End-of-Life Care Through Design

Visualizing Places of Death

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For my brother, Devrath

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Contents

Introduction

1.1 RESEARCH ABSTRACT

This thesis examines the design of clinical and semi-clinical locations of death, in relation to the de/medicalization of the dying experience. It is a visual and empirical ethnography—involving field observations; interviews with healthcare professionals; and a comparison of hospice versus hospital settings of palliation, undertaken through two case studies. I am studying the delivery and organization of care at these end-of-life sites, as units that operate within the public healthcare system.

To do this, I first consider the application of design thinking in health-related problems in general, then identify expectations and needs within palliative care design and, finally, compare between two care spaces in Alberta, Canada—the Red Deer Hospice Society (Red Deer) and the Intensive Palliative Care (IPC) Unit at Foothills Medical Centre (Calgary). Through site visits and interviews with healthcare professionals, I have tried to learn how such places are designed, operated, and perceived, while also gaining insights into some of the uncertainties of institutionalized dying in contemporary times.

This research attempts to raise questions about how the design of places of death—and ideas associated with them—might affect patient experiences in, public accessibility of, and social attitudes towards palliative resources.

1.2 BACKGROUND

A GOOD DEATH IN A GOOD PLACE

Over the past few decades, the desire to enhance end-of-life care has transformed from being the interest of a small section of the medical community to a globally relevant social concern. With Canada’s 2016 legislation for *Medical Assistance in Dying (MAiD)*, new questions about patient choice and end-of-life decision-making arise—not just in terms of how a *good death* may be facilitated, but also where it may be situated. Despite the growing momentum of palliative care policy and practice, a *good death* remains a vaguely understood idea. Among the many definitions of a good death, a widely cited one is the definition provided by the 1997 Institute of Medicine (IOM) report on end-of-life care:

> A decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards.[1]

Studies conducted over the years have concluded that the notion of a good death is fluid and difficult to pin down, precisely because it is a highly individual one. What appears a good death to one, may not be so, to another. Health practitioners and researchers must ensure that the care given to patients is not coloured by their own views of what a good death means; instead, assisting every patient in realizing this very personal goal. Some people may also differ in their framing of death as being a *process* versus an *event,* with the acknowledgement that the quality of the dying experience may change as this process or event unfolds.[2] The nature of such a framing may itself slightly alter the qualities that constitute a good death.

At the Duke University School of Medicine (USA), Karen Steinhauser and co-authors, in their landmark research, outline the following markers of a good death experience: "pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the *whole person.*"[3] Similarly, Karen Kehl, at the National Institute of Nursing Research (USA), conducts an analysis of 42 literature sources, expanding upon Steinhauser et al's set of characteristics.

Measuring the quality of death in such ways helps distill the complexity and variability of the dying experience into certain criteria, which may then be applied towards the building of a suitable location, and the operation of a care model within it:

> The perspectives of physicians, nurses, and patients, as well as literature in sociology, agree on the following attributes of a good death: being in control, being comfortable, sense of closure, affirmation/value of the dying person recognized, trust in care providers, recognition of impending death, beliefs and values honored, burden minimized, relationships optimized, appropriateness of death, leaving a legacy and family care.[4]

That the quality of death is linked to the location of death becomes clearer upon examining numerous studies which reveal both—patient as well as practitioner—critiques of medicalized care sites.[5-7] Other studies have shown that family members favour home or hospice palliation over hospital or nursing home settings.[8,9] In 2011, a large national study in the United States found that the bereaved family members of dementia patients in a nursing home or hospital (68.9%), reported a greater rate of "unmet needs for symptom management, concerns with physician communication about medical decision making, a lack of emotional support for themselves, and a belief that their dying family member was not always treated with respect."[10] In contrast, family members of patients with home hospice services (as opposed to other settings of care) reported higher satisfaction, fewer concerns with care, and fewer unmet needs.[11] The report concluded that these findings were consistent with previous smaller and less generalizable studies that examined the impact of hospice or palliative care services on the perceived quality of death. Other research has similarly shown that while most terminal cancer patients receive end-of-life care in an institutional setting, the vast majority prefer to receive palliative care at home.[12]

In overview, there is significant evidence to suggest that—despite the limitations of home-based care—patients, families and healthcare providers generally agree that medicalized settings are under-equipped to meet the needs and expections of dying persons.

1.3 RATIONALE

Design for the End of life

This thesis focuses on care being provided to those who are at the end of life, although it acknowledges that such care is also provided to others who have non-terminal—but life-limiting—chronic conditions. For the sake of simplicity, the terms *palliative* and *end-of-life* are used interchangeably within this document. The World Health Organization (WHO) defines palliative care as:

> [A]n approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[13]

Surgeon Atul Gawande, at the 2014 BBC lecture, *The Future of Medicine,* discussed our society's increasing discontent with clinical models of care for the dying. He called for the re-configuration of death as an opportunity to discover and provide to patients what really matters most.[14] Herein lies the opportunity for design intervention. In March 2015, *Marie Curie's End of Life Care Design Programme* convened a meeting at the University of Cambridge (UK), inviting industry professionals in design and healthcare to talk about the role of design in the current landscape of death and dying. The proceedings of the meeting were published as *Reinventing Death for the Twenty-first Century* in the UK Design Council's *The Design Economy* series.[15] Design for end-of-life care operates at two levels. First, as design critic, Alice Rawsthorn suggests, it applies to the social framing of and medical organizations around death and dying:

> When well-designed technology can help improve our every living moment, why should it desert us in death? In theory, design could—and should—have a useful part to play in improving the quality of any aspect of daily life that is no longer fit for purpose, and death is no exception [...] analysing the strengths and weaknesses of present systems and rituals with an open mind, and applying grace, foresight, rigour, sensitivity and imagination to envisaging better outcomes could help us to die more humanely.[16]

Second, it also involves fundamental aesthetic considerations in physical locations of care, according to anthropologist, Jamer Hunt, Director, *Transdisciplinary Design, Parsons School of Design* (USA) and co-curator, *Design and Violence, MoMA*. This includes "making it [the care experience] feel less and less awful. Because people aren't working in a way that's been consciously and empathically designed, there are many unintentional bad moments that add to the difficulty of the situation."[17] Both Rawsthorn and Hunt warn designers that there exists the risk of "crassly commercialising or commodifying death."[18] Dying is a sphere where "the interests of [the] government, religion, the law, capitalism and free will all converge, making it an unusually complex field,"[19] in which "incrementalism is more important than transformation."[20]

The UK Design Council, while acknowledging these complexities, urges designers to venture into the field with sensitivity, humility, and purpose.[21] Continuing in the same vein as the designers above, I would like to reiterate that spaces for the dying are essentially spaces populated by the living. Design has been defined as that which proposes and implements "courses of action aimed at changing existing situations into preferred ones."[22] This thesis hopes to show that death—one of life's most vulnerable and profound situations—falls directly within design's ambit—and registers an urgent call to designers today.

Designing Care Experiences

Alan Duncan, Associate Director, Mayo Clinic (USA) and Margaret Breslin, Centre for Innovation, Mayo Clinic, write that understanding human experience is of paramount importance if healthcare bodies and medical institutions are to deliver effective services, improve patient satisfaction and address complex patient needs.[23] However, innovating health servicescapes can be particularly daunting due to "the structure of health care financing, the lack of vertical and horizontal integration, and the slow translation of basic research into meaningful health outcomes."[24] The *SPARC Innovation Program* was developed by the Mayo Clinic to meet these challenges and innovate care delivery by synthesizing design thinking and business strategy. *SPARC* brings together designers, business analysts, healthcare professionals and patients to enhance care experiences.

The *Planetree Program (1985),* launched at the Pacific Presbyterian Medical Centre, San Francisco (USA), triggered many hospital care unit innovations. In the book *Putting Patients First,* Frampton et al from the Planetree Institute described what the patient-centred model is, showcasing the many facilities that have adopted it to create healing environments that might transform healthcare. *Planetree* defines patient-centred care as:

> [C]are organized around the patient. It is a model in which

> providers partner with patients and families to identify and satisfy the full range of patient needs and preferences. Not to be overlooked in defining patient-centred care is its concurrent focus on staff. To succeed, a patient-centred approach must also address the staff experience, as staff's ability and inclination to effectively care for patients is unquestionably compromised if they do not feel cared for themselves.[25]

They outlined four types of care that enhance health experiences:

- "care that is rooted in kindness, compassion, and dignity;
- care that recognizes the role of the patient's family;
- care that understands the influence of the physical environment in healing; and
- care that responds to the patient's psychological, emotional, spiritual, and social needs."[26]

Across cultures and societies, human beings exhibit behaviors, responses and values that link to physical spaces and material objects. Investigating these links reveals that appropriately designed spaces can benefit both individuals and society. An example to illustrate how design can improve perceptions of care quality is seen in the *Adopt-a-Room* project at the University of Minnesota Children's Hospital (USA). In collaboration with the architectural firm, *Perkins + Will*, this project was led by a client, Brian Schepperle, whose daughter fought leukemia for ten years in hospital environments. He explains, "Fighting a disease is about more than the quality of care; it's also about environment… while we can't control the illness, we *can* control the environment."[27]

As per the Council for Interior Design Accreditation (USA), design practitioners, educators, and the industries they design for, have identified, among desirable qualities in the future of design, the importance of empathy.[28] Gathering over 2 million views since its 2013 release, the Cleveland Clinic's Youtube video, *Empathy: Exploring Human Connection,* claims that, "[E]mpathy takes on a new dimension in a hospital, where there is the push and pull of health and sickness, and where giving and receiving care happens every day."[29] Effective health systems operate on strong partnerships and understandings between physicians, patients and families. Embedding empathic design in healthcare is one way of transcending client-provider equations. The *Empathy* video presents a montage of several patient profiles and a number of intimate hospital experiences. As the inner lives of the patients, familes, and care providers unfold on camera, a simple question is asked: *"If you could stand in someone else's shoes...Hear what they hear. See what they see. Feel what they feel. Would you treat them differently?"*[30] In sensitive medical contexts, such as at life's end, it is even more important for patient needs, desires, and preferences to be viewed as an extension of the universal human condition.

Stephen Verderber, Professor of Architecture and Public Health at the University of Toronto (Canada), writes in *Innovations in Hospital Architecture,* that human beings are pacified by spatial conditions implying security, privacy, instrinsic meaning and value. In times of sickness, feelings of uncertainty, isolation, powerlessness, alienation and depression affect the acceptance of matters pertaining to life and death, ultimately influencing the patient's outlooks, attitudes and outcomes. He believes that the ability to accept existential situations, find contentment with health services, and experience a sense of control—are all directly manifested in the physical appearance and design of care spaces.[31]

1.4 DESIGN RESEARCH METHODS

Participatory design has its roots in collaborative work done in the 1970s by trade unions and employer federations in Scandinavia, at which time, it was called *co-operative design*. In the 1980s, the *UTOPIA* and *Florence Projects,* were important early influences on systems design and technology use in organizations.[32] Such frameworks often overlap with terms like *co-design* and *co-creation,* especially after C.K. Prahalad and Venkat Ramaswamy popularized these notions in their work, *The Future of Competition: Co-Creating Unique Value with Customers.*[33] User experience designer, Todd Cherkasky, explains that:

> Participatory design provides a framework for individual designers to deal with issues raised during collaboration in design, including how to negotiate conflicting constraints and values, make visible diverse stakeholders' interests and knowledge, and assess design success along a variety of metrics . . . The field provides an enormous set of resources for investigating the social thread of design, including organisational structures and collaborative tools.[34]

According to Judith Gregory, Associate Professor in the Systems Development, University of Oslo (Norway), participatory design methods should involve stakeholders in every phase of the design process in:

- "determining design objectives on social {not only technical} bases;
- analysis of the current situation and co-construction of problem formulation;
- conceptualisation of design, designing and evaluating possible design solutions;
- implementing changes including training people for new practices;
- evaluation, maintenance and ongoing improvements;
- iterative design."[35]

In this research, participation through interviews is sought—at a preliminary *scoping* level—from representatives of one stakeholder group, that is, palliative care workers. Participatory design, in such a context, improves the knowledge upon which systems are built; decreases resistance to change; and increases workplace democracy by giving the members of an organization the right to participate in decisions that are likely to affect their work.[36]

IDEO, a global human-centred design firm, qualifies *design thinking* as an empathic, integrative, optimistic, experimental, and collaborative process.[37] According to CEO, Tim Brown, "By taking a *people-first approach*, design thinkers can imagine solutions that are inherently desirable and meet explicit or latent needs. Great design thinkers have the ability to *observe the world in minute detail*. They notice things that others do not and use their insights to inspire innovation."[38] In my capacity as a design thinker, I apply two key points from Brown's advice for identifying some of these "explicit or latent needs":

(i) A people-first approach: *Semi-structured interviews*

In palliative scenarios, *people* can be broadly divided into two main groups: *care providers* (administrative staff, nursing staff, physicians, therapists, volunteers) and *care receivers* (patients, families). For the purpose of this study, I have focused on the former, that is, those who work within the palliative profession. Semi-structured interviews were conducted with people working in the end-of-life spectrum, to derive knowledge about the operation of palliative facilities and their opinions on where improvements could be made.

(ii) Observe the world in minute detail: *Ethnographic Documentation*

Field research was undertaken at two sites in Alberta—a small independent hospice and a palliative unit at a large general hospital. Qualitative data was collected through field notes, photographs and personal reflections, which were used to generate a critical commentary of the locations studied—in terms of structural, organizational, ambient and experiential design. Imitating the experience of navigating through care spaces exposed me to the everyday inner workings of such sites. While patients did not directly participate in this study, placing myself in their lived environment helped unpack and document the tacit relationships between patients and the places they occupy.

1.5 CHAPTER OVERVIEWS

The following is a brief summary of what subsequent chapters cover:

Chapter 2: Literature Review

This chapter first presents a selection of existing research relevant to connections between health and design. The aim of this chapter is to make a case for how and why design thinking processes and participatory methods might benefit a variety of healthcare institutions, medical research, workplace environments, patient experiences and communication contexts. The latter half looks at literature on end-of-life environments and identifies the current gap in scholarly research and design practice within this architectural specialty.

Chapter 3: A Place to Die: *Location & the Anxiety of Death*

This chapter begins with a general discussion on the nature and meaning of place, distinguishing geographic territory from locations imbued with social relevance. It goes on to apply anthropological conceptions of space and place to medicalized environments of death and care. The bulk of this chapter is dedicated to understanding how time and aesthetics manifest themselves in architectural activities and artifacts, and why these might be linked to the awareness and anticipation of human mortality.

Chapter 4: Discussion: *Field Research*

Field research is discussed in this section, first, through a content analysis of the sites I visited. Photographic material gathered on location is accompanied by textual commentary generated from my own observations and field notes. The objective is to provide an inside view of palliative facilities, with key observations on specific design-related details. Major design implications inferred from these observations are summarized later in research findings. Summarized analyses of four semi-structured interviews form the second part of this chapter. Full interview transcripts are available on request.

Chapter 5: Research Findings: *Imagining the Last Place*

Research findings from site visits, interviews, and reviewed literature, are compiled in the form of individual aspects to consider in existing and in future palliative facilities. These are presented as a set of loose guidelines for end-of-life design. Recommendations are classified under six major categories, which are further divided into various factors.

