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Data repositories have only recently been used to support qualitative research teams and offer interdisciplinary, multi-sectoral, geographically-dispersed researchers the opportunities to manage, analyze and share data. Paralleling the emergence of these online technologies are increasing calls from national funding boards, universities and publishers for the development of data management strategies that support storing, finding, repurposing of research data (Brown, 2015; Chauvette, Schick-Makaroff & Molzahn, 2019; Stuart et al., 2018; Wilkinson et al., 2016). Most specifically, this involves development of a data management plan detailing how data will be stored, accessed and shared across the research study life cycle. In this paper, we discuss strategies and limitations of using a data repository in relation to a nursing study involving longitudinal qualitative data.

**Paradigmatic Differences for Data Repositories and Data Management**

While there are varying models and definitions of digital data repositories, they all have web-based platforms that facilitate researchers’ abilities to securely access and manage their research data remotely. Data repositories were originally designed to securely store vast amounts of quantitative clinical data, collected by multiple institutions. They can range from thousands of data sets supported by funding and government agencies to support data sharing across research teams (DuBois, Strait, & Walsh, 2017) to small scale repositories designed by a research team for a single study where secondary access is granted through formalized proposals (Perazzo, Rodriguez, Currie, Salata, & Webel, 2019). They may also be implemented within academic institutions to support multiple research studies with a range of methodologies (University of Alberta, 2019; Wilkinson et al., 2016).

One of the original aims for use of data repositories was to increase the transparency of numerical, clinical trial data for verification of findings by providing data access outside of the formal research team (Institute of Medicine, 2015). They have been used less often by qualitative researchers to securely store vast amounts of potentially identifiable, contextual data. Further, there have been multiple demands from various sectors for "good data stewardship" including considerations for data sharing and repurposing (Wilkinson et al., 2016). Yet, this perspective towards data sharing may dictate research processes that may not easily align with an interpretive approach. Most specifically, approaches that support quantitative data sharing through a data repository may be creeping into qualitative data management without sufficient recognition of the contextual information that prohibits qualitative data from being fully de-identified (Guishard, 2017; Jones, et al., 2018; McCurdy & Ross, 2017).

Similarly, the strategies applied within data management plans have emerged from quantitative research (Perazzo et al., 2019) and may not always be transferable to qualitative research. Details are focused on spreadsheets and meta data records, and less attention has been given to managing data that has been transformed from audio recordings, to transcripts, to de-identified transcripts and through to knowledge translation (DCC, 2013; Michener, 2015). Additionally, data management plans often emphasize particular values around data ownership, intellectual property rights, quality assurance and quality control (DCC, 2013; Michener, 2015; University of California Curation Center, 2019; Williams, Bagwell, & Nahm Zozus, 2017). The language, and more critically, the philosophical position of current data management plan templates, understandably, may discourage qualitative researchers from adopting data management principles that have been founded within a particular paradigm. For example, the concept of ownership has methodological implications specific to qualitative researchers, who commonly view data as being co-constructed rather than being owned by participants, researchers, or an institution (Guba & Lincoln, 2005; Jones et al., 2018; McCurdy & Ross, 2017).

Quality assurance and quality control as they relate to current data management plan templates contrast with qualitative research concepts of trustworthiness and credibility. Quality within qualitative research is often presented as providing an audit trail of key decision points where evaluation of trustworthiness is based on interpretations and methods of analysis (Connelly, 2016; DuBois, 2017; Rolfe, 2006). Less focus has been given on how this trustworthiness within qualitative research can be impacted by poor data management strategies that result in data being lost through accidental deletions or misfiling, or transformed through inconsistent de-identification and cleaning of textual data. White, Oelke, and Friesen (2012), in a large qualitative nursing research project, provide one of the few examples of examining trustworthiness through data management. They consider not only how credibility is impacted by data collection procedures, but how dependability and transferability are influenced by data processes and analysis. However, this study was published prior to funding agencies' recommendations in favor of data repositories and detailed qualitative data management plans (Jones et al., 2018). Although Perazzo et al. (2019) detail a recent example of a data repository that was developed specifically for a nursing quantitative study, no publications were found where management of qualitative data within a data repository was described. Thus, Perazzo et al. (2019) call for further examination of the distinct considerations in utilizing data repositories for qualitative research.

