

Co-Designing Evidence-Based Videos in Health Care: A Case Exemplar of Developing Creative Knowledge Translation “Evidence-Experience” Resources

International Journal of Qualitative Methods
Volume 20: 1–10
© The Author(s) 2021
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/16094069211019623
journals.sagepub.com/home/ijq


Mandy Archibald^{1,2,3,4} , Rachel Ambagtsheer^{2,5} , Michael T. Lawless^{2,3,4},
Mark O. Thompson⁶, Timothy Shultz^{2,6}, Mellick J. Chehade^{2,6}, Lyn Whiteway⁷,
Anna Sheppard⁷, Maria Pinero-de Plaza^{2,3,4}, and Alison L. Kitson^{2,3,4}

Abstract

Objective: Well-designed evidence-based resources that reflect participant experiences and priorities are imperative for informed consumer health decision-making and to combat the pervasive health misinformation existing today. Qualitative research data can inform the development of such resources, but the process of reconciling qualitative research data with other sources of evidence through co-design processes is not well described in the literature. In response to the need for such evidence-based materials and corresponding methodological guidance, we co-designed a series of video resources through transdisciplinary and community partnership. In this manuscript, we provide methodological insight into the process of collaborative co-design to improve the utilization of qualitative research evidence into evidence-based resources for the public. **Methods:** Following from a large qualitative research study, we engaged in a collaborative and creative co-design process involving a multi-stakeholder advisory group guided by Boyd’s co-design framework. We explicate this process, drawing from a case exemplar of transdisciplinary frailty research. **Results:** We utilized thematic qualitative data to co-produce: (i) an animation, (ii) a documentary-style video, (iii) a video vignette with key messages embedded in narratives of older adults, and (iv) a key-message video delivered by academic health researchers and clinicians. **Discussion:** The integration of experiential evidence of health care consumers with other sources of research evidence through co-design is an epistemological and procedural challenge with potential to improve public awareness, knowledge, and to support evidence-based decision making.

Keywords

arts based methods, case study, focus groups, interpretive description, methods in qualitative inquiry, mixed methods, virtual environments

¹ Helen Glass Centre for Nursing, University of Manitoba, Winnipeg, Manitoba, Canada

² National Health and Medical Research Council, Centre of Research Excellence in Transdisciplinary Frailty Research to Achieve Healthy Ageing, Adelaide, South Australia, Australia

³ Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Bedford Park, South Australia, Australia

⁴ College of Nursing and Health Sciences, Flinders University, Bedford Park, South Australia, Australia

⁵ Torrens University Australia, Adelaide, South Australia, Australia

⁶ The University of Adelaide, South Australia, Australia

⁷ Consumer Representatives

Corresponding Author:

Mandy Archibald, Helen Glass Centre for Nursing, University of Manitoba, 99 Curry Pl, Winnipeg, Manitoba, Canada R3T 2M6.

Email: mandy.archibald@umanitoba.ca



Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (<https://creativecommons.org/licenses/by-nc/4.0/>) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (<https://us.sagepub.com/en-us/nam/open-access-at-sage>).

Introduction

The need for engaging, accessible and informative resources for the public is being recognized across industries as diverse as finance, education, environmental studies, and increasingly, in the health sciences (Bradford & Bharadwaj, 2015; Mondal et al., 2016; PR Newswire, 2013; Tremblay & Jayme, 2015). In a climate rife with misinformation, the public—as knowledge users—face the onerous task of determining the legitimacy of a vast range of information sources. Health researchers face a comparably onerous task, increasingly required to consider knowledge translation (KT) plans and methods to impart research evidence in meaningful and impactful ways. With video-based content expected to account for 82% of all consumer Internet traffic by 2022 (Cisco, 2020), health researchers have an opportunity to leverage the video-based learning economy to communicate evidence-based information to knowledge users to support knowledge, awareness, and decision-making. However, integrating diverse sources of research evidence, including qualitative evidence of patient experience to develop such resources has not been well described in the literature. This potentially limits the meaningful integration of qualitative evidence into evidence-based resources.

Indeed, while misinformation is a predominant threat to evidence-based decision making, another less commonly considered threat is *evidence misalignments*. Early conceptualizations of evidence-based medicine forwarded by Sackett and colleagues (1996) acknowledged the relevance of patient preferences as well as clinician experience, with the orientation of this integration occurring in the clinical environment. How qualitative evidence is used to inform evidence-based resources has received less attention. We build upon this and coin the term *evidence misalignments* to reflect the often-overlooked differences between the valued forms of research evidence dominant in health care and KT, and evidence of lived experience as expressed by the individual. The former reflects evidence derived from the population level and often “controlling” for context (e.g., randomized controlled trials) and then extrapolated to the individual level, frequently without sufficient consideration of the unique context of an individuals’ lived experience. The resulting misalignment is another type of gap requiring consideration in KT initiatives, which is understood here as the generation, synthesis, exchange and application of knowledge for and with diverse stakeholder groups (Canadian Institutes of Health Research, 2016). Our position aligns with a growing movement toward incorporating multiple perspectives of evidence in KT (Harvey & Kitson, 2016; Kitson, 2009; Kitson et al., 2008). In this paper, we describe how we addressed such misalignments and integrated qualitative evidence of older adults lived experience through the co-design of four video-based resources in the context of a transdisciplinary Centre of Research Excellence (CRE) in frailty research predicated on collaborative KT (Archibald, Ambagtsheer, et al., 2017; Archibald, Kitson, et al., 2017; Kitson et al., 2013). We describe the research context of creative

KT then focus on a case exemplar of co-developing video resources, framed by Boyd’s (2010) co-design framework.

Storytelling as Learning: Incorporating Lived Experience With Other Forms of Evidence

Through story, we make sense of our experiences and find the structure to communicate these experiences to the world. The stories that we tell provide a roadmap to our collective understanding, and as a blueprint, help us decode the complexities associated with constructing and navigating our place in the world. Stories can carry with them a sense of placelessness and timelessness; through their telling and re-telling events of the past are reborn, and through our immersion in the acts of telling and listening, events are re-experienced in the present. Stories also tell us something about the future. Some are like a compass, orientating us toward future directions. Others invite reconsideration, a re-examination of the fit between narratives and our own experiences. With this examination comes opportunity to re-visit, and potentially re-write the story. It is through this act of retelling and constructing new narratives that the new potentials of our individual and collective actions can be realized.