Chapter 6: Conclusion: *Moving On*

This chapter begins with a general overview of the aspects that affected the research process and their significance in future research within this domain. Challenges encountered and limitations surrounding my research process are discussed. Finally, the thesis concludes with comments on some of the more complex and ambiguous issues revealed through literature review, semi-structured interviews and site visits. These pertain to the changing face of palliative conditions in the country, as well as how they affect the conception, design, and management of end-of-life care sites for tomorrow.

1.6 SUMMARY

While design that celebrates, optimizes and sustains living conditions is plentiful, relatively little design concerns itself with death and dying. As a result, even within care spaces, palliative zones are much less visible and consciously built than curative ones. This study proposes that designing well-considered, physically comfortable, emotionally sensitive, aesthetic, and functional spaces can relieve stress and increase satisfaction with the quality care being received.

On the following pages, I will discuss prior research that has brought design thinking to healthcare, and consider the extent to which similar connections have been made within palliative care design.

ENDNOTES

1: Field and Cassel, *Approaching Death,* 24.
2, 4: Kehl, "Moving Toward Peace," 281.
3: Steinhauser et al, "In Search of a Good Death," 825.
5: Low and Payne, "The Good and Bad Death," 237–241.
6: Murray et al, "Where the Dying Live," 69–77.
7: Patrick et al, "Evaluating the Quality of Dying and Death." 717–726.
8: Teno et al, "Does Hospice Improve Quality of Care...?" 1531–1536.
9: Catalan-Fernandez et al, "Dying of Cancer," 841–852.
10, 11: Teno, *Quoted quoted in* Stanford School of Medicine, "Patient and Family..."
12: Pierson et al, "A Good Death," 587–598.
13: United Nations, *World Population Ageing.*
14: Gawande, *The Future of Medicine.*

15, 21: Pallister, James, "Reinventing Death for the Twenty-First Century."

16, 19: Rawthorn, *quoted in* Pallister.

17, 18, 20: Hunt, *quoted in* Pallister.

22: Simon, "The Science of Design," 67.

23, 24: Duncan and Breslin, "Innovating Health Care Delivery," 13–20.

25: Frampton et al, "Patient-centered care improvement guide," 4

26: Frampton et al *quoted in* Carmel-Gilfilen et al, "Designing with Empathy," 133.

27: Schepperle, *quoted in* Cary, *The Power of Pro Bono,"* 176.

28: Council for Interior Design Accreditation, "Accreditation standards."

29, 30: Cleveland Clinic, "Empathy."

31: Verderber, *Innovations in Hospital Architecture.*

32, 35, 36: Gregory, "Scandinavian Approaches," 64, 66.

33: Prahalad and Ramaswamy, *The Future of Competition.*

34: Cherkasky, "Designing Experience," 11.

37: Carmel-Gilfilen and Portillo, "Designing With Empathy," 132.

38: Brown, "Design thinking," 87.

Literature Review

In her doctoral study of a participatory healthcare design project, Cecelia Sjöberg, ICT Division Head, Swedish Governmental Agency for Innovation Systems, recognizes the design process as a "culture of argument [that] frames doubt and doubts, openness, incompleteness and lack of closure, iterative processes, critique of both the product and processes of design, and argumentation, as important resources to be valued in the design process."[39] She believes that *democratic dialogue* unfolds through participatory design because, "[p]ower and dominance are . . . meant to be visualised, not neutralised"[40] The following sections will examine some of the ways and means through which such dialogues may be facilitated; healthcare may utilize design thinking for identifying complex problems; and the nature of knowledge gaps may be determined.

A hybrid vocabulary shared by both—design and health practitioners, scholars and critics—is often used interchangeably and with significant overlaps when discussing design research methods. This chapter will not focus on the history and definition of each term, but instead, understand them through case-based contexts. These are, therefore, viewed as broad frameworks from which we may draw diverse interpretations to apply towards similar design problems. This chapter intends to review the role of design within medicine, particularly those that involve places of care.

2.1 DESIGNING FOR HEALTHCARE SERVICES

SOME APPROACHES SEEN IN OTHER RESEARCH

Human-centred Community-based Design

Human-centred design (HCD), an important paradigm for building systems with care, aims to consider the needs and desires of all stakeholders who operate within that system. Understanding the values of all groups who will ultimately interact with—and within—the designed service outcome, is a key determinant of its success. HCD is a powerful method for addressing the social determinants of health—resulting in product, service, and strategy innovations that prioritize the target population's needs.

In 2012, the School of Public Health at the University of California, Berkeley (USA), led the *Best Babies Zone (BBZ)* initiative—a national, multi-year, place-based project—aiming to reduce inequities in infant mortality rates.[41] The *Alameda County Public Health Department (ACPHD)* at the *Oakland BBZ* site partnered with a social innovation design consultancy, *Gobee Group,* to develop a three month pilot *Design Sprint,* involving 14 professionals from 9 organizations in the use of human-centred design (HCD) thinking to stimulate a vibrant local economy. All 14 individuals participated in 30–60 minute semi-structured interviews to provide insights towards program improvement.

Their HCD process was divided into *Understanding, Ideation* and *Implementation* phases. In the *Understanding* phase, the team members undertook two neighbourhood walks, observing the physical environment, involving residents in conversations (about informal economy, small businesses and childcare), and inferring their motivations and emotions. These team members, none of whom had any formal design training, all possessed other types of expertise applicable towards the generation of a robust local economy. Neighbourhood walks re-balanced their view of the community beyond bleak poverty and crime rate statistics. Halfway through the *Design Sprint,* the team collated their insights to re-structure and re-orient their goal of systemic change towards actionable outcomes at a small, but visible, level that might lead to community success. Stating their aims to work with the community and deploy existing assets and resources, they explicitly encouraged local leadership. Following the *Understanding* phase, the team transitioned into *Ideation,* brainstorming over 100 concepts and encouraging visual creative thinking. Team members paired up to identify ideas with the best potential for high impact, based on attainability within the short term. Interactive poster sessions served as small and simple tests to quickly envision solutions and engage residents directly in program planning.[42]

The study showed how human-centred, community-based, design thinking gleans local knowledge from the start of program planning, rather than having to rely upon minor feedback during the service implementation stage. HCD outlines no preset outcomes, and therefore, carves out opportunity for new innovations by openly acknowledging ambiguity in its process. It recognizes geographic, cultural, and institutional contexts, along with the need to utilize social capital, local values and knowledge, in activating community transformations.[43]

In another example, service design & communication agency, *thinkpublic,* illustrated how better health systems might be constructed through a similar approach.[44] In 2004, this London-based agency formed a local *Design Squad* in the *East Greenwich* community. Local residents self-identified health concerns, acquired skills that created new employment opportunities, and spearheaded the changes that they wanted to see. They were then linked with other groups and organizations to create connections between mental health, relationships, housing, environments and neighbourhoods. A design-led community healthcare model emerged, demonstrating how health services may be decentralized and sustainable communities built, using existing local intelligence. In a larger project with the UK *National Health Services (NHS),* the team at *thinkpublic* set up *Journeys,* a healthcare feedback system that "logs and monitors patients' experiences and then acts both, as a means of patient empowerment, and as an evidence-gathering mechanism for frontline staff wishing to make service improvements."[45] The *Journeys* project was essentially a digital mapping platform for patients to log their experiences as they went along their treatment routes. The NHS Modernisation Agency (UK) reports that charting patient journeys is pivotal in assessing the efficacy of healthcare delivery: "The *Journeys* interactive feedback systems would allow patients to freely enter their experiences as they experienced them and is central to allowing the health care system to continuously audit patient emotional response and dynamically adjust their systems."[46]

The frameworks that have emerged from these three studies make a strong argument for the role of health service design in:

- identifying problem areas (such as bottlenecks, miscommunications, and organizational barriers) in the health system;
- devolving decision-making power and budgetary control;
- driving sustainable change through creative methodologies and fresh solutions;
- creating new partnerships between stakeholders;
- enabling co-designed services and enhancing communication; between healthcare providers and users; and
- handing patients ownership and directing their own care.[47]

Experience-Based Design

The NHS Institute for Innovation and Improvement (UK), has developed an experience-based design (EBD) strategy for healthcare innovation that draws upon methods in participatory action research and practice-based research.[48] EBD concentrates on building meaningful user interactions and creating user touchpoints with services and places, while placing equal importance on both, patient experience and clinical objectives. The NHS EBD process involves four phases: "capturing the experience of patients and staff; understanding the meaning of experience and identifying problematic elements; co-designing and implementing improvements; and measuring improvement."[49]

Applying the NHS EBD strategy to solve a specific healthcare concern, the Royal Hallamshire Hospital, Sheffield (UK), tried to improve medical outpatient services for seniors. The design team tackled the recurrent problem of missed appointments, which showed that patients were being deprived of much-needed treatment, accumulating a cost of £600m per year for the NHS. Writing about this research, Wolstenhome et al assert that the failure of a health system to meet the user needs indicates a compromise of their independence, dignity and confidence.[50] Seniors, as a result, may view outpatient visits with mistrust, thereby losing out on the clinical care and support that they need, causing a further decline in their health and wellbeing. Using EBD in this scenario facilitated the co-creation of contextual knowledge about particular practices in a healthcare setting, enabling several solutions at individual, systemic and strategic levels, for both short-term and long-term implementation. The design team noted that patients rarely mentioned the primary purpose of using outpatient services when describing their hospital experience. Instead, they were more concerned about other factors, such as "the responses of individual staff; the performance of hospital systems; the layout, legibility and accessibility of buildings; and transportation between home and hospital."[51]

Through the use of human-centred, community-based, and experience-based design approaches, indirect and less tangible factors influencing patient experience and the perceived quality of care are made visible. Effective design thinking strategies can therefore systematize public health innovation by:

- creating a structured inclusive process without relying upon singular leadership;

- shortening planning timeframes;
- enabling community members and cross-sector partners to co-create;
- leveraging the existing strengths, insights, resources and assets of team and community members;
- increasing the likelihood of successful solutions;
- respecting community members as experts;
- helping to learn from fast, simple and efficient prototyping;
- gearing lessons learnt towards developing more robust future solutions; and
- demonstrating that small beginnings can later address systemic issues.[52]

Wolstenholme et al conclude that traditional methods such as statistical process control and the use of reductionist techniques like satisfaction surveys cannot capture the full scope of human factor issues, because they exclude users and practitioners beyond the consultation stages.[53] On the other hand, design thinking works within the system to envision and deliver creative fixes to practical problems, by considering lived human experience and adopting diverse ways of knowing.

Photovoice, Phenomenology & Ethnographic Enquiry

Comparing the foundational ethos, histories and methodologies of both—phenomenological enquiry and the nursing sciences—it has been argued that photovoice is a promising tool for recording lived experience.[54] As nursing research and practice bears historical and continuing links to social justice, capturing the voices of marginalized individuals is vital to research in healthcare. By understanding lived human experience, policy-makers and health practitioners may be able to make more informed decisions, creating opportunities for the enhanced care of vulnerable segments. In interpretive phenomenology, interviews between the researcher and study participants aim to investigate the phenomenon under study by measuring interactions between humans and environments.[55] On the other hand, photovoice—a participatory research method for health promotion—creates spaces and opportunities for less heard voices to emerge.[56] As an approach that draws upon the theories of critical consciousness, feminism, and documentary photography,[57] photovoice has been hailed as a channel for critical reflection on community issues, with the ability to influence change at community and policy levels.[58] The method primarily directs participants to take pictures that are most representative of the issue under consideration and discuss them in photo-sharing sessions with other participants. Logbooks may be used for the written documentation of experience and perspective along with the photographs. Photovoice has previously been used to facilitate change among community health advisors,[59] to study the notions of play for children,[60] and to understand leisure concepts in dementia.[61]

According to the founding father of phenomenology, Edmund Husserl, pure experience is descriptive and the phenomenon does not concern the mental acts that accompany it.[62] Therefore, he believes phenomenology to be that which occurs pre-reflexively and has yet to be placed within social, cultural, personal or other contexts. Philosopher, Martin Heidegger, opposes this view of phenomenology by proposing that experience can neither be made distinct from its associated contexts, nor detached from consciousness.[63] The latter perspective on phenomenology has come to be known as *interpretive phenomenology.* Although the values and facts of experiential meaning must be unearthed by asking, researchers' biases may affect the nature of questions asked, shape the responses obtained, and alter the representation of what is actually important to those who experience the phenomenon.[64] This is where photovoice may allow participants to better control the nature of information, helping the researcher view what holds most value to them, while also allowing supplementary data to be gathered alongside narrative interview data. The value of photovoice is most felt in the dialogical interpretation between researchers and those taking the pictures. Worldviews that we would not usually be exposed to are revealed through this resultant group dialogue, deepening our perceptions of daily experience. Educator, phenomenologist and Professor Emeritus at the University of Alberta (Canada), Max van Manen, suggests that the expressiveness of storytelling assists phenomenological investigation in meeting its objectives.[65] Poetry and novels, for example, demonstrate meanings felt and grasped at the core of our being,[66] filling the "epitemological silences" created by objective spoken language.[67]

Photo-elicitation, now used extensively in social and health research, was a term first used by sociologist, John Collier, in his work with families and mental health in the 1950s.[68] In photo-elicitation, images may be taken by the researcher, the press, the study participants, or they may be historical photographs. Similarly, the photo-novella focuses on empowerment through self-portraiture, enabling participants to share their voices using documentary photography, reflecting upon their needs, initiating dialogue, calling for action and possibly informing policy. Wendy Ewald, who taught Appalachian children to document their lives using cameras, may be considered the foremother of the photo-novella.[69] The method has been successfully used to capture the hospital discharge experiences of elderly women[70] and to tell the stories of Bosnian children who came to Canada in the 1990s.[71] van Manen notes that a good phenomenological description is one with an "adequate elucidation of some aspect of the lifeworld."[72] Integrating the photovoice method into phenomenological inquiry may encourage critical thinking, build spaces for oppressed voices to be heard, and allow interpretations of lived experience to authenticate our understanding of the lifeworlds within which it occurs. van Manen has proposed six interactive approaches for interpretive phenomenological inquiry:

- "orienting oneself to the phenomenon of interest and explicating assumptions and pre-understandings;
- investigating experiences as lived through conversational interviews rather than as they are conceptualized;
- conducting thematic analyses to characterize the phenomenon and interpreting through conversations;
- describing the phenomenon through the art of writing (rethinking, reflecting, recognizing);
- maintaining a strong relation to the fundamental question about the phenomenon; and
- balancing the research context by considering parts and wholes."[73]

As mentioned previously, there are overlaps in the terms design researchers use to present and realise their methodologies. Similarities to van Manen's ideas can be observed in a different study conducted in Norrlands University Hospital (NUS), Umeå (Sweden).[74] Researchers involved in this project used an ethnographic approach for investigating patient experience in cancer care, focusing particularly on the emotional impact of fixation devices in radiotherapy sessions. Mullaney et al write that since anxiety is a commonly documented emotional aspect of undergoing cancer treatment, patient perceptions of the care environment and staff may significantly shape their overall hospital experience.[75] As radiotherapy is a recurring form of treatment, it is particularly critical to ensure that patient positioning and immobilization can be replicated for each session in the same way. Immobilization within cancer care is needed so that body movement during radiotherapy can be as limited as possible, minimizing risk of missed target volume or accidental dosing of surrounding organs. In order to anticipate and manage the stress resulting from immobilization, it is necessary to examine the embedded social construct of the *passive patient* within the design of a fixation device. Fixation devices require patients to forgo control over their physical movement, often resulting in a feeling of powerlessness. Physical restraint and the emotional impact of containment must be considered in order to alleviate the negative feelings associated with fixation devices. Mullaney et al conclude that technology is embedded with social values and may facilitate or restrain our actions. According to the social script of illness behavior, the sick individual is obligated to go to the hospital and cooperate with medical professionals. These roles are so ingrained within medical semantics that many patient experiences are rooted in a sense of unequal power.[76]

A patient-centred care approach was utilized to identify triggers of situational anxiety in curative care and determine potential solution spaces. During the course of this study, researchers spent two weeks shadowing radiotherapy staff, immersing themselves in the observance of behaviours, interactions and working processes within the research environment. They mapped out the radiotherapy workflow using information diagrams, making note of points where different technologies were used, and how staff planned and delivered treatment. By identifying the various actors within the process, they were able to assess the role of practitioners and technologies at key junctures. Salience hierarchy was employed to pinpoint what data needed recording and where similarities or differences lay between individual patient experiences. Observations began in the waiting room, following patients into the pre-treatment and treatment rooms. Photographs and extensive fieldnotes were used to record the features of these spaces, such as the general ambience, the amount of time spent in them, and what these spaces were used for.