**Purpose**

Drawing on our experiences from using a data repository to support a large narrative inquiry study, in this paper we: 1) provide insights on qualitative data management within an university's established data repository, and 2) offer practical recommendations in developing a qualitative data management plan. To begin, we introduce the exemplar nursing study and data repository, demonstrate strategies we utilized as part of our data management plan, and critically examine the experience of accessing qualitative data stored within a data repository.

**Methods**

**Overview of the Exemplar Study and Data Repository**

The purpose of the “Liminality”study was to explore the difficult and uncertain or liminal experiences of living and dying with a fatal chronic condition. Participants included people living with one of four illnesses (end-stage renal disease, heart failure, chronic obstructive pulmonary disease and advanced cancer) and their family members. Most participants completed separate confidential interviews, however, at times spouses preferred to be interviewed together. The informed consent process detailed that information would not be shared between dyads where interviews were conducted separately. During interviews, participants shared experiences of living-and-dying that they rarely spoke about and may never have shared with others.

The study was longitudinal and involved interviews where multiple forms of data were collected. Over a period of 6 to 12 months, participants (n=82) were asked to complete three in-depth interviews. Field notes were recorded at the completion of each interview, and when interviewers wanted to document further reflections. In order to facilitate photo-elicitation (Lapenta, 2011), participants were asked to take three photographs that represented their experiences of uncertainty while living with life-limiting illness. Additionally, some participants offered pieces that they had created to further represent their experiences of living with illness (e.g., poetry, DVDs, booklets). Although not all participants completed the series of interviews, or contributed photos, it was not uncommon for participants to offer more than three photographs. Over 575 photos and 217 interviews (with corresponding field notes) were gathered and stored. The interviews and field notes were saved in three different formats: audio recordings, raw transcripts and cleaned transcripts. Thus, by the end of the study there were more than 1800 data objects: (575 photos) + (217 interviews x 3) + (217 field notes x 3). The collection and analysis of sensitive dyadic data within this large qualitative study necessitated that robust data management strategies were in place from the outset.

A key decision for the Liminality research team was to use the *Health* *Research Data Repository* (HRDR) for data storage, transfer, access and management, and coordination of transcription services and access to coding software (University of Alberta, 2019). The HRDR aligned with the security guidelines outlined by funding agencies and institutional ethics boards in providing a confidential environment for housing and managing and repurposing of sensitive health related qualitative and quantitative research data. The research team's previous collaboration on a narrative inquiry study and experiences in using the data repository for other research studies influenced the decision in selecting the HRDR for data management. With servers physically housed in Canada, the HRDR could be securely accessed by any research team member with Wi-Fi access from anywhere around the world.

Conducted across two Canadian provinces, the Liminality study involved researchers from two post-secondary institutions and recruitment included participants linked with multiple health organizations. The research team included the principal investigator, six co-investigators, and two doctoral fellows (one who held the role of research coordinator). Five research assistants located in three cities were hired at different points of times to conduct interviews and clean transcribed interviews. The HRDR staff were outside the formal research team, and contributed data management expertise and support.

## Features of the Data Repository

The features within HRDR fit within three categories recognized as important considerations within the Canadian Tri-Council Policy Statement for protecting participants’ information - physical, technical, and administrative (Government of Canada, 2018a). Physical features consist of servers and hardware required to operate the environment, technical features may include software that allows users to securely and remotely access the environment, and administrative features involve the personnel and policies and procedures related to data security. A data repository may also offer a "suite of services" across these three categories, which extend beyond its core function of providing secure data access and storage.

**Physical.**The HRDR had built-in procedures to protect against data duplication and loss, and provide disaster recovery assurances (e.g., daily, weekly and monthly back-up of servers, both on and off site). A foundational design principle within the HRDR was that documents could not be downloaded or printed by the research team. This maintained security by preventing duplication of data across multiple sites.

**Technical*.*** The technical aspects for data management were present throughout data collection, coding and analysis phases. These considerations began with very simple processes for team members such as learning how to sign into the HRDR, and navigating and understanding the technical capacities of working within a virtual environment. As the HRDR was configured within a PC based platform, troubleshooting was required to assist team members with other platforms (e.g., Applecomputers).