The power of stories in healthcare has been realized through several iterations. For instance, narrative medicine (Greenhalgh & Hurwitz, 1999), communicating research through story (Archibald et al., 2018; Scott et al., 2012), storytelling through song (Bekalu & Eggermont, 2015), and story-based metaphors for information sharing (Chung et al., 2010) reflect an understanding that our experiences are rooted in and cultivated through socialized and cultural practices. From this basis comes recognition of the ambiguity and individual interpretation of evidence and experience. Technologically mediated stories, including approaches like digital storytelling (e.g., short audio-visual work incorporating narration and images; De Jager et al., 2017), require technological hardware for their construction and communication, and are also growing in popularity. Some video-mediated storytelling approaches demonstrate significant impacts, even on physiological outcomes such as blood pressure (Houston et al., 2011). Documentary film as a research methodology rooted in story reflects another powerful way of communicating and reflecting the narratives and positions encountered in our individual and shared experiences of the social world (Franceschelli & Galipò, 2020).

Combining the power of stories with visual representations such as animation and art for example, in order to create and communicate engaging evidence-based narratives, has been of growing interest to KT, health communication, and public health scholars. Myriad forms have been explored, including graphic medicine, which combines comic style illustration with written text; research-based theater, which leverages the power of story through performance to convey some aspect of research; and visual art and story-based e-books for example, which have been developed in various health contexts to communicate research evidence embedded in the stories of lived experiences of healthcare user groups (Archibald et al., 2018;

Scott et al., 2012). Depending on the disciplinary practice and geographic location, these methods can be referred to as arts-based KT (ABKT), defined as the use of any art form to communicate research evidence through exchange or dissemination (Archibald et al., 2014).

Video-based research approaches including documentary film have proliferated under the practice-based umbrella (Fitzgerald & Lowe, 2020). While notable diversity within this genre exists, the use of film for data collection over sustained engagement periods with communities is a characteristic attribute. Of particular interest to this manuscript however, is a genre with some unique attributes from the use of documentary film as research methodology. Specifically, we employ video-delivered stories of various methodologies (e.g., animation, first-person narrative) designed with stakeholders to communicate key messages about health and self-management, in the context of narratives of lived experience derived from interpretive qualitative research. Unlike many approaches to documentary film which involve the use of video as the foremost data-collection strategy, the process discussed here involves the co-design of video-based representations, in various forms, within a narrative framework derived from inductively analyzed, foundational qualitative research, with attention to other forms of research evidence. Indeed, the proliferation, uptake, and accessibility of digital technologies has provided new avenues for health researchers looking to improve the breadth and reach of health messaging for the public, leveraging the power of video long realized in fields such as visual ethnography (Pink, 2013). Methodological case studies provide an opportunity for insight into this process, enabling researchers to consider and anticipate tensions, challenges, and partnerships for effective co-design in this rapidly expanding field of research and dissemination. While such case studies appear more often in social science and environmental research fields (Franceschelli & Galipò, 2020; Gandy, 2009; Vasi et al., 2015) perhaps reflecting a strong methodological influence of visual ethnography in the social sciences, such exemplars relevant to the health sciences are less apparent. Even less common are case examples focusing on the dynamic interplay of diverse evidence sources and the negotiation of these through co-design.

Context: A Case Exemplar of Video-Resource Co-Design for Frailty

In healthcare, frailty carries a distinct meaning of age-related vulnerability to external stressors resulting in poor health outcomes (Hoogendijk et al., 2019). This definition does not reflect the personalized meanings of aging held by individuals, or capture the breadth of impact on individual's daily life. Complexities in the medical identification and management of frailty mirror the complexities expressed by aging individuals who may or may not identify with frailty. Our previous research exploring perceptions of frailty and healthy aging with older South Australians demonstrated that many frailty-related concepts are frightening and poorly understood (Archibald

et al., 2018, 2020), replicating previous studies (Schoenborn et al., 2018; Warmoth et al., 2016). Consequently, older adults are unlikely to discuss frailty with health care providers or to be open to the concept of frailty screening, based on associations of frailty with the end of life, being broken and irreparable, and because of stigma and shame associated with the term (Archibald et al., 2020). However, research demonstrates that frailty is not an inevitable result of aging. With early identification and appropriate management, frailty can be prevented, delayed, or reversed for some individuals (Cameron et al., 2013; Kim et al., 2015; Li et al., 2010; Ng et al., 2015; Puts et al., 2017; Tarazona-Santabalbina et al., 2016). Delivering this and other key messages identified through our foundational research presented a formidable KT challenge.

Recognizing the pressing need for engaging and meaningful mobilization of diverse evidence sources around frailty and healthy aging in South Australia, we co-designed four creative video-based resources with and for older persons and their carers in South Australia. The aims of these resources are to: (1) incorporate the best available evidence on frailty and healthy aging; (2) reflect and honor the diverse experiences and narratives of older South Australians along the frailty trajectory; and (3) respond to a documented need for such resources as identified in our previous research with the National Health and Medical Research Council (NHMRC) funded *CRE in Frailty and Healthy Ageing*.

Methods: Process of Development

Developing the frailty videos aligned with Boyd's (2010) six steps of co-design, including Engaging, Planning, Exploring, Developing, Deciding, and Changing. Each component of the co-design corresponds with the five specific steps below, as indicated in brackets. Except for steps 1 and 5, the steps occurred iteratively, enabling feedback to inform further development and revision of the video resources.