In terms of their project, Mullaney et al discuss *evidence-based medicine,* which "integrates individual clinical expertise with the best available external clinical evidence from systematic research in order to ensure the best prediction of outcomes in medical treatment."[77] Because this approach requires objectivity and neutrality, doctors favour measurable variables such as test results, over less quantifiable aspects of disease, like patient wellbeing. Design thinking, as seen in this case, is focused on creating change through interventions that directly affect the triggers of situational anxiety. According to IDEO, designers examine "the needs, dreams, and behaviors of the people [that they] want to affect with [their] solutions."[78] Mullaney et al suggest that giving patients access to the medical equipment in non-clinical settings may help them in becoming familiar with the machines. The researchers emphasized the value of designing technologies that enable patient relaxation, allowing them to work with their bodies and find appropriate positions for treatment.[79]

Ethnographic documentation, pulling methodologies from previously discussed models in photo-elicitation and phenomenology, collects data about users' needs and preferences. These methods are aimed at observing people's lives, asking questions and listening for answers—that is, absorbing available data to learn about anything that concerns the research issue. While ethnographic processes are usually undertaken over an extended period of time, Handwerker suggests *quick ethnography* as a means for gathering high-quality data in a period of 90 days or less, often without even requiring direct interaction with the object of study.[80] Apart from patient observations, the researchers may conduct informal interviews with staff to gain further insight into patient interactions and the patients' emotional responses. Healthcare practitioners, like Dr. Nicholas LaRusso of the Mayo Clinic's Centre for Innovation, advocate the notion of service-focused design as a mode of healthcare reform.[81]

Transforming the social perception of patient identities from those of implicated actors to empowered healthcare users, requires the application of human-centred design principles towards large scale systemic change within organizations and communities.[82]

Narrative Enquiry

Human-centred—which in this case, implies patient-centred—outcomes can be achieved by embedding narrative in the design process, that is, by obtaining "insight[s] into the thoughts, feelings, and experiences of others."[83] A similar approach has been discussed above with the NHS experience-based design (EBD) model. Re-wording the NHS EBD strategy as *narrative enquiry* in an interior design studio course at the University of Florida (USA), 18 students investigated the perspectives of patients, families and staff, to design a two-story model of a 46,000 sq.ft. outpatient cancer treatment centre, including public areas, clinical zones, support spaces and staff areas.

Students began by referring to over 75 peer-reviewed scholarly articles. Healthcare design experts from *Herman Miller, Inc.* a major furniture manufacturing firm, supported and guided the students, enabled tours in their manufacturing facility, and helped them learn from their prototyping methods. They benchmarked various local and national facilities; made observations; and conducted interviews with patients, nurses, residents and cancer care physicians. Students read patient stories and explored *narrative dialogue* to frame feelings and situations from the various perspectives of all involved parties. Through narrative enquiry, students learnt to think beyond spatial aesthetics and consider other aspects of environmental design—for e.g., multi-sensory stimuli—such as smells, acoustics, and movements involved in healthcare environments. Treatment spaces were made adaptable for quick conversion to private, semiprivate, and public places, in accordance with the wants, needs, moods, and preferences of the patient. Arrangements were made to provide for outdoor treatment in times of suitable weather conditions. Carmel-Gilfilen and Portillo classify the results of this research under the following three categories:

- *Design Empowerment:* The challenge lay in reflecting inner strength and motivation in the facility's ambience and in avoiding the usual sterile appearance of treatment centres. Instead of waiting areas, *public empowerment zones* were designed to engage communities and channelize the resiliency of everyone involved in the cancer care journey. Positive sensory stimuli was included in these spaces, such as, freshly baked cookies in the reception or big interactive touchscreens to find 5K runs for cancer research. Similarly, *private empowerment areas* provided space for prayer or reflection, while also allowing for intimate socialization within smaller groups.

- *Advocacy Spaces:* These were designed to link current patients, cancer survivors, staff, family members, and community members, through access to new cancer research, treatment protocols and outreach programs. With the use of technology, patients were able to virtually connect with the worldwide cancer community. A *story wall* displayed the experiences and insights of patients and staff, using images and words that might inspire those navigating the corridor.

- *Design for Healing:* Biophilia principles were used to infuse feelings of peacefulness, wellness and positive energy from nature. An embracing and warm design was conceptualized to inspire calm reflection. A *healing garden* was made visible from every vantage point in the building. Specific cues in flooring and ceiling materials were deliberately selected so as to visually link common pathways up to the gardens. Another *healing garden* was designed with a

> community cafe for staff, visitors, and patients to encourage further socialization. To help temporarily disconnect from daily stresses, losses and patient setbacks, *staff respite areas* were placed adjacent to the healing gardens. The healing narrative was thus expanded to include all user groups. Student interactions with the local cancer centre's *arts in medicine program* inspired them to envision outlets for creative self-expression through open art therapy spaces. These areas were designed to welcome social interaction and exude a sense of community strength.[84]

The project revealed how medical architecture and environmental design can benefit from verbal, written and visual storytelling and exposed ways in which designers can place enquiry within the context of the care experience.

This section has showcased key examples where designers and healthcare researchers have worked together to prompt change in health servicescapes. In the next section, I will establish what previous research suggests about the the design of palliative environments; how these sites are being conceived and built; and if there is sufficient knowledge to inform current and future practice within this design specialism.

2.2 DESIGNING END-OF-LIFE ENVIRONMENTS

In 2014, the World Health Organization (WHO) reported that access to palliative care is significantly limited around the globe, with only 14% of those in need receiving it.[85] The need for specialized facilities, within which staff are well-supported for providing better patient care, is expected to rapidly increase over the next few decades.[86] In the growing area of healthcare design, many studies have established the relationship between the physical environment and positive care experiences at the end of life.[87, 88]

Architect, Douglas Macleod, believes that *evidence-based design*—which borrows its rationale from *evidence-based medicine* to "carefully observe, quantify and analyse the way people use buildings"—is much needed in Canada, where there is a lack of published data on the subject.[89] What is now linked to the subfield termed as *evidence-based design,* started with early studies in the 1970s, showing that hospital premises were difficult for patients to navigate. Most wayfinding problems were caused by long winding corridors, complex floor plans, convoluted routes, and overall, disorienting, overwhelming, and tedious health campuses. Wayfinding became one of the key factors for which hospitals were criticized as core design failures.[90] At first, navigation challenges were met by painting signage on colour-coded stripes on the ground. Later, signage with big lettering and bold colour schemes, what Annmarie Adams, architectural historian and medical sociologist at McGill University (Canada), has likened to *disney park* graphics,[91] were plastered around hospital interiors, in an attempt to disguise the underlying problem. But despite its weaknesses and limitations, eventually *evidence-based design* did ultimately bring some coherence to hospital spaces:

> Formerly blind corridors now provide views out, connecting circulation elements now afford transparency, inside-outside spatial orientation aids for occupants are now provided, as are landmarks in the form of works of art, water elements, skylights, and clerestories. In tandem, these function to establish identity and *genius loci* [...] The wayfinder, upon arrival, keys into the destination and then proceeds on the journey. The route is punctuated with landmarks in the form of architectural elements (floors, walls, ceilings, formal devices, and so on), exterior views, and art, with a voice in the headset or PDA providing route directions.[92]

At present, *evidence-based design* attempts to reduce the contribution of built space towards medical errors and healthcare obstructions. The *Evidence-based Design Accreditation and Certification (EDAC)* protocol has published a set of study guides for design, architecture, planning, and management professionals in healthcare, outlining three organizing principles of *evidence-based design*:

- "patients should be able to devote their energies to healing and recovery without having to cope with an unsupportive built environment;
- healthcare providers should be able to perform their duties without becoming ill themselves or being injured due to an unsupportive built environment; and
- non-carbon reductive and high energy consuming buildings for healthcare are tantamount to an unsupportive built environment."[93]

There is a worldwide shortage of literature focusing on palliative architecture, with only two major publications offering comprehensive coverage of the field: Stephen Verderber and Ben J. Refuerzo's *Innovations in Hospice Architecture (2003),* and Ken Worpole's *Modern Hospice Design: The Architecture of Palliative Care (2009)*. Both books critically assess standards of practice in architectural, landscaping, interior and ambient design, discussing examples of buildings (mostly hospices, but also comparisons against hospitals), that have been built in several parts of the world over the years.

Verderber and Refuerzo's book makes the case that hospice architecture generally aligns with what we broadly view as palliative design, but differs greatly from hospital architecture.[94] It builds this argument by tracing the development of palliative care in hospitals and homes—from medieval, through modern, to postmodern times—and culminating in a detailed analysis of 18 care facilities from around the world. Another key point the authors make is that nature and architecture must be harmoniously reconciled in future building prototypes, because natural spaces have immense therapeutic benefits for the dying person.

Ken Worpole's *Modern Hospice Design* compiles examples of palliative hospices and infers useful lessons from the designs of these buildings. In addition, the book also includes many actual architectural briefs, all of which prioritize designing *positive* environments, rather than stressing excessively on any architectural particularities. Worpole remains fairly critical of hospitals as places of death throughout his work. Noting that the palliative movement originated in response to institutional paradigms of death, he states, "It is within this burgeoning concern with the institutionalisation of death that the hospice movement gained a foothold and a purchase on the modern social imagination."[95] His book is deeply concerned with envisioning the site of death not only as a material construction, but also as a metaphoric construct—imbued with social, existential, and personal meanings.

In the first half of the twentieth century, hospital geriatric wards housed the aged and the invalids, usually those with incurable ailments, in the back end of the building, away from the heart of social life and activity. Non-terminal patients were assigned the front wards, a spatial arrangement that reflected institutional and social hierarchy.[96] Widely accepted as the first modern hospice, London's 1967 St. Christopher's Hospice, is critiqued by Verderber and Refuerzo for reflecting the sterile and unemotional aesthetic language commonly associated with hospital buildings, possibly a result of NHS frameworks that hospice designers were required to follow.[97] Founders Cicely Saunders and David Tasma had hoped that St. Christopher's would evade the hospital's dispirited atmosphere, and instead, bear a *home-like* environment to strengthen and *uplift* the patient. Yet, the hospice has garnered much critcism for its many design problems, such as, its overwhelming scale, institutional appearance, and cold ambience.[98]

At the time when St. Christopher's was built, the so-called nineteenth century *death-houses* were still associated with the hospice movement, even within the medical community itself.[99] Inspired by psychiatrist, Elisabeth Kubler-Ross' seminal work, *On Death and Dying (1969),* Dr. Balfour Mount—Founding Director of several palliative care programs at McGill University (Canada), and now eminent as the *Father of Palliative Care* in North America—decided to visit St. Christopher's Hospice in 1973. Soon after his return, he set up a similar ward at the Royal Victoria Hospital (Montreal), which became Canada's first facility of its kind. In order to dissociate the negative connotations of the word *hospice* in French, Dr. Mount coined the term *palliative care.*[100]

In 1982, Verderber authored a monograph titled *Environment-Behaviour Design Factors in the Architecture of Hospice.* Not long afterwards, in 1986, Deborah Allen Carey published the report, *Hospice Inpatient Environments: Compendium and Guidelines.* While these publications showed an awakening interest in healthcare design, Verderber writes that it was still too early for most people to imagine palliative architecture as a specific type, or in fact, anything beyond a care philosophy.[101] By 2000, however, hospitals were under heavy criticism for their large scale, noisy environments, and inaccessible design. An alternative began to emerge in the form of the hospice building, which Verderber claims was, and still is, a utopian ideal.[102] From a design perspective, the hospice sought to overturn all that had come to be associated with the postmodern hospital building:

> Ordinariness is … the hallmark of successful hospice design. A home for the dying is not the place for avant garde experimentation, but, rather, familiarity and unobtrusiveness.

> It helps people feel that they're part of the neighbourhood and the neighbourhood feels that the people there are living the same lives that they are.[103]

Verderber & Refuerzo refer to the above sentiment as *residentialism,* a philosophy that rejected the hospital as the *medical machine*—and instead, gave postmodernist expression to its opposite—the natural and the domestic.[104] They write at length about the therapeutic and cognitive effect of gardens seamlessly integrated within architecture to provide "solace, strength, and meaning…in both metaphoric and instrumental ways."[105] As the palliative model became a global movement, there began to emerge a greater degree of concern around the symbolic significance of its operative facilities. Worpole cites the brief for St. Patrick's Hospital's hospice in Cork (Ireland), which envisions itself as:

> [A] place where ordinary people face up to extraordinary challenges and with the help of skilled and dedicated health care professionals, triumph in the face of progressive physical deterioration and sequential losses. People live until they die and it is the job of the hospice to support and enable each patient to live their life as fully as possible. It is a place for reflection and a place to search for meaning and purpose. For many, it is perhaps the first time that they have seriously addressed the fundamental issues of life and death. The hospice building must be sympathetic to, and supportive of, our best efforts. The building must be planned to the finest detail, because we cannot afford to get it wrong.[106]

The brief for Maggie's Centres—which have arguably become one of the most visible proponents of thoughtful design in healthcare—calls for a building that can "rise to the occasion,"[107] and communicate its purpose through "the redemptive power of space, light, and sculptural form."[108] Maggie's are a group of small cancer care buildings, designed by some of the foremost names in architecture, such as, Frank Gehry, Zaha Hadid, Richard Rogers, Kisho Kurokawa, etc. An initiative started by cancer patient, Maggie Jencks, and her architectural-theorist husband, Charles Jencks, Maggie's Centres are resolute, conspicuous, outspoken structures that evade conformity to residential or hospital templates. In deliberately avoiding these frequent associations, they make a crucial statement—that a healthy society confronts sickness and death openly, with forethought, empathy and courage.[109] Bold and powerful, they exemplify what Adams has called "look-at-me architecture, an image that is normally reserved for larger, monumental building types such as museums, and are thus a counterpoint to the history of hospices, which tended to be rather invisible in buildings designed as houses."[110]

The first Maggie's Centre was built in 1994 by Richard Murphy, who details the dilemmas of pioneering a new building-type. Much of his uncertainty is still valid today and designers would benefit from contemplating the questions that he did, when first approached with the project. He says: "There were problems with the brief, the wooliness of it. What exactly was the building for? We knew it wasn't going to be a clinical building, but Maggie was going on about all kinds of things, relaxation, a library, meetings, yoga, beauty care. How would we fit all this in?"[111] The risk taken by Murphy paid off, and ultimately the Edinburgh Maggie's Centre, marked a pivotal point in palliative architecture, one that affected the tone and conception of all subsequent Maggie's Centres.