**Administrative*.*** Administration procedures were developed to coordinate data management between the HRDR staff and research team members. Access to the HRDR was provided to each team member once they completed an HRDR orientation and training session, and signed the HRDR 'Terms of Use'. Upon approval of the PI, the HRDR could be customized for members to have access to different folders. For example, only a few team members were given access to the back-up folders to prevent accidental deletions. Additionally, the ability to designate subsets of data for a set timeframe within specific sections folders of the HRDR allowed for our research team to offer opportunities for secondary data analysis to students for approved projects. Administrative charges for use of the HRDR included an annual fixed fee for use of the repository as well as direct billing for the additional transcription services.

**Suite of services.** The selection of the HRDR for supporting the Liminality study was further influenced by access to an additional suite of services. The availability of a centralized transcribing service overseen by the data manager meant that the research coordinator did not have to dedicate time to data transferring and invoicing for transcription. Access to qualitative coding software reduced the costs involved in paying for individual software licenses. The team opted to use the software available through HRDR based on previous experience, and fit with the study design. However, if the team had wanted to employ additional software programs within the data repository, negotiations with the faculty supporting the HRDR would have been required.

**Qualitative Data Management Strategies within a Data Repository**

Utilizing the HRDR effectively for the Liminality study involved commitment by the research team to use the data repository, while recognizing that specific processes and policies within it had to be implemented to support our study design. The following sections detail some practical strategies based on the Liminality team's experience with the HRDR that assisted in successful data management. Additionally, Figure 1 provides a series of questions the research team considered at key decision points in the study. Other research teams may work through these same stages and questions to develop a qualitative data management plan, and gauge their needs and strategies when using a data repository for their qualitative study.

**Collaboration between the research team and data repository staff*.*** Prior to data collection within the Liminality study, a meeting was held with the principal investigator, research coordinator from the previous study (and now co-investigator for the Liminality study), current research coordinator, and HRDR manager. This meeting was critical in determining the overall folder structure of the study, which established the framework for a standardized naming system for all forms of data. These meetings continued at key stages of the project (e.g., transitions to new HRDR managers, addition of research assistants, and beginning of coding). The HRDR staff provided “audits” during data transferring, storing, sorting, and allowed for a “second set of eyes” in reviewing file naming structure to ensure data were accurately identified and not lost through misfiling. The team’s research coordinator, with a strong background in data management, provided the linkage and communication between data collection by research assistants, and data uploads managed by the HRDR staff. Another team member worked closely with the research coordinator to ensure processes were maintained.This collaborative approach to research data management translated into sound data organization from the outset, and made it less labor intensive to track and access data.

**File naming structure.** With 15 people (14 research team members and one HRDR data manager) potentially having to log up to 1800 pieces of data, it was essential to develop a naming convention that could allow the team to readily identify files, and so that any issues of locating or accessing were clearly communicated and subsequently addressed. This file naming was mirrored in set-up of the folder structure within the HRDR (see Figures 2 and 3). The HRDR manager and research coordinator collaborated on the file naming structure. Early on we decided that only two people could add folders in the HRDR. This allowed for coverage, yet insured that "too many cooks" did not add confusion to the overall data repository format.

**Developing protocols and written agreements*.*** Utilizing the HRDR effectively meant that processes within the HRDR had to be implemented to match our study design. To support trustworthiness of data, specific protocols were created for 1) transcriptionists that detailed de-identification as well as handling of pauses and voice inflections, and 2) interviewers in using the recording device, conducting interviews, guiding questions for field notes, and cleaning transcripts. Additionally, as analysis progressed, the research team went through several iterations of the codebook, before embarking on coding transcripts within the HRDR.

A written agreement between the research team and the HRDR staff was essential to ensuring responsibilities were clearly laid out and encouraged a smooth transition during staff changes. We negotiated and valued the support of the HRDR manager for verification of file transfers and for auditing file names/structure. However, when new employees were hired for the HRDR, we learned that this was not usual for other projects, thus demonstrating the importance of detailed written agreements.

**Creating tracking documents*.*** In addition to folders for data storage, an administration section for tracking documents was created within the HRDR. These key tracking documents provided an immediate snapshot of participant recruitment and interviews, enabled tracking of the vast amount of contextual data inherent within this qualitative research project, and supported communication with research assistants who were geographically-dispersed. As per our national research funding guidelines for maintaining confidentiality, a limited number of people were given access to the tracking documents (Government of Canada, 2018b). This limited access also meant that information in these reports could only be entered by specific team members, resulting in consistent data entry across multiple geographic sites. To ensure the most recent data were within these reports, a system to identify the file version was established. Each time the report was updated, the most recent file was labeled with the date of revision and the previous version was moved and archived into a separate folder. The archived file allowed us to go back to previous versions if anything needed to be corrected or cross-checked.