Qualitative Research Into Older Adults Perceptions of Frailty and Frailty Screening to Understand Needs and Experiences (Engaging)

The first aspect of the overall project involved a large qualitative study of older adults perceptions of frailty and frailty screening (Archibald, Ambagtsheer, et al., 2017; Archibald et al., 2020). Through seven focus groups with 39 non-frail, pre-frail, and frail South Australian older adults from community and residential aged care, this study generated a rich interpretive description (Thorne, 2008) of the frailty-related experiences, perceptions, and needs of older persons. Although we achieved some ethnic diversity in our sample, our sample did not include Indigenous South Australians—an important area for future research. The sample is well described in our foundational research (Archibald et al., 2020).

Through our interpretive research we identified three predominant perceptions of frailty including: (1) the old and frail: a static state near the end of life; (2) frailty at any age: a

Table 1. FRDT Attributes and Designations.

Team Member	Affiliation and Representation	Justification for Inclusion
Consumer 1 Consumer 2 Consumer 3	Lay public & carer Lay public & carer Lay public	Combination of lived experiences as an older person with multiple co-morbidities; experience as a carer for frail older persons; advisory panel experience; previous professional experience as a physiotherapist for older adults; engaged community citizens; attributes: creativity, open communication; knowledge of issues around access to services and information
Clinician/academic 1	Occupational Therapy	Relevant clinical experience as a therapist with older, often marginalized, individuals; research experience with CRE team in frailty; holistic perspectives on health and illness; personal experience as an artist.
Clinician/academic 2	Orthopedic Surgery	Relevant clinical experience as a surgeon with older populations often affected by conditions pertinent to frailty (e.g., sarcopenia, osteoporotic fractures); research experience with CRE team in frailty; holistic perspective on health; interest in the arts and video
Clinician/academic 3 (lead investigator)	Nursing	Relevant clinical experience as front line nurse; research experience with CRE in frailty team, including specialist in collaborative KT and creative (arts-based) resource development; personal and professional experience as an artist
Academic 1	Nursing	Research experience with CRE in frailty team, emphasizing clinical effectiveness of frailty interventions through systematic reviews pertinent to the evidence base underlying video production
Academic 2	Psychology, Nursing	Research experience with CRE in frailty team with interest and experience in communication; previous visual arts training
Academic 3	General Practice	Research experience with CRE in frailty with focus on frailty identification in primary care

disability model; and (3) frailty as a loss of independence: control, actions, and identity (Archibald et al., 2020). As reported in Archibald et al. (2020), the term frailty generally carried negative connotations. Dominant misconceptions about frailty as an unmodifiable and inevitable consequence of aging helped to solidify core messages that might be amendable to targeted messaging through creative video-based KT resources. Perceptions of frailty as stigmatizing, frightening, something people did not want to know about, and something not previously discussed with health providers were catalysts for considering video as the creative KT approach. We considered video as amendable to concise key message delivery and disruption of key assumptions, in accordance with the arts-based KT classification schema (Archibald et al., 2014). The lead investigator (MA) presented interim findings and actionable items to the CRE investigator team in 2017. During this meeting, the team contributed ideas for research dissemination and provided support for videos designed to integrate participants' experiences with research evidence on frailty identification, prevention and management.

Establishing Teams: Frailty Resource Development Team and Consultation Cohort (Engaging, Planning)

A group of nine members was purposively selected on the basis of their gender, experiential, and disciplinary diversity, and formed the Frailty Resource Development Team (FRDT). The purpose of the FRDT was to enable a variety of experiences and preferences to be integrated into the co-design of the video resources. The FRDT was sampled from the established network of CRE investigators, and through a formal recruitment process initiated by the lead investigator MA through the

Health Consumers Alliance of South Australia (SA) in September–November 2018. The FRDT consisted of three older adults recruited through the health consumer alliance, a professional filmmaker, a third party animation company, the lead investigator MA, and an additional FRDT member who has an arts background (ML).

Recruiting older adults into the FRDT involved a position posting and receipt of expressions of interest regarding each person's interest in frailty and healthy aging, and relevant experience(s) with creative processes and patient/public engagement. Eight applications were received; three older adults were interviewed and offered positions. These individuals were selected based on their varied experiences as health consumer representatives on various committees, valuable lived experience as older people with chronic health conditions, professional and personal experience as carers, and personal qualities (e.g., communication skills, enthusiasm, open-mindedness, creativity). In addition to the project lead, five academics and clinicians from the CRE were purposively invited to participate (Table 1). Attributes and designations of the FRDT are detailed in Table 1.

The FRDT involved the lead investigator (a professional artist and arts-based KT researcher), one FRDT member with an arts background, a professional filmmaker, and a third party animation company. An extended consultation cohort was then established in collaborative partnership with the Council on the Aging South Australia (COTA SA), an organization committed to advancing the rights and interests of Australians as they age. The purpose of the extended online cohort was to receive additional feedback from older persons and their carers on key components of the video-resources throughout the co-development process (e.g., key messages), thereby reflecting

greater experiential, socio-demographic, and ethnic diversity than possible through the in-person advisory cohort. The online cohort of 20 individuals was contacted twice throughout development (detailed under feedback cycles, below). Resulting from the FRDT and extended consultation cohort was a mixed stakeholder group consisting of older adults (healthcare consumers), carers, clinicians, and academics/artists, strategically identified to facilitate the meaningful co-design of the video materials with maximum input from knowledge-user groups.

Collaborative Development (Planning, Exploring, Developing, Deciding, Changing)

Four workshop-style meetings of approximately 2 hr each were held over 4 months, in a central location. Numerous emails were exchanged between the in-person FRDT to facilitate video design.

Meeting 1 (December 2018). The aims of the inaugural FRDT meeting was to create a safe and welcoming environment for the open sharing of ideas; introduce and orientate the group; establish a shared understanding of the nature of the problem and project background; set project objectives, and determine a suitable project timeline. Pragmatic considerations, such as the timing, location and frequency of meetings, were also determined. The lead investigator used mixed facilitation inclusive of group work and multi-media sharing (e.g., PowerPoint, video, writing) to encourage momentum toward shared objectives in a limited time frame.

