after surgery, and experiences of patient empowerment. One storyteller spoke about how her struggles with managing her diabetes motivated her to join an international online diabetic community, where members collaboratively developed an app to support diabetics.

The storytellers, together with their facilitators went on to co-present two workshops at academic research conferences on quality of life and patient-oriented research. They presented about the digital storytelling methodology, group reflections on the process of creating their digital story in

a group setting, and reflections on shared similar themes among their stories. One of the storytellers and co-author of this manuscript (VK) reflected on their experience with taking the workshop:

“Creating my digital story became one of the defining moments of my recovery. It pushed me to look closely at what a “good life” meant after my injury, and what recovery required—physically, emotionally, socially, and spiritually. I hadn’t attempted anything creative since getting sick, and I honestly wasn’t sure I could. But I was encouraged to try, and the process showed me how far I had already come.

The workshop felt safe for exploring topics that were still tender. We each arrived with more than one possible story, but through talking together, we found the one that was ready to be expressed. Our facilitators were essential—they helped us avoid stories that were still too raw, which mattered for me after so many painful moments of feeling broken or disconnected from myself.

Working at my own pace, with support from facilitators and peers, made the process manageable. My cognition made organizing and staying focused difficult, so the flexible structure and gentle deadlines were exactly what I needed. Drop-in hours helped when I felt stuck.

Recording my narration was the hardest part. I still had significant aphasia and speech apraxia, and my mouth often refused to make the sounds I needed. It took many attempts to record each sentence. But listening back helped me hear what needed improvement. My speech therapist was shocked at how much progress I’d made, and I still believe DST could be a valuable therapeutic tool for people with aphasia and speech apraxia.

I never expected the story to become so valuable in my life. I use it to explain my disability, introduce my assistance dog, support the organization that trained her, and remind myself of how far I’ve come. The process helped me make peace with my limitations, and the video still encourages me on difficult days.

I also use the story to show medical professionals the importance of holistic recovery. My doctors focused on medication and therapy, but what helped me most—like the daily structure and connection my assistance dog gave me—was never considered treatment. DST helped me

show that healing comes not just from clinical interventions but from relational support, belonging, emotional safety, and steady companionship.

I appreciated experiencing “living consent” for the first time, being asked repeatedly whether I still felt comfortable sharing my story. That sense of safety mattered.

To me, DST is powerful because it reaches people in ways that data and numbers never can. Healthcare often speaks in statistics, but humans don’t connect through metrics—we connect through stories. A real voice, a real face, a real moment of lived experience can spark understanding and compassion in a way a chart never will. DST brings humanity back into the conversation, and that’s what truly inspires change.”

Another storyteller reflected on the meaning of quality of life:

“These stories reminded us that quality of life isn’t defined by what people are up against, but by the meaning they build in the middle of it. Through digital storytelling, lived experience became strength you can see evidence of how people keep finding their way forward, even when the path is uneven. Their voices didn’t just describe life with a chronic condition; they showed the courage it takes to keep shaping a life that’s still theirs.” - Clifford Ballantyne

Workshop 2: GUT FEELINGS

Six patient partners living with inflammatory bowel disease (IBD) and/or irritable bowel syndrome (IBS) participated in our workshop to create digital stories for the IMAGINE (Inflammation, Microbiome, and Alimentation: Gastro-Intestinal and Neuropsychiatric Effects) Chronic Disease Network. All the stories aligned with the themes of diet and/or mental health. Some patient partners chose to focus their stories on their experiences leading up to surgery or how they dealt with surgery, while others chose to focus their stories on the experience of living with their condition (for instance bathroom anxiety and struggles with diet). One patient partner spoke about the experience of receiving compassionate care from her family doctor, and her journey to becoming a patient partner.

These six digital stories are currently publicly available on the IMAGINE IBD website <https://imaginespor.com/patient-stories/>. Collaboratively, our team and the IMAGINE SPOR team including the patient partners hosted an educational webinar about the experience of living with IBD and IBS. In the webinar, the digital stories were showcased, and audience members

had the opportunity to reflect and ask questions to the storytellers. One of the questions asked was on the difficulty in recruiting men for this workshop. The storytellers reflected that men are not as open to talk about their health and experiences compared to women, which may have led to more women interested participating in the DST workshop.

“As a patient living with a chronic illness, digital story telling has highlighted the impact of the most pivotal events within my disease journey and how they have defined how I’ve navigated my everyday life since being diagnosed. Digital storytelling has enabled me to better understand the importance of documenting your chronic illness journey as it acts as a catalyst to not only advocate for your health needs but also as a community. Digital storytelling exercises have provided patients like myself with an avenue to not only reflect on the past, but also thoughtfully map the future positioning the right tools and resources when needed. Overall, digital storytelling has the power to provide patients across various stages of life with the power to comprehend, grieve, and build acceptance around one’s chronic illness.” Ashley Patel

Workshop 3: Bias and Stigmatization in Healthcare

Four patient partners working with the team participated in the workshop to share their stories of facing bias and stigmatization in healthcare. Some of the stories that patient partners shared were on the negative experiences they encountered while they were in hospital. For instance, one patient partner shared a story of their surgeon openly making rude comments about the patient’s weight with other healthcare providers in the room. Another patient partner shared a story about being discriminated against in hospital due to her mental health condition. Collaboratively, our team and the Bias and Stigma research team worked and carried out an educational workshop on bias and stigmatization for a patient-oriented research conference.