The vast amount of data collected resulted in team discussions of what exactly needed to be tracked. These decisions were based on what would be most efficient for overall management of the research study, and were specific to addressing the research questions. Categories were not duplicated across these tracking documents in order to prevent accidentally applying outdated participant information. For example, attrition was tracked in a single document, so that the research coordinator knew who had withdrawn from the study, and thus these participants would not be inadvertently contacted. To minimize the amount of text, color coding was used to enable quick visual identification within these documents. For example, in order to track the status of processing of the interview data for each participant, the 'interview date' was color coded based on stages including 'sent to transcription', 'transcribed' or 'cleaned'.

Tracking documents for the Liminality study included 'Contact List', 'Demographics', 'Interview Tracking', 'Photo Tracking’, 'Pseudonym Tracking', and 'Publication Quotations'. The latter four documents were of particular significance to the narrative study design. To ensure that each participant was contacted at the various interview stages, the 'Participant Interview Tracking' listed interactions with each participant as well as other documentation (e.g., ongoing informed consent). Photographs were tracked in a 'Research Data' document, identifying whether the person had provided a photo release form when images contained people. To assist in analysis, this document also listed the nature of the object in the photos and participants' key words in reference to the photo. Participants' names and pseudonyms were recorded in the 'Pseudonym' document in order to prevent participants’ actual names from inadvertently appearing in publications. This tracking system also ensured that a pseudonym would only be used in a single publication, eliminating the ability to track and identify a single participant's data through multiple publications. Similarly, to represent a range of participants' experiences and avoid using the same quote across multiple publications, the 'Publication Quotation' document tracked participant number, selected quote and the transcript file name and line number.

**Competing Priorities of Access and Privacy/Security**

The challenges and strengths encountered in using the data repository were most evident when our team had to balance data access for our narrative analysis with data privacy resulting from security requirements. The goal of the HRDR and its staff was that the data repository would function to support the research undertaking, rather than drive the research process. Yet, there were times when the data repository could not be accessed, and thus the team was delayed in conducting research activities. The HRDR was designed to support numerous research projects and multiple people within multiple research teams. At times, there were busy periods where many people wanted to access their data simultaneously and our team members were unable to log onto HRDR, or access software programs because of the limited number of site licenses. The standardized procedures that were implemented as part of the security requirements for the HRDR did not always align with the needs of the research team. For example, the HRDR was programmed to deny access after three months of inactivity. Thus, periodic users would have to wait until HRDR staff work hours to have their access renewed. When researchers were logged into the HRDR, they were required to be active on their computer within thirty minutes to prevent being logged out due to the HRDR's pre-programmed feature of detecting "inactivity". This impacted analysis, when researchers were listening to audio recordings of lengthly interviews, but were disrupted by having to re-log in.

The core interfaces that were needed in operating the HRDR resulted in unanticipated upgrades to external platforms and software programs. As with any project, the team recognized that technical challenges were to be expected. However, these issues were magnified in the HRDR for their potential impact on all team members, and were more complicated, since it was difficult to determine whether an issue was with a research assistant's platform or the data repository.

The research team had multiple discussions regarding the challenges created by the HRDR's security environment. Research team members appreciated knowing that data could not be unknowingly downloaded into unfamiliar folders on their personal computers. Yet, many of us were frustrated by not being able to print transcripts (printing could be done by HRDR staff but they were not always in the same physical location) and the requirement to be online to conduct analysis. As the team entered analysis, we decided to establish and maintain an additional secure separate data management platform with the same folder structure as the HRDR. Before transferring the data set to this secondary secure site, printing documents was a multi-day process that required the involvement of the HRDR manager and research coordinator in moving data outside of the HRDR. When our funding ended we were no longer able to support the HRDR administrative fees, so this secondary data site proved to be a necessity.