A fundamental component of the first meeting was using existing video resources as a means of eliciting reflection, feedback, and to enable observation of the responses and behaviors that these videos stimulated. Four videos were purposively selected in advance of the meeting to reflect a range of possible modalities (e.g., documentary-style; animation); formats (e.g., first-person, narrator); moods (e.g., moody, hopeful); presentations (e.g., levels of production), and lengths. Responses were recorded and used to facilitate discussion following an open-ended period of sharing impressions. Based on the project budget, possibilities for engagement and team objectives, the FRDT agreed upon the scope (three videos), timeframe (6 months), mood (positive, hopeful, realistic) and video objectives (raise public knowledge and awareness; share experiences of a broad range of people; reduce negative affiliations with terminology). Given that this project was identified as the first in a series of resources to be developed for older persons, a general target audience of older people in the community aged 55–65 was identified, recognizing that the content may remain of interest to an older, more frail cohort. Several specific target audiences were identified for the videos, including healthcare providers, older people living with frailty, older people of robust health, and caregivers of older people. During this meeting, we started identifying critical information about frailty for people in the community and began discussing the possibilities and shortcomings of various delivery modalities.

Meeting 2 (January 2019). The aims of the second FRDT meeting were to co-create: possible key messages for the videos; a draft working script and storyboard for the animated video; and the first online survey for the online cohort. Ongoing email-based group correspondence from the first meeting was discussed. For example, one team member identified a need to “push harder to challenge stigma around the term frailty”; possible strategies to achieve this were discussed. At times, we were able to accommodate the inclusion of content within the videos. Other times the team determined alternative solutions to the content and questions raised by team members, such as including additional information in the comments section underneath each video or targeting specific components in future videos. Approximate lengths for each video were also established.

Preliminary key messages were generated that reflected the FRDT perspectives on what is important to know about frailty, what knowledge could result in behavior change, what statements reflect the state of the knowledge in frailty research (i.e., where is the strongest evidence), and what statements are needed to address the findings of the qualitative study (Archibald et al., 2020, 2021). Key messages reflected concepts around frailty definitions, modifiability, risks factors, impact, label, stigma, identification, prevention, management, social factors, healthcare provider communication, and resource navigation. The broader CRE team was then engaged over email to identify additional key messages. The comprehensive list of 11 key messages was provided to COTA for the first online cohort survey.

Meeting 3 (February 2019). The results of the first online cohort survey were obtained and discussed in detail in meeting three. Feedback was used to improve message clarity, reduce redundancy, and ensure that the most pertinent messages were communicated. The script for the animated whiteboard was modified accordingly. Applications submitted to the public call for video participants were reviewed, and participants selected. The design of the second online cohort survey was discussed.

Meeting 4 (March 2019). The purpose of the final in-person FRDT meeting was to review the drafts of the animated and documentary-style videos, observe group responses and behaviors, and determine necessary modifications. Keywords were identified to facilitate online access through keyword searching. Directions and future priorities were determined, and the meeting was closed with reflections on process and expectations for future correspondence.

Feedback Cycles: Consultation Cohorts (Planning, Exploring, Developing, Deciding, Changing)

In varying capacities, we engaged with the three groups (FRDT, online cohort, extended CRE team) throughout the processes of data collection through video-design using a series of feedback and revision cycles, corresponding to the “decide and change components” of Boyd’s framework. We engaged

with a social enterprise branch of COTA (i.e., the PLUG-IN) to access a broader online consumer cohort for review of the materials, and consequent revision of the videos.

Information was sought from CRE investigators at multiple periods during the initial planning phase (e.g., developing the original research to understand older adults' needs and experiences; sharing emerging findings; prioritizing findings during workshops), and at two key periods of video development. First, after video-based delivery was selected, MA sought input into key messages during the storyboarding phase. This involved having each investigator identify key research findings and messages from their CRE-research as well as related research from the frailty and healthy aging literature. Second, MA sought and incorporated feedback on the drafted videos before finalization.

The online cohort of 15 older adults was surveyed twice throughout video development to inform key message development and presentation, and to identify optimal methods for online search and retrieval. The first survey was conducted between January and February 2019 with 15 respondents. Participants were asked to rate each key message as extremely relevant, very relevant, somewhat relevant, not so relevant, or not at all relevant in the categories of importance for public knowledge, importance for personal knowledge, and contribution of key messages to the understanding of frailty. They also provided information on whether any key message would cause specific actions, such as seeking more information, or speaking with a healthcare provider for example; provided feedback on the clarity and comprehensibility of key messages including suggestions for improvement; and identifying additional key messages for consideration. Several suggestions were provided for how to simplify and consolidate the key messages, including which key messages to emphasize. Feedback was considered during the FRDT meetings and used to modify key messages.

The second survey was administered in April 2019 with 11 older adult respondents. This provided information about the search terms and strategies that older people might use when seeking information about frailty; helped identify how older people are using online sources for information seeking; what information older people are looking for online; how the quality of video-based information is assessed; and whether and how public comments made on online videos are considered. This information was used to inform an evaluation and dissemination strategy.

Development of Evaluation and Dissemination Strategy

Evaluation of the video-resources is currently underway and will involve combining a learning-based planning and evaluation framework, LEAP (Barr & Dailly, 2007) with other strategies for benchmarking the comprehension and communication efficacy of the co-developed resources. This approach is guided by an overall framework for evaluating participatory research products (Pinero de Plaza et al., 2021), and was informed, in part, by the viewing and evaluation of

video 1 with two diverse stakeholder groups. This evaluation considered five key communicational components in the evaluation, including (1) rational comprehension, (2) emotional comprehension, (3) noise in the communication, (4) inducement to change, and (5) future accessibility. This evaluation method is intended to inform strategies for optimizing the success, dissemination and promotion of the video resources. The procedure generates a customer-centric benchmark that allows evaluative comparisons across different audiences, platforms and in relation to other participatory resources. Although details of the co-design evaluation will be provided in a subsequent manuscript (Pinero de Plaza et al., 2021), the data did signify a high degree of resonance with the video content and approach, which provided evidence of the strength of the co-design process.