Maggie's Centres co-founder, Charles Jencks, in the book, *The Architecture of Hope,* writes about the difficulties of classifying these buildings, calling them a *mixed type.* He believes that they are houses, but not homes; community hospitals, but not institutions; places for spirituality, but non-denominational; art galleries, but not museums.[112] American architect, Frank Gehry, whose design for the Maggie's Centre in Dundee (Scotland), received much public and media interest, said at its opening:

> I wanted to create a building that would be calming and accommodating, and one that would be a fitting tribute to Maggie. I think it's an inviting building, I think people will want to come inside and spend time there, and I really hope that in some small way, it might contribute to a sense of rejuvenated vigor for moving forward and living life.[113]

Despite the fact that Maggie's are always non-residential and outwardly undemure, they bask in an interior domestic warmth—or to use Jencks' term—they celebrate *kitchenism*. The dining space is always a core design element that sustains the idea of hearth and home—with tea, coffee, cookies and cushions forming a recurrent motif throughout the interiors.[114, 115] According to Jencks, a Maggie's Centre is:

> a welcoming, warm, skittish, personal, small-scaled [building] and centred around the kitchen [or dining] place to make coffee and tea. The centrality of food and drink allows people to enter and exit without declaring themselves, try things out, listen or leave without being noticed.[116]

Offices, counselling rooms, meeting rooms, and toilets are all secondary, but the garden is integral, with a continuous floor between interior and outdoor spaces.[117] These elements come together to reject cancer's ghastly otherworldliness, and bring patients under the fold of everyday normalcy, community acceptance, and yet, provide personal space and emotional dignity. Writing in praise of Zaha Hadid's compelling Maggie's Centre in Fife (Scotland), the design critic, Edwin Heathcote has demanded provocatively: "Why should spaces built to contain some of our more traumatic moments always be modest and domestic; bland and inoffensive as an old folks' dining room or a municipal crematorium?"[118]

In recent times, with increasing attention on *patient-centred care* models, hospitals have tried revamping their institutional look to become more accessible and navigable. In *Medicine Moves to the Mall,* Sloane and Sloane explain that "[p]atient- centred medicine empowers people to be involved in their care, to educate themselves about their illness, and to evaluate the people and place[s] that provide their care."[119] Others have described these new medical buildings as resembling "suburban office parks, with spreading pavilions, circular drop-offs and gardens, and brightly coloured facades…[with] multistory atria and retail establishments, looking more like shopping malls than homes."[120] Citing historians, Alex Mold and Nancy Tomes, Adams proposes a view of the patient as the consumer, comparing the sensorial assemblage in the postmodern hospital to that in a high-end hotel[121]—an observation also made by Worpole: "[T]he hospital was, by definition, a guest-house, a sanctuary, and a residential retreat."[122] Verderber & Refuerzo and Worpole have both complained that palliative units in hospitals are rarely situated on the ground floor, nor surrounded by natural landscape. Often adjacent to cancer or geriatric wards, they are frequently tucked away from sight in "the uppermost levels or most distant areas, perhaps as an effort to either safeguard it; ensure peace and quiet; or to minimalize the visual impact of death."[123]

Verderber has authored a subsequent book following the template laid out in his previous one on hospices. This later publication titled *Innovations in Hospital Architecture (2010),* traces the history of hospital buildings and considers case studies of specific facilities. Because hospital-based palliative units are not usually built following separate design guidelines for end-of-life architecture, it is worthwhile to look at how hospitals are designed in general. Verderber draws attention to Finnish architect, Alvar Aalto's acclaimed *Paimio Sanatorium (1929),* which remains a landmark monument to this day. Prior to the discovery of tuberculosis treatment protocols, the sanatorium was built to fight the disease primarily through the therapeutic benefits of sun and clean dry air. With a series of pavilions connecting to the main administrative block, the building contained respite terraces, with careful detailing in its various window features. Verderber says, "Perhaps the most remarkable aspect of this place was that it was built at all in the era of the pre-World War II urban skyscraper hospital."[124] Constructed in the middle of a forest, it aimed to foster a communal atmosphere for staff and patients, at the same time harnessing the healing powers of sunlight, fresh air, and natural heat, in intricately planned ways. Today, most hospitals are poorly integrated into their surrounding sites and "the outer walls of the hospital slam to the street like a giant guillotine. This unfortunate guillotine syndrome can occur either by design or by default…"[125] As an alternate solution to this problem, Verderber uses the term, *theraserialization,* a hybrid of *therapeutic* and *serialisation,* defining it thus:

> It is defined as a continuum to indoor and outdoor space, consciously defined in support of biophilic environmental design principles. It entails the interpretation of space as being serialized, as layered, collaged, superimposed, transparent, and fluid. It is about the creation of serialized space from the public, to semi-public, to semi-private, to private. It is about the spaces in between, and about illusion. *Theraserialization* is applicable to a single continuum or multiple continua on the same site. It is horizontal and it is vertical, it can reach upward from subterranean spaces to the ground plane, ascending to the sky.[126]

Some of what Verderber is referring to can be seen in Maggie's Centres, where tight, overlapping spaces, surprising corners, and continuations of —or connections between—indoor and outdoor areas are a recurrent keynote of the designs. Finally, Verderber critiques postmodern medicine's *functional deconstruction*—that is—the fragmentation of healthcare services and the over-definitiveness new care spaces, many of which are built in suburban roadside strip malls, for e.g., dental clinics, diagnostic centres, cardiac health institutes, etc. He believes such a fractured and stripped-down model points towards cultural rootlessness and results in a loss of critical regionalism, local vernacular and the sense of place.[127] This kind of medical-mall culture may be compared against the development of *health villages,* such as the *Freeport Health Care Village* in Kitchener, Ontario, or the *Hogeweyk Dementia Village* in the Netherlands. A *health village* may be defined as "an aggregation of health-related services, geographically located on a single campus, such as a medical centre…or as a loose affiliation of independent facilities located in close proximity yet non-contagious to one another."[128] A *health village* may provide a much better way to *functionally deconstruct* the modern megahospital, because the former setting is much more "human-scaled, patient and family-centred, is a one-stop point of service care model, and is an antidote to unchecked sprawl when the health village is located at the core of a population centre, not on its periphery."[129]

2.3 SUMMARY

This chapter has presented various ways of approaching and enhancing health services, systems and environments through design thinking and principles. Researchers in both design and healthcare draw upon interdisciplinary methods, strategies and terminologies to define and develop new models for research within the field. These can be interpreted for application in overlapping and combined ways to stimulate dialogue, collaborative interventions and healthcare reform.

Speaking of innovation in palliative design, it has been noted that a "culture of silence" is palpable in many of our buildings of death.[130] This chapter has talked about Maggie's Centres, which are not, strictly speaking, palliative sites, but offer useful lessons for visible and communicative architectures at the end of life. Maggie's are included here as examples which show how medicine can be supported through thoughtful design. Such buildings declare the power of design to deepen and expand our conceptions of sickness, dying, and death; bring difficult medical situations to the forefront of social dialogue; emphasize the value of supportive communities; and assuage profound human angst.

The next chapter will discuss in more detail the social meaning of places and why built space may be associated with fundamental questions of human existence and experience.

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91, 109, 110, 115, 120, 130: Adams, "Home and/or Hospital," 247, 261, 253, 255, 257, 261.

94, 96, 97, 98, 99, 101, 102, 104, 105: Verderber and Refuerzo. *Innovations in Hospice Architecture.* 13, 16, 16, 14, 16, 17, 31, 31.

95: Worpole, *Modern Hospice Design,"* 6.

100: Duffy, "A Moral Force," E8.

103: Botello, *quoted in* Verderber and Refuerzo, 18.

106, 107, 122: Worpole, 36, 10, 11.

111, 112, 114, 116: Jencks and Heathcote, *The Architecture of Hope,* 94, 14, 13, 13.

113: Gehry, *Opening Address:* Maggie's Centre: Dundee.

117: Jencks and Heathcote, *quoted in* Adams.

108, 118: Heathcote, "Maggie's centres," 1304, 1305.

119: Sloane and Sloane, *Medicine Moves to the Mall,* 10.

121: Mold; Tomes, *quoted in* Adams, 257.

123: Verderber and Refuerzo; Worpole, *quoted in* Adams, 259.

A Place to Die

Location & the Anxiety of Death

This chapter will look at how we register our anxieties around death and dying within the clinical and semi-clinical places of care. As quality of life improves with better and more accessible healthcare, the population is aging. Yet, fewer people die at home now than ever before.[131] With recent developments in advance care planning and the legalization of medical assistance in dying, we face a future where our conception of a good death is re-positioned in many ways. At this juncture, I ask whether and how location figures into an improved quality of death. Do places have the power to mediate our experiences of and attitudes towards dying? Since we have limited authority over how and what kills us, do we then root our control of, dignity in, and reconciliation with, a good death based on where we die? Does design help us assert forms of control over the death experience through place? Drawing links between architecture, end-of-life studies and the anthropology of place, I will consider how and why we might connect designed spaces, death and care.

3.1 FROM SPACE TO PLACE

SOME GENERAL COMMENTS

First conceived and explained in such manner by scholars in phenomenological geography,[132-134] space is now increasingly understood as that which is "universal, abstract, [and] quantifiable," while place may be considered as a "qualitative, historically emergent, experientially grounded mode of inhabiting or dwelling in the world that invests particular locations with personal and collective significance."[135] All sites are imbued with meanings which have been established, sustained and re-structured over time by the people that populate them, their social practices, their connections to other sites, and the material objects placed within and without these sites. Dissolving the contestation between space and place, Professor of Archeology at the Memorial University of Newfoundland (Canada), Peter Whitridge, acknowledges that there is no "imaginative place-world wholly apart from quantifiably real landscapes, bodies, and things, but neither is there a material world that is not thoroughly invested with significance as a precondition of human thought and action."[136] It may be stated then that all location is bridled with some manner of social substance, inextricably linked to other semantic networks, and articulated distinctly in various cultures through multimodal ways of knowing.

Professor of Anthropology at McGill University (Canada), Peter Johansen, believes human dwelling to occur within cultural landscapes, which are formulated from "spatial and temporal fields of action [where] material and conceptual contexts are constructed and negotiated through the processual articulation of social action, structure and the physical environment."[137] Moving beyond the mere inhabitation of space, philosopher Martin Heidegger notes that, to *dwell* somewhere implies the inscription of meaning through man's *lived relationships* in space.[138] Therefore, place is born "from particular localities and not from *space itself,*"[139] projecting past physical territory onto a psychological map.[140, 141] Sociologist, Henri Lefebvre, has described the *production of space* as involving an abstract conglomeration of material objects within it, while *social space* as being created when human activity unfolds through experience, cognition, and imagination.[142]

In the field of architecture, scholars Bill Hillier and Julienne Hanson at University College London (UK), first developed the *space syntax theory* to examine the social impact of designed space and built layouts. Spatial organization reveals how a society functions by uncovering nuances of social hierarchies, interactions, inter-relationships and navigational patterns.[143-145] According to Hillier, buildings:

- "elaborate spaces into socially workable patterns to generate and constrain some socially sanctioned [...] pattern of encounter and avoidance, and;
- elaborate physical forms and surfaces into patterns through which culturally or aesthetically sanctioned identities are expressed."[146]

While built space acquires meaning and identity from both its practical functionality and from social processes, it is important to note that these spaces can, in turn, shape practical functions as well as social processes. Jeremy Bentham's panopticon, a design that enables a centralized view of all inmates in a prison, provides a classic example of how built spaces launch discourses of omniscient power, surveillance and social control.[147, 148] The panoptician notion of watching and being watched is applied in many modern spaces—shopping malls, airports, hospitals, political institutions, and the like—that is, wherever a certain authority, whether governmental or corporate, asserts power and control over the collective. For designers, architects and social scientists, it is imperative to consider how "idiosyncrasies of style, building and settlement… though most puzzling and variable" form our "expressions of culture," social order and everyday practices.[149]

3.2 MEDICAL ARCHITECTURE AND THE DE/MEDICALIZATION OF PLACES OF DEATH

In *The Birth of the Clinic*, Foucault grapples with the spatialization of classes, and discusses how domains of illness and cure are not only "pathological spaces," but also "social spaces," offering clues towards dynamics between involved persons:

> In the rational space of disease, doctors and patients do not occupy a place as of right; they are tolerated as disturbances that can hardly be avoided: the paradoxical role of medicine consists, above all, in neutralizing them, in maintaining the

> maximum difference between them, so that, in the void that appears between them, the ideal configuration of the disease becomes a concrete, free form, totalized at last in a motionless, simultaneous picture, lacking both density and secrecy, where recognition opens of itself onto the order of essences.[150]

For medicine to achieve *maximum difference* or a working distance between the care provider and the care receiver, a *neutral space* is sought to be built, frequently resulting in what architect, Ian Clarke, calls "exercises in sensory deprivation."[151] Healthcare facilities, in many ways, standardize human behaviour, direct patterns of navigation, and ensure that most human interactions occur not just publicly, but also in dictated forms. The mediscape becomes a place where power relations fix the patient in the role of the recipient of treatment, rather than an equal participant in the care journey. Hospital architecture may hence take on a disciplinary role; the *London Asylum* being an early and oft-cited example, resembling the panoptician "physical enclosure in which docile bodies are subject to constant surveillance."[152] In medical institutions, control and segregation is achieved through a sophisticated corpus of directional signage, explicit rules for sanitation, implicit rules for social conduct between involved parties, regulated points of contact between practitioners and patients, and designated areas for different medical procedures, seating, waiting, consulting, and grieving.

Professor of Sociology at Queen's University (Canada), Lindsay Prior argues, however, that control and segregation are not the sole purposes of spatial organization in hospitals. She draws attention to how an architect might use disciplinary spatial divisioning as per bodily functions or cultural habit and, finally, according to the distribution of labour within the professional sphere:

> The bathrooms, day rooms, airing grounds, wash-houses, bedrooms, spell out in some detail the elements of a culture in which the body and its functions are closely regulated… Such a division of space and time [is made] according to bodily function and the principles of privacy… we see before us a history of the body as well as a history of illness and disease, for the building represented by these plans constitute[s] our modern image of bodily care and organization… Finally, we see expressed in this architecture a nascent division of labour… one's place in the hierarchy of labour, and volume and status overlap so as to ensure that those who inhabit the higher echelons of the disciplinary apparatus obtain the largest amount of space. The greatest amounts of space to supervisors, less to the keepers, yet still less to the menial functionaries. It is an architecture of social hierarchy which echoes throughout the nineteenth and twentieth centuries, and serves to underpin the strict division of tasks which define modern medical practice.[153]

In determining what future places of death might aspire to look like, it may, at least, be agreed upon that construction styles bearing the historical nostalgia of gloom and melancholy are best avoided. Writer, activist, and social critic, Susan Sontag writes of such structures, namely hospitals, as ugly, derelict buildings that invoke despair and hopelessness—designs that re-affirm the idea of illness as punishment and confinement.[154] While illness—and especially terminal illness—is certainly no reward, palliative design—as opposed to broader medical design—is concerned with envisioning spaces for care that feel less disciplinary.