There were also the broader system-level implications of federal and provincial legislation around access and privacy. This was most evident in our discussions around the US Patriot Act (2001), where legislation specific to information and privacy had been amended in some provinces.(Information and Privacy Commissioner for BC, 2004). By being held in one jurisdiction, the HRDR met the legislative and ethics boards' requirements in addressing the risk of citizens unknowingly providing access to their personal health information for other jurisdictions. However, the data manager was unfamiliar with the multitude of privacy and security considerations outside of their jurisdiction. Thus, when it came time to move data outside of the data repository into another provincial site, discussions were needed among the principal investigator, HRDR data manager, research coordinator and external privacy experts

**Discussion**

Although the HRDR supported our ability to organize and maintain vast amounts of data, our team had ongoing concerns over the broader promotion of data repositories for data repurposing and sharing. We shared Guishard (2017) concerns in juggling the "precarious terrain" of data sharing through data repositories, with our methodological position on relational accountability, transparency, data ownership and knowledge dissemination. In a survey of data sharing for quantitative data, Stuart et al. (2018) found researchers were more likely to share larger datasets. However, we found that the vast amount of longitudinal data made sharing prohibitive. Large quantitative data sets are characteristic of a vast number of participants, and their associated variables that undergo a structured process of de-identification (Jones et al., 2018; Meystre, Friedlin, South, Shen, & Samore, 2010). However, as exemplified with our large qualitative study, the narrative approach in collecting contextual information from individuals over a period of three interviews made full de-identification particularly challenging, and we sought to maintain, rather than remove contextual elements. Yet, we also recognized that as a research team we had an ethical obligation to share participants' stories, thus at the onset of our funding application we sought and established ways for data sharing through secondary data analysis. Documents created within the data repository to track pseudonyms and publication quotations were essential in establishing de-identification of qualitative data. These qualitative data management processes were driven by the research team, and not part of the initial processes established within the HRDR.

Paralleling funding agencies and research ethics boards’ movement towards guidelines for good data stewardship, is research that supports inclusion across all populations (National Sciences and Engineering Research Council of Canada, 2019). Similar to studies detailed in Silverman (2013), our research team’s experience from a previous narrative study was that participants were often not concerned about confidentiality of their data and wanted to assist others by offering their stories (University of Victoria, 2011). However, during recruitment of the Liminality study, one individual opted not to participate, citing concerns about the confidentiality and privacy details within the informed consent – raising awareness as to how specific populations may be excluded by standardized ethics board language and policies. The evolution of data repositories is occurring concurrently with the growing mistrusts and fears around online environments. Populations that are identified as “vulnerable” or who have historically been stigmatized often report decreased trust in healthcare services, and this mistrust is now translating to online environments (Antonio, Petrovskaya & Lau, 2019). This highlights how "trustworthiness" within research should not just be in reference to quality assurance, but also needs to address distinct considerations related to how different individuals and populations may respond to data repositories that promote data sharing and repurposing.

The challenges that we faced in working within the HRDR demonstrate a broader conceptual issue with use of data repositories for qualitative research. Data repositories were designed for the systematic structure of quantitative research where tools are determined prior to study implementation, data are tracked as variables and statistical software is used for analysis (Jones, et al., 2018). Our qualitative research study, within a social constructivist lens, included contextual data in transcripts, audios and photos, and interpretation from team members. The data repository introduced a “third actor,” where emphasis on security constructed how the team could conduct analysis. This "construction" was beyond a philosophical level, but experiential, where the restriction to an online environment did not support "anywhere" access for researchers to conduct iterative analysis through reading, listening, reflecting, and circling back to the text.

The tensions we experienced in introducing a technology to our research process is not distinct to data repositories. Tape recorders and transcription software in qualitative research have raised similar debates around how technologies influence data management, analysis, and overall methodology (Tessier, 2012). We learned not to be driven by the tools and policies established to support the technological aims, but to recognize when we needed to move to processes that maintained our commitment to methodologically rigorous, as well as ethical research. This is not to say that the data repository did not support our research: data management within the HRDR served us well during data collection. The procedures that were established through the protocols and the HRDR structure were critical to ensuring trustworthiness, in that we did not lose any data during the intensive data collection stage, when there were multiple research assistants across multiple locations, who were often conducting interviews on the same day. However, during analysis we found the data repository restrictive in supporting the emergent design required for our narrative inquiry.