While the details of this empirical evaluation are forthcoming, we continue to regard the public hosting of the video-works with interest. We regard the metrics associated with this hosting as indicators of the scope of reach of the work; they also provide some indication of the video modalities that are captivating viewers interests. For instance, video 1 (Frailty: Every Step You Take Matters; <https://www.youtube.com/watch?v=41cMkvsO0M>) has received over 7,000 views since posting in March 2019, has generated over 18,000 impressions on YouTube, with viewers from 14 countries (i.e., Australia, Canada, Singapore, United Kingdom, Slovenia, Japan, Bangladesh, United States, Italy, Turkey, Brazil, Nigeria, Hong Kong, and Belgium, listed in order of percentage of total views attained). In contrast, the much longer video 2 (Perceptions of Frailty and Healthy Ageing; <https://www.youtube.com/watch?v=5i7y5X-KJnM&t=1s>) posted 1 year later (March 2020) has not yet registered sufficient views to provide meaningful analytic data. Video 3 published in September of 2019 (What Is Frailty and What Can Be Done About It; <https://www.youtube.com/watch?v=Kzklk94ysAg&t=30s>), has generated over 680 views with over 25.5 hr of total watch time, and 3,300 YouTube impressions. Video 4 (Understanding Frailty: Researchers and Clinicians Share Key Considerations; <https://www.youtube.com/watch?v=Cig3Oqs4TAk>) was published in March of 2021.

Learning From the Case Example: Opportunities and Challenges

Co-design inclusive of multiple stakeholder perspectives permits a higher extent of creative ideation than what is possible with any one individual. Ideally, from using this approach, the engagement process and associated resources produced may be more meaningful and more likely to influence behavior change; satisfaction with resources and care provision may be improved; and participants may derive a sense of pride and accomplishment, along with knowledge and skills, as a by-product of contributing to the research process (Graham et al., 2018; Slattery et al., 2020). Aligned with the ethos of community-based participatory research, the co-production of such knowledge is critical to its integration in the attitudes,

behaviors and decisions of stakeholders, as well ensuring services and policies reflect end-user perspectives (Kwan & Walsh, 2018). Individuals invariably speak from their unique standpoint, reflecting the formative forces of life experience, disciplinary training, perception, cognition, and emotional responsiveness. By purposefully constructing intra-team diversity, there is a higher likelihood that a broader triangulation of perspectives can be achieved (Archibald, 2016). Narratives, in their inherent complexities and ambiguity, benefit from a diverse range of interpreters during their formation, as this reflects the inevitabilities of diverse interpretation facing the narratives once in the public sphere. Indeed, the breadth and diversity of the team is among of the key factors differentiating film from other academic projects as noted by Gandy (2009) in his reflections on filmmaking. Others, such as resource constraints (e.g., budgetary, time), complexity and ranges of responsibilities involved, and the corresponding need for flexibility, were also identified as key lessons. We note additional lessons and corresponding strategies of use to consider when engaging in video-based co-design.

The potentials of co-design are best achieved when engagement moves beyond tokenistic involvement characterized by superficial consultation, toward entwined collaboration and co-production wherein stakeholders can influence the direction of the process, direct decision making to authentically contribute a shared-vision, and thereby increase the likelihood that their voices are reflected in both the process and product (Greenhalgh et al., 2016; Ocloo & Matthews, 2016). Skilled facilitation by an individual experienced in co-design and attentive to these differentials; explicit determination of group values from the onset of collaboration indicating the prioritization of stakeholder perspectives over academic priorities, and capacity for individuals to shape decisions can go some way toward mitigating the power imbalances inherent in the research process (Kwan & Walsh, 2018) and were perceived as beneficial to our group process and outputs. Other practical strategies aimed at equity employed in this project involved forthright discussions regarding meeting times and locations, and utilizing methods of communication driven by the unique needs of the group; reflecting in part, the flexibility required by the team and team leader, coordinator, or facilitator (Gandy, 2009). Considerations specific to ethical review may also arise and include questions of when engagement becomes research (Goodyear-Smith et al., 2015), as may tensions between the function of engagingly designed information “products” that are also contingent upon aesthetics and form (Lee, 2008).

In addition to the formidable and longstanding challenge of attending and negotiating power relationships in participatory and co-design research are required attentiveness to cultural diversity and the resultant need for sensitivity. In the context of co-designing evidence-experience resources leading from foundational research, many of the considerations with representation are dictated by the composition of the original participant sample. Consistency between the resulting representation (i.e., in video) and the research underpinning the representation and directing its narrative (e.g., qualitative

research) becomes an issue of quality, with at a minimum, direct implications for credibility (i.e., believable perspectives of participants), transferability (i.e., degree to which experiences can be generalized), and dependability (i.e., are decisions to extrapolate from the original contexts of participants to the video resource clear and justified?) (Fitzgerald & Lowe, 2020; Lincoln & Guba, 1985). In the context of the video-resources produced, our team was sensitive to the distinction between the need for resource(s) that reflect the experiences of diverse cultures, and our ability to create such resources based on the representation achieved in our foundational research. We sought to balance this consideration with the potential reach that translating the videos could have for non-English speaking South Australians. As such, through our collaborative process, we determined that the animation video would be the most amendable to translation. We then had the video professionally translated into Mandarin to reflect the primary non-English language spoken by older South Australian minority groups. An additional consideration however is the imperative to consider the positionality of collaborators employed in the methods of film production (e.g., film production crew), whose cultural backgrounds, knowledge and embeddedness can bring notable perspective and practical know-how to the project. Such locality can also help avoid losing the context of the material in post-production (Gandy, 2009).

Within the context of health narratives and evidence-based resources, honoring participants’ narratives while recognizing that these experiences may not reflect “ideal” (i.e., evidence-based) management scenarios (a disconnect previously considered as “balancing the actual with the ideal”; Archibald et al., 2018) is paramount to this form of resource development. Early in the paper, we proposed the term “*evidence-experience resources*” to reflect such epistemological complexities raised in the legitimization and prioritization of evidence sources that invariably needs to occur in considering evidence-based narrative videos, or with arts-based KT work more generally. Such resources may offer an approach to rectifying the “evidence misalignments” encountered when trying to make gold-standard evidence “fit” with participants lived experience.