In earlier periods of history, death was more randomized and unforeseeable as lesser understood diseases were able to suddenly strike people of all ages. But as medicine advances, immunization becomes widespread, and healthcare grows increasingly accessible and often state-funded, developed societies tranform into *ageing societies*.[155] As a result, the demographic has shifted and death is now more frequently associated with old age. Much of the older generation still harbours memories and myths of the high-walled, outwardly stern, dark hospital with forbidding entrances, often built adjacent to cemeteries.[156] Interiors of such buildings are still reminiscent of long labyrinthine corridors, harsh neon lighting, generic furniture, the distinct odours of disinfectants, and easily sanitizable, but cold or impersonable, metal and polymer surfaces. The assemblage of these unsavoury material and sensorial details continue to reinforce the connection between a certain kind of place—one that is much alienated from other places where social life exists outside this particular life-world.

Upon tracing where people have been spending their final days, from medieval times and up until the present, it becomes clear that the place of death has shifted constantly to reflect social and medical trends. This movement has come almost full circle—from the home at first, to hospitals with the promise of advanced treatments, to the *last homes* first conceived by early palliative professionals, to modern hospice spaces, and now back to home again. Despite the modern notion of the home as the ideal place to die, institutional sites remain significant locations of death today. Architectural scholar, Sarah McGann at the University of Notre Dame (Australia), counters the view of the home as a preferred place of death. She suggests that dying at home is an idea reliant upon older conceptions of home, family and community, borrowed from a time when the birth, death, sickness and care were visible, commonplace, and expected occurrences in the domestic domain. She claims that *care* was an assumed characteristic of relationships between family and community members, just as the designs of older homes also involved spatial considerations for these activities across the spectrum of life.[157] Today, dying is generally not imagined as one of the obvious purposes for which a house is built or lived in. Additionally, she argues that the nature of modern social life determines whether or not every person has family members with the capacity to become suitable carers.

> How people live at home in contemporary society would affect how people might die at home in the future. Living alone through divorce, widowhood, or by choice, residing in an apartment building, shared or rented houses, or in an aged-care unit, and moving houses, neighbourhoods, suburbs and cities frequently — all these patterns affect how we live, as they affect the notion of "home" and our capacity to die there [...] and families may be unable, through economic, geographical or other reasons, to be carers.[158]

McGann cites the work of Julia Lawton, whose discussion of individual patient cases reveal an alternate view of privacy in care spaces. Lawton's study showed that patients might not wish for family members to witness their bodily decline, but would be willing to receive professional palliative care to manage their disease.[159] In such a situation, the dying person's sense of dignity necessitates deliberate dissociation from the overly intimate space of home. Writing in reference to a particular case in Lawton's study, McGann explains:

> The first [reason] is that the place, in this instance the patient's own home, did not allow for patient privacy, as the hospice did, and the second is that the patient's sense of privacy excluded her family, but included staff, in ways that allowed the patient to be 'presented' to the family rather than seen deteriorating by them. This suggests that home is not always the most suitable nor is family necessarily the most suitable carers. [160]

Medical sociologist, Annmarie Adams, applies a similar skepticism to the hyperidealized projection of homeliness seen in hospice designs, discussed as *residentialism* in the previous chapter:

> This view of the house as *uplifting* pointed to the role of dwellings as the centre of family life, as places of warmth, comfort, nourishment, parental love, and intimacy; and as places of empowerment, perhaps linked to control over the material trappings of home (a sort of architectural security blanket, so to speak) and possibly even to the long history…of home ownership as a major mark of success […] Alternative interpretations of the home as sites of family violence, intense loneliness, repression, and financial hardship played no part in this idealized vision of the home as the best place to die. Middle-class domestic architecture (as imagined in a utopian, perfect state) thus became the most appropriate architectural model for hospice design.[161]

Adams has raised concerns with how frequently modern palliative architecture borrows its aesthetics from either the ideal home or from new oncology units. Palliative sites currently exist in the shadow-space between highly visible cancer care centres (such as Maggie's) and residential housing templates.[162] However, this is not to completely dismiss the value of designing home-like buildings. There are other reasons why people associate residential structures with sentiments of comfort, safety, nourishment, and empowerment. The metaphor of the *last journey* is often used by patients and staff to describe the place of death, alluding to the experience of time and key thresholds in its trajectory. Architect and design critic, Edwin Heathcote, has noted that in the hospital "your time doesn't really matter anymore"[163]—an assessment that hospice philosophy hopes to overturn, in its attempts to make time count for those it serves. In that respect, it makes sense to conclude that the awareness of time's passage is heightened at life's end. Since we associate the *slowing* of time with spaces of domesticity and private ownership, material and spatial devices in these architectures may yet offer valuable lessons for the future of palliative design.

3.3 CULTIVATING TIME AND PLACE THROUGH ARCHITECTURE

Sociologist, Zygmunt Bauman, in discussing modern attitudes towards death, has commented upon our tendency of "dissolving the issue of the struggle against death by an ever growing and never exhausted set of battles against particular diseases and threats to life."[164] In terms of architecture, designing an appropriate place to die may then be thought of as a form of escape and a deep ache—if not an extended pretence—that death can somehow be managed, solved or, at least, made better. To improve our understanding of the type of place we wish to cultivate in our future medical and architectural endeavours, I will now discuss the relationships between time, building and death.

> [A]rchitecture has to create a specificity of space and place, and at the same time, evoke the experience of a temporal continuum ... enable us to see and understand slow processes of history, and to participate in time cycles that surpass the scope of an individual life.[165]

Finnish architectural theorist, Juhani Pallasmaa, laments that the notion of a space-time continuum attends more to theoretical physics than to man's existential "anxiety of death, disappearance, insignificance and non-existence."[166] He argues that architecture's fundamental function is not only to grant us "our domicile in space," but also to arbitrate our relationship with the "fleeting element of time."[167] Apart from keeping out environmental hostilities, enclosed space seeks to alleviate man's metaphysical despair. With concrete structures, we assert our lust for the permanent, the indestructible and the ageless, by recollecting instances of past unperturbed life.

Similarly, Karsten Harries, scholar of Philosophy, Architecture and Environmental Design at Yale University (USA), draws upon Platonian aesthetics to interpret beauty in relation to human temporality and architecture. He writes that humans construct physical boundaries not only to keep out the unfriendly outdoors, but also to "wrest place from space,"[168] through psychological symbols. At the same time, he questions whether man's fervent building activity successfully averts the deep "terror of time," or if construction and technology actually heighten the very terror they seek to eliminate.[169] Harries proclaims that man, as per Plato, is fundamentally spirit, containing the element of something eternal, indestructible by time. It is also true that although man exists in finitude, he longs for plenitude in the form of "an escape from time."[170] Beauty, by creating the illusion of "permanent qualities and values" provides precisely such an escape, because "the language of beauty is essentially the language of timeless reality."[171] The acts of building and designing link us to the true home, and afford us *belonging,* while relieving us from *becoming*.

> To create a beautiful object is to link time and eternity; to construct a beautiful building is to help make man's dwelling a repetition of a more essential being-at-home, denied to him by his body, which subjects him to time. That the embodied self cannot take comfort in such beauty is evident. It dreams of a home in time, demands the redemption rather than the devaluation of temporal reality.[172]

French philosopher, Gaston Bachelard, agrees with Harries when he says that "life begins well, it begins enclosed, protected, all warm in the bosom of the house."[173] He suggests that the oneiric house offers comfort by invoking memories of protection and, therefore, all buildings invariably contain at least some notion of the home. Such images of tranquility are unearthed from life's early beginnings—from what he terms as the *Motionless Childhood*—a placid place, unravaged by time. The quality of *motionlessness* implies that with each building newly constructed, the recollected image is not merely the past, but an *idealized past*. Since the immemorial is immune to erosion or decay, it anchors the present and seemingly halts time's passage, providing "proofs or illusions of stability [becoming] an instrument by which we confront the cosmos..."[174] New places we build or inhabit, he explains, involve "fixations of happiness" borrowed from past places in which we have lived earlier.[175]

Critical of the "increasingly rushed and impatient" qualities of buildings in the post-industrial era, Pallasmaa urges a return to the earlier embodiment of "benevolently unhurried time"[176] in architectural space. He references philosophers such as Marcel Proust, for his novels that celebrate the "tactile sense of time,"[177] and Merleau-Ponty, who views architecture as that which can concretize and frame human existence in the "flesh of the world."[178] Pallasmaa considers the primacy of the sense of vision in modern thought to have resulted in consumerist buildings of instant visual consumption:

> Instead of creating existential microcosms, embodied representations of the world, architecture projects retinal images for the purpose of immediate persuasion. Flatness of surfaces and materials, uniformity of illumination, as well as the elimination of micro-climatic differences, further reinforce the tiresome and soporific uniformity of experience. All in all, the tendency of technological culture to standardize environmental conditions and make the environment entirely

> predictable is causing a serious sensory impoverishment. Our buildings have lost their opacity and depth, sensory invitation and discovery, mystery and shadow.[179]

In order for man to reconcile himself with the fact of his mortality, Pallasmaa suggests that architects consciously embrace the "devices of time."[180-182] These include signs of erosion and wear, imperfect materials, natural elements such as water and gardens, and the provision for human error and personable faults in design. By incorporating such elements in our built spaces, we discard the arrogant autocracy of modern structures, embracing instead fragility, individuality and weakness in buildings that mirror the human condition. The experience of materialised or *petrified time* in architectural narratives not only reminds us of our own biological mortality, but also situates us firmly and comfortingly in life's continuum.[183] Because all physical matter traces temporal duration through erosion and change, Pallasmaa favours the haptic and emotive in architecture, over the formal, technical, and uniformly functional. He argues that man's desire to consume images of the built ruin stems from the heightened sense of *being in time* that these images produce. Historical settings measure and mark out the processes of birth, decay, death and renewal. Modern buildings can similarly evoke and pacify our complex relationship with time—through the layering of materials, styles, and activities—creating space for performing the everyday and the ceremonial, the functional and the metaphorical. In future, such buildings can offer us slow participation in dense visual, auditory and tactile stimuli, nourishing our experience of inhabiting both place and time, and appeasing our anxieties of deterioration and demise.[184, 185]

3.4 SUMMARY

To return to a critical appraisal of hospitals (and hospital-like buildings), Dutch architect Cor Waagenaar, has noted:

> Hospitals are also built catastrophes, anonymous institutional complexes run by vast bureaucracies, and totally unfit for the purpose they have been designed for [...] They are hardly ever functional, and instead of making patients feel at home, they produce stress and anxiety.[186]

In view of his sentiments, questioning traditional approaches in medical architecture holds value when designing for palliation. An important difference between places for the sick and places for the dying is that one is primarily a curative space, while the other is not enirely so. When a place does not offer treatment towards a return to health and normalcy, but instead, palliative assistance towards a terminal point, then its architectural mood should embody notions of reflection, reconciliation, and dignity in death for patients, families and care staff—qualities that may not perfectly fit into the curative paradigm. Moreover, the architectural needs and operational scale of a large organization serving different user groups may often be directly opposed to design specifications for end-of-life care, which seeks to provide respite from the very features of a hospital environment. Yet, others have argued that completely segregating places of death from the medical institution or disguising them in residential buildings, may inadvertently foreground the idea of a place apart, to which a patient is sentenced, after all hope has been exhausted.

> Palliative care is camouflaged as an extension of oncology; and hidden from view in many purpose-built residences for aging. The key design elements architects and administrators need to encourage include an easily accessible, first-floor location; sightlines and access to the outside world; and dignified gathering spaces for patients and their families.

> These architectural features challenge the constant search for profit in American hospitals and for public savings in countries with universal healthcare, like Canada. The intractable presence of high-tech medicine's accoutrements, now conveniently located in patient rooms, come with associated human costs.[187]

To summarize, it may be concluded from the discussion above that design for the end of life must attend to the dying individual's social, spatial, and emotional needs. Collaborative research and co-design initiatives between architects, designers, and the medical community are needed to understand how buildings for the dying may be medically equipped, while reflecting a humane sensibility and fulfilling the "societal mission of architecture."[188]

Research continues to reveal that the public is death-denying and that conversation about death and dying is still relatively taboo.[189, 190] But cultural attitudes towards death and how society deals with it are poised at a turning point today. The advent of the hospice movement, on the one hand, and increasing legislations sanctioning medically assisted death, on the other, have renewed public debate around these concerns. In 2016, Canada passed the *Medical Assistance in Dying (MAiD)* law and healthcare authorities emphasized the relevance of *Advance Care* planning. These events are opening up conversation about the choices that people might make regarding how and where they die. Considering the current changes to end-of-life issues in Canada and elsewhere in the world, the time is ripe to re-examine the nature and meaning of our places of death and their readiness for the future of dying.

The next chapter will detail primary qualitative research undertaken as part of this thesis. It will pragmatically investigate what care facilities might look like, and critially assess how design configures into these spaces. The evaluation of these sites is further supplemented by interview data, presenting the perspectives, opinions and experiences of those employed within the palliative profession.

ENDNOTES

131: Verderber and Refuerzo; Worpole, *quoted in* Adams, "Home and/or Hospital," 248–263.

131, 155, 156: Worpole, *Modern Hospice Design,* 2, 5, 3.

132: Relph, *Place and Placelessness, 2*4–25.

133: Tuan, *Space and Place: The Perspective of Experience*.

134, 138, 139, 141: Heidegger, "Building, Dwelling, Thinking," 332.

135, 136: Whitridge, "Landscapes, Houses, Bodies, Things" 214, 216.

137: Johansen, Peter. "Landscape, Monumental Architecture, and Ritual," 310.

142: Lefebvre, *The Production of Space*.

140: Strang, "Uncommon Ground," 51–59.

143: Hillier and Hanson, *The Social Logic of Space*.

144, 146, 149: Hillier, *Space is the Machine,* 24, 10.

145: Bafna, "Space Syntax," 17–29.

147: Foucault, *Discipline and Punish*.

148: Leone, "A Historical Archaeology of Capitalism," 251–268.

150: Foucault, *The Birth of the Clinic,* 8.

151: Clarke, *quoted in* Worpole, 5.

152, 153: Prior, "The Architecture of the Hospital," 101, 105.

154: Sontag and Broun. *Illness as Metaphor.*

157, 158, 160: McGann, "Spatial Practices," 495, 496.

159: Lawton, *quoted in* McGann, 496, 497.

161, 162, 187: Adams, "Home and/or Hospital," 252, 253, 261.

163: Heathcote, "Where Architecture Meets Healing."

164: Bauman, *Mortality, Immortality and Other Life Strategies,* 10.