The two predominant functions of data repositories are to promote data reuse and sharing, and provide a secure online research environment for data management and collection (University of Alberta, 2017; PLOS One, 2017; QDR and UK Data Source, 2016). However, in our experience of using a data repository, we found these two functions of sharing and security were often in conflict with our narrative approach. In Figure 4, we aim to make explicit that 'support of the qualitative research process' should be the central purpose of data repositories, yet is often hidden in this dichotomy. By emphasizing this central purpose, we draw attention to the "peculiarities" of qualitative research projects (Qualitative Data Repository (QDR), 2019) that should be considered within data repositories. Philosophical position, relational accountability, and sensitivity and de-identification of contextual data have been discussed in a prior debate on data sharing through data repositories (Dubois, Strait & Walsh, 2017; Guishard, 2017, McCurdy & Ross, 2017). In introducing 'stages', we offer additional considerations for data repositories that support qualitative research. Although current designs of qualitative data repositories are offering new ways for knowledge translation by providing broader reach in connecting data to other researchers (QDR, 2019), we suggest that greater attention should be given to supporting contextual data management and access for immersive analysis often required within qualitative research.

Our experience in using the HRDR, revealed that resistance to adopting data repositories for qualitative research is much broader than the present focus on data sharing (Brown, 2015; Chauvette et al., 2019; DuBois et al., 2017; Guishard, 2017; Jones et al., 2018; McCurdy & Ross, 2017). Rather, current designs of data repositories may not be supporting the messy, unknown and emergent aspects of qualitative analysis. To reach their potential in encouraging a collaborative research environment where patients' voices are shared, data repositories need to offer more adaptable processes that represent the range of methodological approaches, and considerations beyond management, collection, secure storage and sharing. Ultimately, a data repository does not operate on its own. It necessitates commitment of the research team to be actively engaged and familiar with the platform, the data repository staff to collaborate on providing overall support for secure data storage, management and access, and a design that matches with the methodological approach.

**References**

Antonio, M.G., Petrovskaya, O., & Lau, F. (2019). Is research on patient portals attuned to health equity: A scoping review, *Journal of American Medical Informatics Association*, ocz054. doi: <https://doi.org/10.1093/jamia/ocz054>

Brown, S., Bruce, R., & Kernohan, D. (2015). *Directions for research data management in UK universities*. Bristol, UK Retrieved from <https://www.fosteropenscience.eu/sites/default/files/pdf/1240.pdf>.

Chauvette, A., Schick-Makraroff, K., & Molzahn, A.E. (2019). Open Data in Qualitative Research. *International Journal of Qualitative Methods, 18*, 1-6. doi:10.1177/1609406918823863

Connelly, L. M. (2016). Trustworthiness in qualitative research. *Medsurg Nursing, 25*(6), 435.

DCC. (2013). Checklist for a data management plan. v.4.0. Retrieved from <http://www.dcc.ac.uk/resources/data-management-plans>

DuBois, J. M., Strait, M., & Walsh, H. (2017). Is it time to share qualitative research data? *Qualitative Psychology*. doi:10.1037/qup0000076

Government of Canada. (2018a). *The TCPS 2 tutorial -Course on research ethics*. Ottawa, Ontario Retrieved from <http://www.pre.ethics.gc.ca/eng/education/tutorial-didacticiel/>.

Government of Canada. (2018b). *TCPS - Chapter 5 - Privacy and confidentiality*. Ottawa, Ontario Retrieved from <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter5-chapitre5/#toc05-1c>.

Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (Vol. 3rd, pp. 191-215). Thousand Oaks: Sage Publications.

Guishard, M. A. (2017). Now’s not the time! Qualitative data repositories on tricky ground: Comment on DuBois et al. (2017). *Qualitative Psychology*. doi:10.1037/qup0000085

Information and Privacy Commissioner for British Columbia. (2004). Privacy and the USA Patriot Act: Implications for British Columbia public sector outsourcing. Library and Archives Canada Cataloguing in Publication Data.

Institute of Medicine. (2015). *Sharing clinical trial data: maximizing benefits, minimizing risk*. Washington, D.C: The National Academies Press.