Workshop 4: Indigenous Grandmother’s Wisdom Network

In this DST workshop, we collaborated with four grandmothers who work with a research team on the development of Indigenous-focused early interventions to improve health outcomes in later life for Indigenous communities. The theme of the workshop was on restoring and

strengthening traditional family systems. The digital storytelling workshop was modified to align with the needs and comfort of the grandmothers we worked with. Rather than the facilitators leading the workshop, the grandmothers were given control on how they wanted the sessions to go, including the storycircle. The digital storytelling process with the Indigenous grandmothers is summarized in this thesis dissertation.(9) In prior discussions with their research team, the grandmothers expressed their desire to create a project that would focus on nurturing the well-being of the entire family unit (and extending to the broader community). The grandmothers were asked to reflect on a time they felt connected to their traditions or culture, a time when they felt most connected to family, or something they would like to pass down to their grandkids. The grandmothers each had unique stories focusing on family, community, and sacred teachings. For instance, one grandmother created a DST on the process of creating moss bags and their impact. Another grandmother reflected on sacred teachings she had been taught as a child that she would like to pass down.

Discussion

This paper described the digital storytelling workshops and collaborations with patient partners across Canada. We described our digital storytelling process for all four workshops, the reflections from patient partners, common themes in the created stories, and knowledge translation outputs. Within the literature, most studies utilizing digital storytelling methods in health research have been published in North America (United States and Canada).(10) These studies mainly used digital storytelling as a data collection and/or for knowledge translation with research participants.(10) For instance, Sitter et. al shared advanced cancer patients' experiences creating digital stories through found poetry.(11) In their study, the patient experience of creating digital stories was found to have an emotional impact, provided patients with a sense of purpose, and the support and collaboration they received from the facilitators in the process.(11) There were also studies that utilized digital storytelling as a health intervention tool.(10) For instance, Yuan et al.'s study highlights how digital storytelling facilitates a comfortable environment for patients, and encourages collective support.(12) While the aim of our workshops were not to use DST as a health intervention tool, patient partners from our workshops also reflected on the therapeutic group environment of digital storytelling and supportive nature of the digital storytelling process. Additionally, patient partners let us know they shared their digital stories with their network, communities, friends, and families. Social connectedness from sharing digital

stories has been identified as another outcome from other studies.(13) Our team utilized DST as a knowledge translation activity within patient-oriented research projects. Through the workshops, we built meaningful collaborations with our patient partners to co-present at conferences, co-develop workshops and webinars, and bring awareness to their health conditions and use of digital storytelling. In the 2022 systematic review by West et. al, they found that most articles that used digital storytelling in health research had limited knowledge translation to academic publications.(10)

While the digital storytelling methodology guided our entire process, the SPOR patient engagement framework guided our process of engaging patient partners through the four principles of inclusiveness, support, mutual respect, and co-build.(5) We were inclusive in our process by engaging patient partners from diverse lived experiences and health conditions who have varied experiences partnering in health research. When reaching out to the patient research partners outside of the workshop, we ensured they were offered the opportunity to co-present and collaborate. Supports that were provided to the patient partners were instructional content and hands-on support in creating their story. The workshops were also at no cost to the patient partners (as they were sponsored by different research teams), and they were provided with a WeVideo (digital editing software) account. The process of partnering with them was built on a foundation of mutual respect. We provided guidance to the patient partners on how to create a digital story, however they chose what story to tell and made all the creative decisions. The principle of co-build was demonstrated throughout this whole process as we worked together to ensure patient partners were satisfied with their digital story in all the seven steps of digital storytelling detailed below.

A strength of our DST work was the collaboration with various research teams which include patient partners across Alberta, Canada. Through our digital storytelling workshops, we have been able to bridge connections to different research teams that conduct patient-oriented research, and work with them in sharing their research outputs to a broader audience. The created digital stories contributed to bringing person-centred care to the forefront, by highlighting challenges, experiences, and hopes from patients when navigating their conditions and health systems. Through all the stories that focused on healthcare experiences, it was evident that patients needed to be engaged by healthcare providers from the very beginning in their care.

The digital storytelling workshops have been used as both a team building initiative as well as knowledge translation activity for these research teams. The collaborative activities after the workshop have provided further opportunities for patient partners to be involved in the dissemination of research, awareness building, encouraging discussion on their topics, and fostering community. The activities (webinars, conference workshops and presentations) have also provided an avenue for research teams to share their research widely and build awareness on their research topics.

Another strength of the digital storytelling workshops has been that the patient partners maintain autonomy over their stories. They choose the venues and platforms that their digital stories can be shared to, and/or grant permission to the research teams if there is an opportunity to share their digital stories. The 6-week online digital storytelling workshop may need to be adapted depending on the storyteller's comfort level with technology and using video editing software. While the Wevideo editing software is user friendly, it may still be overwhelming for some people. Some individuals may also need extra support with script writing, voice recording, and editing their story. The facilitators gauged the comfort level of all the storytellers and adapted the workshop accordingly or arranged for one-on-one sessions to work with each storyteller individually on their story.

Conclusion

This project detailed the process of developing four digital storytelling workshops to support various patient-oriented research projects as well as outputs of those workshops. We collaborated with patient partners and researchers in creating digital stories for knowledge translation activities. A future direction of our work is the use of digital storytelling as a data collection tool in patient-oriented research. DST can help to reach and elevate the voices of underrepresented populations and can be used as a tool to meaningfully engage populations who value storytelling as a way of knowing and understanding. It could potentially be used as a tool to personalize quantitative data, understand what matters most to patients and as a powerful knowledge translation tool.

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