Indeed, among the most predominant challenge faced relates to the types of evidence integrated, and the procedural implications that this raises. A predominant feature of qualitative evidence is that it is located in the particular; the generalizability of experience of not a fault or indicator of quality, but an attribute. Yet, it is precisely this attribute (a strength of the methodology) that has posed epistemological challenges for practitioners working in the evidence-based practice and KT movements, who seek to move beyond mobilization of lived experience evidence in one-to-one clinical encounters toward a broader (yet legitimate) communication and application of qualitative findings. We have come to explore how such sources of evidence can provide the narrative structure to deliver “other” forms of evidence. Specifically, evidence derived from what is commonly thought of as gold standard in evidence-based medicine and KT, such as randomized controlled trials (RCTs) and systematic reviews (SRs) of effectiveness. These were the

sources of evidence that enabled us to determine misalignments and justify decisions. However, RCTs and SRs are founded in notions of external validity, raising for us a fundamental epistemological challenge with procedural implications—one that we do not rectify but do engage with. We considered tradeoffs between the potential benefit for Australian viewers, afforded by locally based and specific examples of resources (e.g., COTA; South Australian-based exercise programs) for instance, with the lack of generalizability for others outside of South Australia. With sensitivity to this tension, we elected to include more context-specific resource based examples within the comments or descriptions sections of posted videos rather than within the videos themselves.

Managing the expense of developing and editing video-based resources is a key challenge and one noted by others (e.g., Gandy, 2009), especially when incorporating feedback from multiple stakeholders in the context of limited budgets. One potential means of addressing this issue is to ensure that the aims and scope of the project are clearly developed in consultation with stakeholders right from project commencement. Further, using a graduated multiphase process of development with multiple touch points enables recourse should co-designers provide input that would require substantive revision to the resource after it is at an unretractable stage. Ensuring appropriate collaborative brainstorming and storyboarding is necessary to ensure checks-and-balances are in place to prevent costly revisions from oversights. Ongoing email communications wherein specific issues are identified for collaborative problem solving through feedback cycles were crucial in this respect. Ensuring flexibility when working with external providers such as videographers is critical; practical strategies such as using blank “placeholder” slides, or strategically sequencing content (e.g., presenting material in likely need of modification as the opening or concluding scenes in a video) may help prevent costly revisions.

Conclusion

This article has presented a detailed exemplar of co-designing video resources based on diverse evidence sources in order to increase public and health service provider awareness about frailty, with the aim of illuminating the process and key considerations for those engaged in similar endeavors. Underpinning this work is a belief in the power of storytelling as an innate aspect of our human experience, expression of self, and means of learning and relating to the experiences of others. As we (and others) seek to leverage the accessibility of technologies such as video to support and maximize our research and dissemination efforts, we are also reminded that “there is nothing that expresses the roundness of human beings more than storytelling. Stories are the highest technology of being” (Okri, 2015, p. 7). With the power of stories in mind, we sought to explicate an innovative process involving the integration of lived experience evidence with gold-standard evidence from other sources as a novel contribution of this work. We foresee this as a useful contribution for other researchers and

practitioners working toward evidence-based practice within an increasingly experience-oriented health service.

We explicated a structured co-design process to develop these video resources, and to bring to life the stories of participants in a relatable manner. Although the benefits of a co-designed process in achieving this aim are many, such processes are not without their challenges. Overcoming these challenges requires extensive forethought throughout project planning and flexibility throughout project execution, with all the commensurate investment in time and resources that this level of attention entails. Even still, certain challenges—such as those reflecting power and ethical considerations that are inherent to research processes and temporally situated (and hence difficult to completely uncover)—are unlikely to be completely overcome but merit—at a minimum—acknowledgment, engagement, and effort toward mitigation. We believe that such investments are well worth the effort if co-designed resources are to fulfill their promise of modifying perceptions, encouraging evidence-aligned health behaviors; challenging misconceptions resulting from socially constructed knowledge and the proliferation of misinformation within society; and reducing the misalignments between user experiences and what is often considered gold standard evidence. Such achievements are best considered in tandem with the processes that gave way to their production.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: MA was supported during the tenure of the video development by a Canadian Institutes of Health Research Fellowship and fellowship support from the Centre of Research Excellence in Frailty and Healthy Ageing. The initial video development was supported through a G-TRAC Resthaven research grant.

ORCID iD

Mandy Archibald  <https://orcid.org/0000-0003-4767-1031>

Rachel Ambagtsheer  <https://orcid.org/0000-0002-9391-6709>

Supplemental Material

Supplemental material for this article is available online.

References

- Archibald, M., Kitson, A., Frewin, D., & Visvanathan, R. (2017). Transdisciplinary research in frailty: Knowledge translation to inform new models of care. *Journal of Frailty and Aging, 6*(2), 62–64. <https://doi.org/10.14283/jfa.2017.6>
- Archibald, M., Lawless, M., Ambagtsheer, R., & Kitson, A. (2020). Older adults' understandings and perspectives on frailty in community and residential aged care: An interpretive description. *BMJ Open, 10*(3), e035339. <https://doi.org/10.1136/bmjopen-2019-035339>