165, 166, 167, 180, 188: Pallasmaa, "The Space of Time," 56, 55, 54, 56.

176, 181, 183, 184: Pallasmaa, "Inhabiting Time," 54, 57, 55.

168, 169, 170, 171, 172, 179: Harries, "Building and the Terror," 59, 60, 63, 63, 63.

173, 174, 175: Bachelard, *The Poetics of Space,* 7, 17, 6.

177: Proust, *quoted in* Pallasmaa, "Inhabiting Time." 53.

178: Merleau-Ponty, *quoted in* Pallasmaa, "Hapticity and Time," 78.

182, 185: Pallasmaa, "Hapticity and Time," 78–84.

186: Wagenaar, *The Architecture of Hospitals,* 254.

189: Ipsos MORI, "Attitudes Towards Death and Dying."

190: Seymour et al, "Dying Matters."

Discussion

Field Research

This chapter will discuss my field research at two palliative sites. I chose to visit a small-scale hospice and a large-scale general hospital in order to understand the significance of dying in two very differently conceived (and publicly perceived) healthcare spaces. Drawing upon previous approaches in ethnography discussed in Chapter 2, I wanted to immerse myself in the everyday context of these places, study their physical design, contemplate the effects of such design(s) on the experience of dying, and include the perspectives of healthcare professionals who work in—or closely with—care delivery and/or management.

4.1 VISUAL CONTENT ANALYSIS: SITE VISITS

The first section of this chapter is a deconstruction of spatial elements as observed and recorded in field notes, occasionally supplemented by comments made by the people I met at these sites, wherever appropriate. I attempt to provide a photograph-aided tour of field sites, with accompanying critical reflections. Images included in this study were taken in bustling medical scenarios and are meant to be viewed as ethnographic data. The everyday chaos of and time constraints within the studied environments did not allow for photoshoot setups; hence, image composition and lighting is subject to spatial and privacy-related limitations. The second section summarizes the interviews conducted with palliative professionals, aiming to contextualize and expand upon—at a smaller scale—how these places function as locations of care and dying, and—at a larger scale—what this implies for our palliative healthcare system in general. The main lessons for the future of end-of-life design learnt from this field research are presented in the subsequent chapters.

The following two palliative care sites were identified for inclusion in this study:

- **Red Deer Hospice Society (Red Deer, AB, Canada):** A standalone hospice in a small city;
- **Intensive Palliative Care, Unit 47, Foothills Medical Centre, (Calgary, AB, Canada):** An intensive palliative unit in an older, multispecialty hospital in a large city.

4.1.1 RED DEER HOSPICE SOCIETY, RED DEER

Red Deer Hospice Society (RDHS) is a small ten-bed hospice in Red Deer, Alberta. While it receives 40% of its funding from Alberta Health Services (AHS), its operations are largely independent and financed through public donation and fundraising activities. The hospice is currently in its planning stages for further expansion to meet the demand for hospice-based care in Red Deer and surrounding areas. Located in a suburban residential neighbourhood, RDHS is a fairly self-contained, community-integrated hospice, heavily supported in staffing and fundraising by local volunteers.

Exteriors: The building's construction style conforms to the neighbourhood's architectural aesthetic. In both, staff experience and my observations, visitors in the area often mistook it for a residential home, or childcare centre, expressing surprise upon learning that it is a hospice. Apart from reaffirming the building's seamless integration into the suburban landscape, this also highlights the layperson's expectation of what an end-of-life facility might look like. A non-participant who struck up a conversation with me outside the hospice, first articulated shock, followed by a sense of assuaged anxiety, when I told him that this building is a palliative hospice: "So people come here when they are going to die? Well... it doesn't *look* that bad. ...what do you have to do to get in?" [anon., male youth, Red Deer local.]

Fig 1: Front entrance for guests, patients and ambulance access

The above statement demonstrates how the fear of death is projected upon and expressed through the site of death. Chapters 2 and 3 have explored nostalgias of traditional settings and culturally-associated images of death. Conversely, people may also anticipate "seeing" the qualities of pain and grimness physically manifest in such settings. It surprises them when this anticipation flounders, and opens them up to the prospect of entering spaces where death occurs routinely. Borrowing visual cues from the surrounding locations where social life transpires may help normalize the visibility of death, encourage conversation about palliation, and ultimately, promote volunteer involvement for a community-centred model of care.

The Red Deer Hospice is a deep-red brick structure, with pale accents and some stone contouring. The use of rounded stone detailing is reminiscent of mountain and river rocks, invites touch, and offers visual relief by way of colour variations. Windows are placed all around the building, bringing natural sunlight into patient rooms. All rooms feature screen doors to let in light and fresh air, while allowing access to the outside. A smoking area with a table and chairs is provided outside the main entrance for staff, visitors and patients with mobility. An immediately visible missing element is outdoor garden space. Several staff members commented upon the lack of a sitting area with grass and trees. The nearest such space is a memorial park (Figs 31, 32 and 33) behind the building and across the street, where the hospice holds its annual *Butterfly Release* event in memory of the deceased. In winter, the park is not entirely accessible, although some concrete pathways are cleared of snow. Patient mobility issues further restrict access to the park. Staff expressed their wishes in having an indoor garden or some form of natural foliage.

Interiors: The open floor plan places all communal areas in the centre of the building, with patient rooms framing the outer periphery of the layout, prioritizing access to sunlight for the residents. A staff member noted that on overcast days, the kitchen/dining area (Fig 2) can get dark and cold without artificial lighting, creating a somewhat dull and gloomy atmosphere. The shared areas break up the warm colour scheme with blue-grey accents. The wooden flooring adds warmth and richness. Artificial lighting is ample and well-used.

Fig 2: Central dining space

The furniture is of durable, high quality design, with personable qualities similar to the kind found in residential homes. The fireplace mimics the round stone details on the exteriors, continuing the visual language inside. A sunflower wall mural (Fig 2) acknowledges the donations to the hospice and provides a cheerful visual backdrop to the dining space. Sunflowers, being the universal symbol adopted by the palliative care community, are used as artificial plant décor in other indoor spots.

The dining table is not used very frequently as most patients and their family members eat in their private rooms. Nevertheless, it provides opportunity to connect with other families during meal times or over a cup of coffee. Fresh wholesome meals are prepared everyday with an emphasis on light home-style cooking. Patients are welcome to make requests for dishes they may be craving. Reasonable effort is taken to accommodate these requests insofar as their medical conditions and the daily kitchen schedule permits. Baskets of cookies sit atop the kitchen counter, facing which are a row of chairs to sit down and eat at. For hygeine reasons, only kitchen staff enter the kitchen.

Fig 3: Kitchen space
[access only for staff]

The head cook suggested a family-accessible kitchen, for families to prepare meals as per their own/loved one's preference, or simply to enjoy de-stressing shared activity.

Fig 4: Family members or patients have access only to the microwave and coffee machine

Fig 5: Lounge 1

As seen in Fig 5, the lounges do not receive much natural light even on sunny days. Half-walls offer privacy but also block out the light coming in through the front door and the adjacent window.

Fig 6: Seating arrangements, lounge 2

Fig 7: Piano in lounge 2

Lounge 1 (Fig 5) features a fireplace and bookshelves, while lounge 2 (Fig 6 and 7) has a small piano, overlooking a wide window seat. Staff commented that these areas are not used very often; instead, families seek out smaller nooks and crannies along the passages to sit in discreetly (Fig 8).

Fig 8: Chairs in less visible areas of the hospice

It was noted that these places are less noticeable and afford *accidental privacy,* because they are not meant for particularly restful or long duration seating. It was clear that the desire to be less visible seemed as important, if not more, than the need for comfortable, inviting relaxation spots.

The *sun room* (Fig 9) is the hospice's main multi-purpose space, for quiet reflection, larger group conversations, family gatherings, and special occasions, such as Christmas. With a large wooden dome, windows span the circular room, letting in ample sunlight. The sun room is the most airy, well-lit, spacious area, but was surprisingly not a staff favourite. Struggling to describe exactly how the room failed their expectations, staff universally agreed that it seemed too pushy and ceremonial in its projection of an inviting persona. The room was re-arranged several times to create friendly seating clusters. Its original arrangement was described as resembling a pulpit with chairs gathered around, creating a stiff formal atmosphere. Despite rearrangements, the room still receives criticism for its dull, heavy, grey furniture, difficult to move easily, and impeding the room's cheerful, sunny character.

Fig 9: The sun room

Fig 10: Angel ornaments at the windows

Fig 11: Chair clusters in the sun room

Fig 12: More views of the sun room

Patients are bathed in an assisted bathing area (Fig 13) which has large tub with integrated mechanisms to ease assistance to the patient. To ensure safety and hygeine, the patients are not bathed in their private bathrooms, but brought into this carefully santized space. The bath space could use more light, ideally let in through adjustable shutters. The open towel storage racks could be better designed so as to reduce a cluttered look. Having closed cabinets to store equipment and linen might promote visual calm during a process that may trigger feelings of vulnerability, anxiousness or general discomfort from being outside the familiarity of the private suite.

Fig 13: Assisted bathing area

Fig 14: Laundry room [staff access only]

Fig 15: Patient room, view from entry door

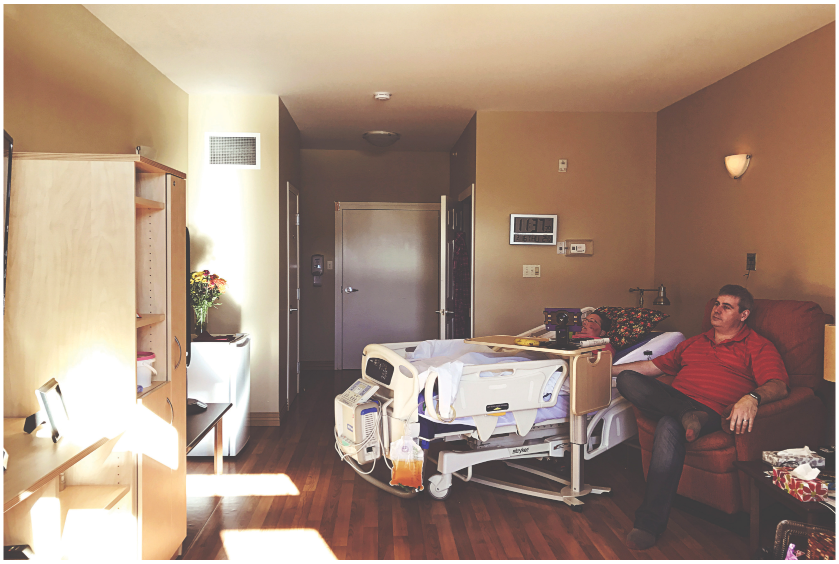

Fig 16: Patient room, view from screen doors

Patient rooms (Figs 15 and 16) are fairly large, extremely well-lit, with a television, ample space for a family member to live in, and the opportunity to personalize it with pictures or other personal items from home. Shuttered screen doors allow access to the outside and enable the patient to decide how bright they want the room to be. The hospice previously allowed patients who smoke to go outside through the screen doors. This has now been discontinued considering the risk of fire hazards as patients may not always be cognizant or otherwise physically able to contain that risk. A staff member noted that this was a limitation, as it remains questionable how fair it is to deny a dying person the ability to smoke if they desire it.

The closet (Fig 17) was designed as a minimal bare-bones structure. Open shelving obstructs privacy, projects a sense of temporariness, hindering the feeling of space ownership. These concerns were not raised by room occupants, but struck me as contradictory to the homely, intimate environment of the hospice.

Fig 17: Closet

The bathroom (Figs 18 and 19) was the only space that the patient's spouse offered negative comments for. He mentioned that it would have benefited from more and better organized storage. A long stay away from home means that personal hygeine and grooming products for both patient and their family member(s) require generous and efficient space planning. Fig 18 shows that the platform around the sink is crowded with items due to the lack of alternative shelf space There are rails for support on the other side of the bathroom (Fig 19) and enough room for wheelchair access.

Fig 18: Bathroom sink area

Fig 19: Toilet

Fig 20 shows a room that was previously used by family members to spend some time away from the bedside. It was later turned into a space for staff to enjoy a meal together or just have a relaxing moment away from patients. The room is now equipped with a television, coffee machine, a small dining table and couches. In the labour-intensive and often emotionally-taxing task of providing end-of-life care, provision for staff respite areas ought to form a part of architectural plans.

Fig 21 shows a small play area for child visitors. A staff member noted the need for a bigger room for children to play in.

Fig 20: Staff room

Fig 21: Play area for child visitors

Fig 22: Bookshelf

The common smoking area (Fig 23) is right outside the main entrance. As mentioned before, patients are no longer allowed to smoke inside their rooms. Most of them are restricted by their mobility to come all the way out to the front for a cigarette and may also find it difficult to do so in cold weather. It does, however, provide a quiet zone for family members and visitors to smoke in, away from private rooms and staff spaces. A barbecue grill lies covered under a tarpaulin in the far corner. Families are welcome to use this whenever they please. Staff members agreed that barbecues make for fun activities during the winter, which the whole hospice community enjoys participating in.

Fig 23: Smoking area

Fig 24: Back exit

The back door (Fig 24) was earlier used by funeral services to move deceased patients discreetly. While this avoids distress to others, it was noted that a clandestine exit is opposed to the dignity of the deceased and their family. The main entrance is now used for all purposes and back exit space is now a makeshift storage area, possibly used for moving furniture and other bulky items in and out of the hospice. Additional photographs from Red Deer Hospice are shown on the next page.

Red Deer Hospice Society: Additional Images

Fig 25: Patient and their spouse

Fig 27: Window seat

Fig 28: Reception

Fig 26: Fireplace

Fig 29: Cookie counter

Fig 30: Red Deer Hospice, building side-view

Fig 31: Memorial park at sunset

Fig 33: Trees in the morning, memorial park

Fig 32: The memorial park behind the hospice is difficult to access in winter

4.1.2 UNIT 47, FOOTHILLS MEDICAL CENTRE, CALGARY

The Foothills Medical Centre is a large multi-specialty hospital in Calgary, Alberta. It is an Alberta Health Services (AHS)-operated institution, financed through government funding. The hospital runs a fully-developed advanced Intensive Palliative Care (IPC) Unit 47, with nursing and practitioner staff specifically trained in palliative medicine. This site was chosen as an example of end-of-life care provided to the general public within the framework of a traditional medical space. It served as a point of comparison against Red Deer Hospice, for both its design aesthetics, as well as its situation within mainstream medical paradigms.

Exteriors: I was unable to take pictures of the exterior spaces and the common waiting spots inside the unit, as I did not have permission to photograph these areas. This was primarily due to the impracticality of finding unpopulated scenes at any time. The palliative unit is housed within a very busy hospital building, frequented by several visitors at once. All the photographs were thus taken inside the patient rooms.

Interiors: Unit 47 is located on the 4th floor of the Special Services Building at the Foothills Medical Centre. The building's main entrance features wide automatic revolving doors for easy wheelchair and wheelbed access. The elevators on the ground floor lead up to the palliative wing, which needs to be accessed through an electronic push button. It was not immediately clear how to activate the unlocking mechanism and failure to do it correctly sets off a loud alarm. In my time at the Unit, two visitors (other than myself) had similar problems, causing irate nurses to stop their work and rush to help each time. A recurrent source of distraction for employees in the midst of their busy schedules is an understandable cause of annoyance. The complicated nature of entry made visitation seem intrusive and unwelcome.