Jones, K., Alexander, S. M., Bennett, N., Bishop, L., Budden, A. Cox, M.,… Winslow, D. (2018). Qualitatve data sharing and re-use for socio-environmental systems research: A synthesis of opportunities, challenges, resources and approaches. *SESYNC White Paper*. doi:10.13016/M2WH2DG59

Lapenta, F. (2011). Some theoretical and methodological views on photo-elicitation. In E. Margolis & L. Pauwels (Eds.), *The SAGE handbook of visual research methods* (pp. 201-213). London, United Kingdom: SAGE Publications Ltd.

McCurdy, S. A., & Ross, M. W. (2017). Qualitative data are not just quantitative data with text but data with context: On the dangers of sharing some qualitative data: Comment on DuBois et al (2017). *Qualitative Psychology*. doi:10.1037/qup0000088

Michener, W. K. (2015). Ten simple rules for creating a good data management plan. *PLOS Computational Biology, 11*(10), e1004525. doi:10.1371/journal.pcbi.1004525

Meystre, S. M., Friedlin, F. J., South, B. R., Shen, S., & Samore, M. H. (2010). Automatic de-identification of textual documents in the electronic health record: a review of recent research. *BMC Medical Research Methodology, 10*(1), 70.

National Sciences and Engineering Research Council of Canada. (2017). *Dimensions: Equity, diversity and inclusion Canada*. Ottawa, Ontario. Retrieved from http://www.nserc-crsng.gc.ca/NSERC-CRSNG/EDI-EDI/Dimensions\_Dimensions\_eng.asp

Perazzo, J., Rodriguez, M., Currie, J., Salata, R., & Webel, A. R. (2019). Creation of data repositories to advance nursing science. *Western Journal of Nursing Research, 41*(1), 78-95. doi:10.1177/0193945917749481

PLOS ONE. (2019). Data Availability. Retrieved from: https://journals.plos.org/plosone/s/data-availability

QDR and UK Data Source. (2016). Managing and sharing data and achieving research transparency. Maxwell School and Syracuse University. Retrieved fromL https://qdr.syr.edu/guidance/teaching

Qualitative Data Repository (QDR). (2019). Managing data. Retrieved from: https://qdr.syr.edu/guidance/managing

Rolfe, G. (2006). Validity, trustworthiness and rigour: Quality and the idea of qualitative research. *Journal of Advanced Nursing, 53*(3), 304-310. doi:10.1111/j.1365-2648.2006.03727.x

Silverman, D. (2013). *Doing qualitative research* (Fourth ed.). Thousand Oaks, California: SAGE Publications Ltd.

Stuart, D., Baynes, G., Hrynaszkiewicz, I., Allin, K., Penny, D., Lucraft, M., & Astell, M. (2018). Practical challenges for researchers in data sharing. *Springer Nature, 59750*(11), v1. doi:<https://doi.org/10.6084/m9.figshare.5971387>

Tessier, S. (2012). From field notes, to transcripts, to tape recordings: Evolution or combination? *International Journal of Qualitative Methods, 11*(4), 446-460. doi:10.1177/160940691201100410

Uniting and Strengthening America by Providing Appropriate Tools Required to Intercept and Obstruct Terrorism (USA PATRIOT ACT) Act of 2001, HR3162. (Congress.gov, 2001).

University of Alberta. (2019). The health research data repository. Retrieved from https://www.ualberta.ca/nursing/research/supports-and-services/hrdr

University of California Curation Center. (2019). DMP tool: Build your data management plan. Retrieved from https://dmptool.org/plans/new

University of Victoria. (2011). Symbols of living in-between: Re-stor(y)ing life within life-threatening illness. Retrieved from https://www.uvic.ca/hsd/illnessnarratives/

White, D. E., Oelke, N. D., & Friesen, S. (2012). Management of a large qualitative data set: Establishing trustworthiness of the data. *International Journal of Qualitative Methods, 11*(3), 244-258. doi:10.1177/160940691201100305

Wilkinson, M. D., Dumontier, M., Aalbersberg, I. J., Appleton, G., Axton, M., Baak, A., . . .Mons, B. (2016). The FAIR Guiding Principles for scientific data management and stewardship. *Scientific Data, 3*, 160018. doi:10.1038/sdata.2016.18

Williams, M., Bagwell, J., & Nahm Zozus, M. (2017). Data management plans: The missing perspective. *Journal of Biomedical Informatics, 71*, 130-142. doi:10.1016/j.jbi.2017.05.004