- Archibald, M. M. (2016). Investigator triangulation: A collaborative strategy with potential for mixed methods research. *Journal of Mixed Methods Research, 10*(3), 228–250. <https://doi.org/10.1177/1558689815570092>
- Archibald, M. M., Ambagtsheer, R., Beilby, J., Chegade, M., Gill, T., Visvanathan, R., & Kitson, A. (2017). Perspectives of frailty and frailty screening: Protocol for a collaborative knowledge translation approach and qualitative study of stakeholder understandings and experiences. *BMC Geriatrics, 17*(1), 87–88. <https://doi.org/10.1186/s12877-017-0483-7>
- Archibald, M. M., Caine, V., & Scott, S. (2014). The development of a classification schema for arts based approaches to knowledge translation. *Worldviews on Evidence-Based Nursing, 11*(5), 316–324. <https://doi.org/10.1111/wvn.12053>
- Archibald, M. M., Hartling, L., Ali, S., Caine, V., & Scott, S. (2018). Developing “my asthma diary”: A process exemplar of a patient-driven arts-based knowledge translation tool. *BMC Pediatrics, 18*(1), 186, 1–10. <https://doi.org/10.1186/s12887-018-1155-2>
- Archibald, M. M., Lawless, M. T., Ambagtsheer, R. C., & Kitson, A. L. (2021). Understanding consumer perspectives of frailty screening to inform knowledge translation and health system improvements. *Age and Ageing, 50*(1), 227–232.
- Barr, A., & Dailly, J. (2007). *LEAP step-by-step: An introductory guide to the LEAP framework* (2nd ed.). Community Development Foundation.
- Bekalu, M., & Eggermont, S. (2015). Aligning HIV/AIDS communication with the oral tradition of Africans: A theory-based content analysis of songs’ potential in prevention efforts. *Health Communication, 30*(5), 441–450. <https://doi.org/10.1080/10410236.2013.867004>
- Boyd, H. (2010). Improving healthcare through the use of co-design. *New Zealand Medical Journal, 125*, 4–15.
- Bradford, L., & Bharadwaj, L. (2015). Whiteboard animation for knowledge mobilization: A test case from the Slave River and Delta, Canada. *International Journal of Circumpolar Health, 74*(1), 28780–28789. <https://doi.org/10.3402/ijch.v74.28780>
- Cameron, I., Fairhall, N., Langron, C., Lockwood, K., Monaghan, N., Aggar, C., Sherrington, C., Lord, S., & Kurrle, S. (2013). A multifactorial interdisciplinary intervention reduces frailty in older people: Randomized trial. *BMC Medicine, 11*(1), 65. <https://doi.org/10.1186/1741-7015-11-65>
- Canadian Institutes of Health Research. (2016). *Knowledge user engagement*. <https://cihr-irsc.gc.ca/e/49505.html>
- Chung, B., Jones, J., Terry, C., Jones, A., Forge, N., & Norris, K. (2010). Story of stone soup: A recipe to improve health disparities. *Ethnicity & Disease, 20*(1 Suppl 2), S2–14.
- Cisco. (2020, March). *Cisco Annual Internet Report (2018–2023) White Paper*. Report for Cisco. <https://www.cisco.com/c/en/us/solutions/collateral/executive-perspectives/annual-internet-report/white-paper-c11-741490.html>
- De Jager, A., Fogarty, A., Tewson, A., Lenette, C., & Boydell, K. (2017). Digital storytelling in research: A systematic review. *Qualitative Report, 22*(10), 2548–2582.
- Fitzgerald, A., & Lowe, M. (2020). Acknowledging documentary filmmaking as not only an output but a research process: A case for quality research practice. *International Journal of Qualitative Methods, 19*, 1–7. <https://doi.org/10.1177/1609406920957462>
- Franceschelli, M., & Galipò, A. (2020). The use of film documentary in social science research: Audio-visual accounts of the “migration crisis” from the Italian island of Lampedusa. *Visual Studies, 1*–13. <https://doi.org/10.1080/1472586X.2020.1769497>
- Gandy, M. (2009). Liquid city: Reflections on making a film. *Cultural Geographies, 16*(3), 403–408. <https://doi.org/10.1177/1474474009105055>
- Goodyear-Smith, F., Jackson, C., & Greenhalgh, T. (2015). Co-design and implementation research: Challenges and solutions for ethics committees. *BMC Medical Ethics, 16*(1), 78. <https://doi.org/10.1186/s12910-015-0072-2>
- Graham, I., Kothari, A., & McCutcheon, C. (2018). Moving knowledge into action for more effective practice, programmes and policy: Protocol for a research programme on integrated knowledge translation. *Implementation Science, 13*(1), 22, 1–15. <https://doi.org/10.1186/s13012-017-0700-y>
- Greenhalgh, T., & Hurwitz, B. (1999). Narrative based medicine: Why study narrative? *British Medical Journal (International Education), 318*(7175), 48–50. <https://doi.org/10.1136/bmj.318.7175.48>
- Greenhalgh, T., Jackson, C., Shaw, S., & Janamian, T. (2016). Achieving research impact through co-creation in community-based health services: Literature review and case study. *Milbank Quarterly, 94*. <https://doi.org/10.1111/1468-0009.12197>
- Harvey, G., & Kitson, A. (2016). PARIHS revisited: From heuristic to integrated framework for the successful implementation of knowledge into practice. *Implementation Science, 11*(1), 33. <https://doi.org/10.1186/s13012-016-0398-2>
- Hoogendijk, E., Afilalo, J., Ensrud, K., Kowal, P., Onder, G., & Fried, L. (2019). Frailty: Implications for clinical practice and public health. *The Lancet (British Edition), 394*(10206), 1365–1375. [https://doi.org/10.1016/s0140-6736\(19\)31786-6](https://doi.org/10.1016/s0140-6736(19)31786-6)
- Houston, T., Allison, J., Sussman, M., Horn, W., Holt, C., Trobaugh, J., Salas, M., Pisu, M., Cuffee, Y., Larkin, D., Person, S., Barton, B., Kiefe, C., & Hullett, S. (2011). Culturally appropriate storytelling to improve blood pressure: A randomized trial. *Annals of Internal Medicine, 154*(2), 77–84. <https://doi.org/10.7326/0003-4819-154-2-201101180-00004>
- Kim, H., Suzuki, T., Kim, M., Kojima, N., Ota, N., Shimotoyodome, A., Hase, T., Hosoi, E., & Yoshida, H. (2015). Effects of exercise and milk fat globule membrane (MFGM) supplementation on body composition, physical function, and hematological parameters in community-dwelling frail Japanese women: A randomized double blind, placebo-controlled, follow-up trial. *PLOS One, 10*(2), e0116256. <https://doi.org/10.1371/journal.pone.0116256>
- Kitson, A. (2009). The need for systems change: Reflections on knowledge translation and organizational change. *Journal of Advanced Nursing, 65*(1), 217–228. <https://doi.org/10.1111/j.1365-2648.2008.04864.x>
- Kitson, A., Powell, K., Hoon, E., Newbury, J., Wilson, A., & Beilby, J. (2013). Knowledge translation within a population health study: How do you do it? *Implementation Science, 8*(1), 54–54. <https://doi.org/10.1186/1748-5908-8-54>
- Kitson, A., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K., & Titchen, A. (2008). Evaluating the successful implementation