In particular, accidentally setting off the alarm might make a visitor feel as if they have made a foolish mistake and disturbed others even before entering the wing. An uncomfortable or embarrassing first interaction immediately foregrounds association with an institutionalized setup where careful adherance to the rules of navigation is mandatory.

Upon entering through the glass doors, enquiries may be made at the front desk, where there are nurses on duty for visitors to speak to. It does, however, usually take some time for them to attend to visitors in between administrative phone calls and a flurry of other professional tasks. Their formal body language revealed a sense of urgency and tension consistent with mainstream hospital spaces. This is in sharp distinction from hospice buildings, where there is often a receptionist or a volunteer at the desk available to greet those who approach the front desk. While the difference may seem small, it goes a long way in reducing wait times and in making the palliative system appear more accessible to the lay person.

Fig 34: Bed space

(i) Shared Room (double): This is a large rectangular room with a large dresser on one end and a window on the other, divided by a curtain in the middle. At first glance, the room appears cluttered with several types of medical equipment crowded around the bed spaces.

Fig 35: Shared space 1

Fig 36: Shared space 2

The bathroom is shared by the occupants of two double rooms built across from each other, that is, by four individuals. Fig 37 shows how two separate double rooms have access via sliding doors on either side of the bathroom. A nurse noted that sharing between four very sick patients can often prove challenging. That there is access from either side can cause further distress in terms of privacy and the need to hurry to vacate it for the next user. Fig 39 shows a rather uninspiring view of the hospital premises. Only one patient can have their bed close to the windows, which cannot be opened, owing to security and germ-control regulations—a fact that patients were vocally unhappy about.

Fig 37: Shared bathroom

Fig 38: Wall beside room entrance

Fig 39: Window view

Fig 40: Room view from window

Fig 41: Toilet chair; other assistive equipment

Fig 42: Bathroom sink

In a staff interview, a nurse pointed out that there is no designated way/space to scrub out the bedpans and dispose of waste. Currently, this is done in the patient bathroom, which can be inconvenient if someone needs to be in there, and necessitates extra disinfection measures. Bathroom-related issues are discussed in more detail in the next section.

(ii) Single room: This room houses a single occupant and was described as "the nicest room we have." (Figs. 43, 44, 45) A spacious, well-lit room, it was visibly full of medical equipment and assistive devices. A large window and a window seat spanned the entire length of one wall. The closet seemed small, especially considering the availability of free space to create a larger one.

The walls were adorned with family photos, hospital-provided paintings, and hand-drawn cards made by the patient's grandchildren. There was a significantly greater presence of the personal in this room. It was not possible to take pictures of the bathroom as it was occupied at the time of my visit.

This patient and their spouse were very eager to converse with me. Some of their insights are used to generate design guidelines in the next chapter. They were, in general, very pleased with the privacy they had and emphasized the importance of avoiding shared rooms at all costs.

Fig 43: Foldable chair-bed for a family member

Fig 44: Single room entrance deftly avoids a view of the bed space

Fig 45: Patient in bed, single room

(iii) Shared room (quadruple): This is shared by four separate patients. I was only able to obtain permission from one of them to photograph their side of the room. Each section is divided by curtains and Fig 46 shows the smallest of them all. The space was roughly equivalent to 60 sq.ft. —extremely cramped, without windows, and with barely any scope for personal customization. At the time of my visit, the other patients had several family members in their spaces. A significant amount of noise carried over to the bedside that I photographed. All four occupants shared a bathroom, which bore a label saying "for patient use only." The family member accompanying the patient was visibly distressed by the presence of so many visitors in the adjoining areas. She commented on the lack of a shower facility for overnight visitors and the inconvenience of having to use the public washrooms outside the living space. The quad-sharing room exhibited a purely functional character in that it had managed to house a patient bed, medical equipment, a folding chair, a food tray, a closet and a wall mounted TV in a very tiny area. Other than providing these necessities, it lacked characteristics of

Fig 46: One of the four patient spaces in the quad-room

homeliness, comfort or quietude. The furniture materials, wall colour and flooring—were all typical of those commonly seen in other areas of the hospital. These details were even more overbearing upon the senses in the quad-room, than in single and double rooms, due to a perceived 'concentrated' effect in a limited physical expanse. From conversations with nurses, I came to understand that there is usually some form of a waiting list from which patients get assigned room types based on a combination of availability and the assessed nature of their illness. The quad-sharing room bore an especially makeshift mood, as if it had been adapted for the purpose of affording bedspace to more patients than originally planned. The patient craned their neck towards the LCD mounted uncomfortably high up on the wall, straining to listen to the playback above the din from adjoining shared areas. The physical design and atmosphere in the quadruple sharing room was, in many ways, worse than a traditional open ward.

Some additional photographs from Intensive Palliative Care (IPC), Unit 47, Foothills Medical Centre are shown below.

IPC, Unit 47, Foothills Medical Centre: Additional Images

Fig 47: Patient in double-sharing room

Fig 48: Patient with spouse, quad-sharing room

Fig 49: Wall art by a child visitor

Fig 50: Patient in single room

Fig 51: Patient in double-sharing room

Fig 52: Patient in double-sharing room

Fig 53: Wall art provided by the hospital

Fig 54: Wheelchair, dresser, wardrobe (far end)

Fig 55: Television (too small and too high)

Fig 56: Window seat

This concludes my analysis of site visits.

The next section will consolidate interviews to re-orient what I have gleaned in terms of healthcare professionals' opinions on the overall nature of end-of-life care and dying within designed care spaces.

4.2 SEMI-STRUCTURED INTERVIEWS

Face-to-face interviews were conducted with the following people:

- **Val Hilario,** Director, Red Deer Hospice (Red Deer, AB)
- **Lola French,** Bereavement Support Coordinator, Red Deer Hospice (Red Deer, AB);
- **Chelsea Hamill,** RN, and **Rhonda Niebrugge,** RN, Unit Managers, Intensive Palliative Care (IPC), Unit 47, Foothills Medical Centre, (Calgary, AB); and
- **Konrad Fassbender,** Health Economist & Scientific Director, Palliative Institute, Covenant Health (Edmonton, AB).

4.2.1 PURPOSE

Choosing a diverse interviewee group gave me an expanded opportunity to understand—on different levels—how palliative spaces are organized, managed and used for care delivery on an everyday basis. Asking participants about areas of concern regarding their places of work, alongside their personal perspectives of dying in these places, unearthed a new layer of knowledge about my research sites. Finally, I learnt how the Canadian public healthcare system integrates care for the dying into its services on a provincial scale.

Interviews served to supplement my prior readings of research in the field, to contextualize ethnographic observations at field sites, and ultimately, to aid me in identifying connections between the two. Rather than trying to gather any specific type of information, I aimed to gather general ideas of how healthcare and health administration professionals viewed the end of life experience and where they felt design interventions might be useful. Interviewees showed remarkable engagement with my research enquiries, speaking at length, diving into many rich tangents and offshoots of deathcare, even beyond subjects of spatial and experiential design.

4.2.2 INTERVIEW FORMAT

With a semi-structured format, I wanted to gauge nuances in what I hoped would be informal, but meaningful dialogue, as opposed to pre-planned, response-oriented questioning. Of course, this depended to a vast extent on the personality of each interviewee, their flexibility and openness, their schedules, and their workplace environments. I prepared 4–5 questions to prompt general conversation. Discussions then assumed a participant-led, naturally free-flowing form, supplemented by additonal cues requesting further clarity wherever needed. A large part of our sessions involved impromptu questions that I brought up based on areas where the interviewee would show expertise and interest in. Data was collected through audio recordings and/or with written notes. The interviews ranged between 30–60 minutes, depending on how much time and inclination each participant demonstrated.

4.2.3 INTERVIEW SYNOPSES

Val Hilario, Director, Red Deer Hospice, Red Deer, AB

> **"I think we need more education! I think we need an understanding from a number of sources. So when it comes to things like our funding, it costs us $500 a day to keep someone here. If you look at the Continuing Care bed, you're looking at about $1600. We're cost-efficient. Yet, there's people in an acute care hospital, that don't need to be in an acute care hospital. So just from a financial standpoint, it makes more sense to have something like this."**

Val Hilario has been the Director of Red Deer Hospice for the past two and a half years. Her background is in rehabilitation and health administration. She stressed the difference between receiving palliation in a hospice, where staff are specially trained to care for the dying, versus in a long-term or supported living facility, which is not primarily intended as a site of specialized palliative medicine. She further compares the hospice—"the next best thing to home"—to hospitals, where nurses may be constrained by administrative protocols and scheduling limitations. This relates to both, the financial implications of providing palliative care in multispecialty facilities and the gaps in care from employing staff whose major area of expertise is not palliative medicine.

Throughout her interview, Hilario emphasized that the hospice embodies a home-like atmosphere, the exterior face of which must reflect the architectural aesthetics of surrounding neighbourhoods as well as the local public's cultural needs and expectations.

In terms of interior design, she appreciated the integration of domesticity, but raised two main concerns—lack of adequate storage space for medical supplies; and the absence of staff respite areas. Over-enthusiasm in building patient-centred hospices and minimizing the visibility of medical equipment, may cause designers to overlook practical spatial provisions and the everyday needs of nursing staff who work in emotionally taxing conditions. In Hilario's opinion, other miscellaneous problem areas at Red Deer Hospice include the lack of natural light in the interior sections and the unwelcoming organization of the *sun room*. The latter is a large polygonal room situated along the corner of the building, with a high, wooden, vaulted ceiling and massive windows. The furniture received much criticism for its clunky shape and arrangement. Significantly, Hilario compared this chapel-like space against two lonesome chairs in a discreet corner wall, hinting that the enormity of the *sun room* might emphasize one's own presence within itself, whereas a cozy hidden seating area might be more attractive to a person seeking solitude.

> **"[W]e don't really have counselling. Because it's [death's] such a short term [event], and grief is such a long term thing, that we cannot do a lot of counselling, more of what we do is support."**

She framed the hospice—and possibly, palliation on the whole—as the realm of family medicine when she said that "We admit the family, we don't just admit one person." Accordingly, Red Deer Hospice staff attempt to create occasion for families to connect with each other and to seek support from Bereavement Coordinators as they journey together towards a loved one's death. These *occasions* may be stimulated by simple design interventions (such as, a shared dining space, a barbecue area, a sun lounge); or by larger planned events, like the annual *Butterfly Release* (memorial event); or through regular fundraising events, like hiking trips. Other than the families of patients, the hospice is uniquely positioned in a suburban community to engage locals in volunteer activities and effect the normalization of death in society.

Hilario confirmed that for many people, hospices provide a hopeful alternative between the medicalized sphere and challenges of dying at home, personifying a site that many envision as a non-threatening, yet efficient care space:

> …the family is like, "We need to get Dad out of here, out of the hospital. And the hospital is like, "Well, he's close." Doesn't matter [to them]. And literally—you wheel them in here, you put them into bed and get them all sort of set up—and he dies. And he didn't die in the hospital…so family feels good about that. I'm sure *he* felt good about that." *(Hilario, Interview)*

The incident described above demonstrates how a hospice, even if only briefly, can be instrumental in delivering the promise of a *good death* to patients and bringing comfort to their families. This is an important social function that goes a long way in upholding the dignity of dying persons. Hilario commented here on the need to educate the public on what kind of palliative options are available to them in order that everyone may receive the death they desire. Discussing hospice in terms of finances, she offered a comparison stating that a *continuing care* bed is more than triple the cost of a bed in hospice. Moreover, the eagerness of local communities in supporting the hospice—to the point where the hospice now has "more volunteers than what we have things to do"—shows encouraging potential for reducing the cost of recreational services for residents, as well as shifting public attitudes towards death.

Hilario noted that most patients are admitted to hospice with a *Palliative Performance Scale (PPS)* score of around 40, on a scale of 0–100, where zero is a person in full health and hundred equals death. While this coincides with a prognosis of 3-4 months of life remaining, the average length of stay at Red Deer Hospice is about 3 weeks. She noted the need for patients to come in when death is very near, alluding to problematic cases when patients arrive too early when they "still have some life to live." Exactly how such a timeframe may be determined was not very clear, especially in view of the discrepancy between the doctor's prognosis and the average length of stay. Her interview revealed that hospice provides alleviation of discomfort associated with dying *only* (discussed in more detail in the next interview: *Lola French*), but secondary infections acquired due to, for instance, a weakened immune system at life's end, would not be "treated." On the one hand, she reiterated the role of the hospice as a final place of care, without the option to go back to hospital for curative medical support, and on the other, she acknowledged this possibility if the patient "chang[ed] their mind." The manner in which a distinction would be made in such a scenario was unclear, pointing towards a possible blurred line between palliation and curation.

Lola French, Bereavement Support Coordinator, Red Deer Hospice, Red Deer, AB

Lola French, with a background in mental healthcare nursing, had joined

Red Deer Hospice as Bereavement Support Coordinator, two weeks prior to my interview with her. Before her appointment at the hospice, she ran a national nonprofit organization for pregnant women. She began the conversation on the note that she was previously engaged with the "other end of life," continually drawing parallels between birth and death as stages in a journey. Interestingly, she did not view these as oppositional, pointing out the similarities in emotional processing and decision-making involved in both—whether in terms of the regrets and stresses many pregnant women face, or in the contentment of accepting death.

"I think that's our philosophy too, is that we're there to help them in their journey as we are invited. Like one of the girls said to me, we are invited to the "dance." That's how she put it: ...But we don't take a front row position. But we're there. We're at the dance. We're "moving" with the family kind of thing. But it's their dance, not ours."

Her conception of death as a natural stage in the life curve is expressed through her philosophy of supporting patients *wherever they are at* in their current journey, also differently worded by Hilario as *object permanence*. French's role at Red Deer Hospice involves care for both patient and family, although families receive care long after the death of the patient. Her services begin with an *orientation* whenever a new family is admitted, continues with regular check-ins and carries on for up to a year (or more), should the family need it. She offers group therapy sessions, where multiple attendees, who have all lost a dear one, benefit from each other's support in a process she called the *normalizing of grief*. French's repeated reference towards the importance of family dynamics was also echoed by Hilario in terms of decisions regarding the care of the dying patient, conflict in such decisions, existing family tensions, sharing of care load, property disputes, and legal concerns.

> **"Yeah, but I think that is our hope that we'll help them in that way [in reconciliation]. But again, it's so important for them to know that this is the *last place*. This is what they're coming for. That this is not *coming for treatment,* you know. And even for the loved ones to really understand that."**

Among design concerns, French strongly recommended a garden with running water or a fountain immediately outside the hospice or an indoor foliage area, referring to patient rooms at the General Hospital (Calgary) where patients can look into these spaces from their windows. She would also like to have a non-denominational spiritual room for private reflection, calling it a "secret quiet place" or "a sanctuary."

French comments on the need to partake in beauty through natural lighting, possibly through skylights, stained glass windows, or lighting-based decor, explaining that "what it does to the heart, and to the mind, I think it helps people… " In her experiences as both, a mental healthcare professional and as a bereaved family member, she believes such additions to allow opportunity for "important things [to be] said and experienced together."