- of evidence into practice using the PARIHS framework: Theoretical and practical challenges. *Implementation Science*, 3(1), 1–1. <https://doi.org/10.1186/1748-5908-3-1>
- Kwan, C., & Walsh, C. A. (2018). Ethical issues in conducting community-based participatory research: A narrative review of the literature. *Qualitative Report*, 23(2), 369–386.
- Lee, Y. (2008). Design participation tactics: The challenges and new roles for designers in the co-design process. *CoDesign*, 4(1), 31–50. <https://doi.org/10.1080/15710880701875613>
- Li, C., Chen, C., Li, C., Wang, W., & Wu, S. (2010). The effectiveness of a comprehensive geriatric assessment intervention program for frailty in community-dwelling older people: A randomized, controlled trial. *Archives of Gerontology and Geriatrics*, 50, S39–S42. [https://doi.org/10.1016/S0167-4943\(10\)70011-X](https://doi.org/10.1016/S0167-4943(10)70011-X)
- Lincoln, Y. S., & Guba, E. (1985). *Naturalistic inquiry*. Sage.
- Mondal, H., Mondal, S., & Das, D. (2016). Learning style preference for basic medical science: A key to instructional design. *International Journal of Clinical and Experimental Physiology*, 3(3), 122–126.
- Ng, T., Feng, L., Nyunt, M., Feng, L., Niti, M., Tan, B., Chan, G., Khoo, S., Chan, S., Yap, P., & Yap, K. (2015). Nutritional, physical, cognitive, and combination interventions and frailty reversal among older adults: A randomized controlled trial. *The American Journal of Medicine*, 128(11), 1225–1236. e1. <https://doi.org/10.1016/j.amjmed.2015.06.017>
- Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: Progressing patient and public involvement in healthcare improvement. *BMJ Quality and Safety*, 25(8), 626–632. <https://doi.org/10.1136/bmjqs-2015-004839>
- Okri, B. (2015). *The mystery feast: Thoughts on storytelling*. Clairview Books Ltd.
- Pinero de Plaza, M. A., Archibald, M., Lawless, M., Ambagtsheer, R., Mudd, M., McMillan, P., & Kitson, A. (2021, February 1). *PRO-LIFERATE: An adaptable framework to evaluate participatory research products*. Preprint (Version 2). <https://www.researchsquare.com/article/rs-146129/v2>
- Pink, S. (2013). *Doing visual ethnography* (3rd ed.). Sage.
- PR Newswire. (2013). *New York life retirement plan services launches animated “whiteboards” to engage 401(k) plan participants*. PR Newswire Association LLC. 2019, December, 17.
- Puts, M., Toubasi, S., Andrew, M., Ashe, M., Ploeg, J., Atkinson, E., Ayala, A., Roy, A., Rodríguez Monforte, M., Bergman, H., & McGilton, K. (2017). Interventions to prevent or reduce the level of frailty in community-dwelling older adults: A scoping review of the literature and international policies. *Age and Ageing*, 46(3), 383–392. <https://doi.org/10.1093/ageing/afw247>
- Sackett, D. L., Rosenberg, W. M., Gray, J. A., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't: It's about integrating individual clinical expertise and the best external evidence. *British Medical Journal*, 312(7023), 71–72.
- Schoenborn, N., Van Pilsum Rasmussen, S., Xue, Q., Walston, J., McAdams-Demarco, M., Segev, D., & Boyd, C. (2018). Older adults' perceptions and informational needs regarding frailty. *BMC Geriatrics*, 18(1), 46–47. <https://doi.org/10.1186/s12877-018-0741-3>
- Scott, S., Hartling, L., O'Leary, K., Archibald, M., & Klassen, T. (2012). Stories—A novel approach to transfer complex health information to parents: A qualitative study. *Arts & Health*, 4(2), 162–173. <https://doi.org/10.1080/17533015.2012.656203>
- Slattery, P., Saeri, A., & Bragge, P. (2020). Research co-design in health: A rapid overview of reviews. *Health Research Policy and Systems*, 18(1), 17, 1–13. <https://doi.org/10.1186/s12961-020-0528-9>
- Tarazona-Santabalbina, F., Gómez-Cabrera, M., Pérez-Ros, P., Martínez-Arnau, F., Cabo, H., Tsaparas, K., Salvador-Pascual, A., Rodríguez-Mañas, L., & Viña, J. (2016). A multicomponent exercise intervention that reverses frailty and improves cognition, emotion, and social networking in the community-dwelling frail elderly: A randomized clinical trial. *Journal of the American Medical Directors Association*, 17(5), 426–433. <https://doi.org/10.1016/j.jamda.2016.01.019>
- Thorne, S. (2008). *Interpretive description*. Left Coast Press.
- Tremblay, C., & Jayme, B. (2015). Community knowledge co-creation through participatory video. *Action Research*, 13(3), 298–314. <https://doi.org/10.1177/1476750315572158>
- Vasi, I. B., Walker, E. T., Johnson, J. S., & Tan, H. F. (2015). “No Fracking way!” documentary film, discursive opportunity, and local opposition against hydraulic fracturing in the United States, 2010 to 2013. *American Sociological Review*, 80(5), 934–959. <https://doi.org/10.1177/0003122415598534>
- Warmoth, K., Lang, I., Phoenix, C., Abraham, C., Andrew, M., Hubbard, R., & Tarrant, M. (2016). “Thinking you're old and frail”: A qualitative study of frailty in older adults. *Ageing and Society*, 36(7), 1483–1500. <https://doi.org/10.1017/S0144686X1500046X>