> **"[S]ome people will go through that process in more of a struggle and some with more of peace and some with more celebration, even. I mean, sometimes, there's families here and they're singing together. Especially from a spiritual perspective, they might be singing some of their loved one's favourite hymns and they're, you know, they're celebrating that person's life and helping them in their passage."**

Following on from what Hilario called the right time to enter hospice, French adopted a similar stance, but drew strong outlines around what hospice does and does not mean. She made it clear that although one might expect medication to assist with anxiety/depression (mental pain commonly associated with the end of life), patients will not be treated if they acquire a secondary infections (such as pneumonia) or suffer lapses in health that are separate from their terminal disease. Similarly, she pointed out that one might receive assistance with difficulty in breathing, but will not receive medication to stop the heart—that is, a hospice will participate neither in curative measures nor in assisted death. She likened the role of the hospice care provider to that of a midwife's who facilitates home births. She firmly stated that the realm of hospice care is distinct from the domain of euthanasia, because "that's not what hospice is about", and also from curative medicine, because this is not the place to "fix anything." However, when asked what would happen if a patient asserts their right to be treated for secondary infections so that they may live until their primary diagnosis kills them, she expresses some hesitation.

It appears that the oppositional framing of hospice-based and hospital-based palliation may create ground for ethical conflict in view of patients' rights to flexible end-of-life choices. There apear to be some challenges in arriving at clear definitions in end-of-life care and these conversations foreground the ethical uncertainties that healthcare professsionals might encounter in their line of work.

Chelsea Hamill, RN, and Rhonda Niebrugge, RN, Unit Managers [both], Intensive Palliative Care, Unit 47, Foothills Medical Centre, Calgary, AB

Chelsea Hamill and Rhonda Niebrugge are both Nurse Managers at the Intensive Palliative Care Unit 47 at Foothills Medical Centre, Calgary. The interview began first with Nurse Hamill, as we were finishing my tour of the rooms and Nurse Niebrugge joined us subsequently. Both nurses were fairly critical of Unit 47's conversion from a non-palliative to a palliative wing. They felt that this caused the unit to be in a state of "mishmash" or general disarray. They noted a number of problems that have arisen specifically due to the conversion, which are discussed below.

As many older buildings or parts of buildings are re-purposed to serve an increasingly ageing population, their feedback is valuable to hospital architects and interior renovators involved in such projects.

Because the design of this space was not originally intended for palliation, the sharing of bathrooms—which may not be as critical a matter for other types of patients—assumes significant concerns for palliative patients. Waiting to use the bathroom while it is occupied by someone else creates stress, discomfort and privacy issues for everyone involved. Since many of these patients are not fully mobile, they frequently require caregiver or mechanical (lift-based) assistance. The first issue here is the management of every patient's unique needs in a common bathroom. A related concern is the challenge of meeting needs of such a private nature with due care for each patient's dignity. A more frequent requirement for cleaning the bathroom arises when it is shared by several patients. Overuse of alcohol-based disinfectants triggers vomiting in those who are already prone to nausea from heavy medication or symptoms of highly advanced disease. The lack of an efficient ventilation system, coupled with windows that do not open (in accordance with AHS health safety protocols), stagnates unpleasant odours around bathroom areas and affects the air quality of adjacent rooms. At present, all room-attached bathrooms are for patient use only, while family members must utilize public washrooms, located down the hall. Naturally, this is inconvenient for those staying overnight, as there is no space for them to shower or take care of other personal grooming needs. During my room tours, the spouse of a non-local patient described to me how exhausting it was for her to find a way to shower, as the couple did not own a home in Calgary. Finally, Nurse Hamill brought up a noteworthy point about the lack of space to clean bedpans. She wondered aloud whether these were meant to be cleaned in the bathing space, which would be a hygeine hazard, and necessitate additional efforts to diligently disinfect the area every time. The other alternative, she said, would be to carry the soiled bedpans out of the rooms, down the hallways, to clean them elsewhere—except that there is no other designated space for doing this either. She drew a suggestion from the design of ICUs, where there are ante-rooms with dishwashers, especially built for the purpose of cleaning bedpans.

"We have an actual spiritual care provider... and a psychologist-in-training. We're just saying that during some of those sessions, like let's say, you're doing movie night or whatnot, right? You know, they [professional therapists] can hear little snippets of distress that's going on, or you know, and because they've had so many years on the Unit, [they] will often tell the right person, but you can't really train someone to do that. If you were a psychology support or spiritual support [therapist] who had the training, it would be way more timely intervention because they can say, 'Oh I was at movie night and I heard you saying that you're really distressed because this may be the last movie that you're ever going to see. Tell me what that means to you?' And say... can dig a bit deeper."

Nurse Niebrugge brought up the possibility for conflict when housing together patients of different religious or cultural backgrounds. At the end of life, many people wish to partake in rituals that might inconvenience others, such as those involving incense or smoke, which may further pose a fire hazard and cross over into the breathing space of other people. She referenced cases where the patient's beliefs required them to be taken outdoors or where the deceased could not be left unattended until the priest arrived. In both these situations, nursing staff would do their best to accomodate the wishes of patients and families. However, such requests are complex to carry out in hospital settings where nurses may have to expend significant time and energy in executing requests with minimal discomfort to the other family/ies in a shared room. In order that they may receive a private death, staff do their best to temporarily swap patients extremely close to dying with the occupant of their only non-sharing room, a few hours prior to death. Nurse Hamill noted that specific hygeine protocol must be followed each time a room swap occurs, which incurs an additional cleaning fee. She concluded that although it may appear that shared rooms reduce operational costs, in the long run, small expenses like recurrent cleaning regimen add up. As staff adjust their schedules to make room for these tasks, there are labour and resource implications of a more urgent nature in a busy hospital than in a small hospice.

The volunteer program is extremely popular among the patients and the unit has received requests for more volunteer-led recreational activities. However, Nurse Niebrugge cautioned against relying upon volunteers for therapy. In particular, she felt that professional therapists should always be present as they have specialized training that volunteers do not. Both nurses felt that their jobs were deeply rewarding and not necessarily as doleful as the general public might perceive. They did, however, reiterate the need for a quiet reflection space to benefit not only families, but also staff, whose work can often become emotionally draining. Commenting on the kind of end-of-life environment people tend to desire, they believed that less institutional spaces are high on everyone's preference lists. They brought up the currently underway construction of a new cancer centre at their hospital, where there are demo rooms for the public to mock-experience and leave feedback on. Comparing the cancer centre's early design testing method to similar NICU-inspired demo rooms for mothers of premature infants, they suggested similar means for testing new palliative unit designs. Nurse Niebrugger recalled past instances when she has gathered design suggestions from other members of staff during the planning stages of room layouts. She described how bedside nursing staff, through their feedback, were able to change architectural plans for bathroom placement—hailing it as a typical example of understanding workplace requirements in a way that no outsider can.

> **“[O]ur palliative unit isn’t the kind where people come to pass away. It is more designed for short stays. So they’re having a pain crisis at home or having nausea that’s uncontrollable, really any uncontrollable symptom that can’t be managed at home, they come to our unit.”**

The nurses thought that much more should be done to enhance technology and entertainment options with a TV, music system, and computer with internet access for each family. They would also like the provision of an easily accessible non-denominational meditation/spirituality room, along with a separate large hall for special occasions. The unit has often hosted events like weddings and graduation parties for patients or their families in their meeting rooms. Having a dedicated space for such events would eliminate the need to book meeting rooms for these purposes. Although not present in the interview, a patient who took a special interest in my research, told Nurse Hamill (off-record) that a balcony or a non-smoking outdoor area would be greatly appreciated. At present, it is not possible for patients to go outside easily as the unit is located on the 4th floor and is mostly surrounded by other hospital buildings.

Nurse Hamill explains that patients enter Unit 47 when a doctor assesses them as having needs that cannot be managed elsewhere. She explained that the unit is not designed as a place for those who are dying, but instead, for the short-term care of terminal illness. However, both nurses discussed several cases where patients have died in their unit and arrangements have been made for last wishes and post-death procedures. Considering that they talked at length about situations around death and dying, it was not very clear why the unit defines itself as a short-term facility, how this unfolds in actual scenarios, and what protocol is followed to determine which patients should go home and which ones should stay on-site until the end.

A lack of explicit service definitions may have implications on public knowledge about the type of care they may expect to receive in a hospital-based palliative ward. It may further be inferred that staff employed at hospital-based palliative units require further clarity about their own roles as caregivers, managers and administrators. This indicates a possible knowledge gap between everyday medical practice and palliative care policy.

Konrad Fassbender, Scientific Director, Palliative Care Institute, Covenant Health, Edmonton, AB

Konrad Fassbender is a health economist, who is currently the Scientific Director at the Palliative Institute, Covenant Health. He also has an academic appointment at the Department of Oncology, University of Alberta (Canada). He brought a systems perspective to my research with his expertise in public health. Fassbender emphasised the need for educating the medical community, pointing towards a revamping of the medical education curriculum. He explained that knowledge can be disseminated among the general public and patient advocacy groups through resources, such as the recommendations for palliative care improvement, outlined in the *Ipsos* report compiled by the Palliative Institute. He made suggestions for the healthcare system to operate through *integrative services,* where:

> **“[T]he way people die has changed in the last 100–200 years. The way that people die now requires further medical input. But there’s also a benefit, because people can die without pain, without being short of breath, without fatigue, without these other symptoms. These symptoms can be managed and most of the... half of the Canadian public is unaware that palliative care can manage these symptoms.”**

> patients can be in a tertiary palliative care unit, in a residential hospice; they can receive palliative home care. We can have a palliative consult service, either in a hospital or in a community setting. *Integrate* means that all of those pieces work together, so that as patients become more and more ill, as they get closer to death, they don't have to make those connections. The healthcare system is doing it.
> *(Fassbender, Interview)*

Speaking of design, Fassbender describes three ways of looking at beds in a hospice— *designated, dedicated,* and *decorated* beds. In a broader sense, this could be seen as three different means of breaking down palliative care resources. *Designated* beds are the number of beds that the Minster of Health may allocate to an institution, of which some may be *dedicated* by that institution solely for palliative patients. A *decorative* bed is one at an institution—often a nursing home or a hospice—signifying a place that offers a non-institutional dying experience, enhanced through a focus on aestheics, among other things. Fassbender explains that "*decorated* means that the people are referring only to those characteristics of the space, not of the people who work within the space… *tertiary* palliative care means its both space and people working together."

"If you go to Toronto, in Toronto, for example, you'll have the Princess Margaret Hospital and you'll have the time the Temmy Latner Centre [for Palliative Care], which is a hospice. They don't talk to each other! So if you're a family... if you're a family member and your mother or father or your loved one is discharged from the Princess Margaret Centre, it's now up to you to bring them over to the Temmy Latner Centre, to the hospice, if they need it."

Fassbender's vision of the *beautiful hospice* may be interpreted as oversimplifying the designed environment as that which is merely ornamental. Nonetheless, he offers an important economic perspective as he describes the health care system in terms of good and services possessing attributes, which are—" location, timing, environment, training of people." In his opinion, the medical expertise of doctors and nurses needs to acquire greater visibility than these other secondary factors.

From his interview, it may be concluded that he believes the imagery associated with a *decorated* bed to be possibly detrimental, causing a resident to doubt the clinical efficiency of that facility. However, it is necessary to remember that his opinion represents one extreme end of the care spectrum. Interviews with staff at both, a hospice and a hospital setting, suggest evidence to the contrary—that dying persons and bereaved families see immense value and comfort in thoughtfully designed, sensorially appealing, sites of care.

> **"Approximately... in Alberta, overspending 17 billion dollars a year on healthcare, 1 out of every 4—that's a little bit over 4 billion dollars—are spent on patients in their last 6 months of life... That's a lot of money! As a taxpayer, you have 4 billion dollars that are [going into the last 6 months of care]. Now, if we lived in a society where we could just pull the plug on these people and say, 'You know what, it's too expensive. Let's pull the plug. We don't have to pay this 4 billion dollars. What's 6 months, anyway, if you live a full life, right?' But we don't live in that kind of society! We live in a society where we determine ourselves—the kind of care and how much care we want—and with our doctors. So if the doctor says, 'I can give you some radiation and chemotherapy.' The patient and family say, 'I'll take it.' They can say, 'You know what, I've lived a full life. I don't need anything. I will go home and...' So there's choice that's involved. The amount of resources that are being used by patients and by families is what we would call *endogenous,* it's determined within the system, it's not *exogenous*."**

Fassbender raised concerns with the overall inaccessibility of palliative care, resulting from a widespread lack of understanding and information about it, not only among the general public, but also among healthcare professionals. He highlighted situations where patients with a terminal diagnosis may receive adequate medical management of symptoms through their primary care providers, but will not necessarily be referred to palliative care facilities. He attributed the problem to inadequate training in palliative medicine among practitioners. In terms of health policy, he discussed the term "medically necessary," which is key when examining how Canada's provincial health system works. Publicly funded healthcare requires that certain criteria be set when determining access to health services. Currently, this means that the Canada Health Act (1984) guarantees to all residents, care which is "medically necessary." In its application to the end of life, defining what may or may not be medically necessary remains uncertain. For example, pain management is a commonly recognized part of end-of-life care, but fatigue associated with waning life, may not be conceived as such. Fassbender makes a distinction here between *pain* and *palliative pain,* claiming that doctors who are trained to recognize and address the one, may not possess the specialized knowledge about the other. Such a gap in knowledge casts into doubt whether the dying body must be treated differently than the diseased body—making it necessary to ask if care for the dying requires alternative criteria to ascertain medical necessity. The question of medical necessity is a crucial one for the healthcare system on a number of levels—ethical, budgetary, organizational and educational. It further affects the primary care practitioner's ability to care appropriately for patients and determine what patients know about the resources available to them.

4.3 SUMMARY

Field research at sites of care, augmented by interview data, has offered a deeper understanding of the peculiarities of palliative care sites as both—medical spaces and designed spaces—framing them as places where healthcare professionals work, communities engage, and the dying receive care. Many concerns which need the expertise of design researchers and medical practitioners have come to light through this study.

The deep human yearning for dying well is difficult to convert materially and spatially. Hence, we often fall back on what we do *not* want our places of death to look like. By exemplifying the opposite of 'ugly' hospital architecture: is the ideal palliative building finally just a beautiful structure that disguises temporal distress and death's unsightliness with the embodiment of an exalted sight/site? The next chapter will use research findings to arrive at recommendations for future projects concerning the design of our last places of nurturance, rest, reconciliation and care—a dwelling for the end of life.

Research Findings
Imagining the Last Place

5.1 DESIGN RECOMMENDATIONS FOR THE END OF LIFE

Some common themes that arose throughout this research foreground frequent challenges faced by those who design, build, work in and occupy palliative care sites. These are utilized to inform how we might conceive the ideal sanctuary for rest, care, and death. Many of these are based on my own observations, supplemented by comments gathered through interviews (both on and off record) or from direct and indirect communication with families and patients (off-record).

Presented below are a set of recommendations, classified under six categories, for tangible and intangible features in such spaces, with the hope to inspire a core *design ethos* for the end of life.

5.1.1 LOCATIONAL CONTEXTS

It is imperative that palliative care spaces exude a sense of security, welcome and warmth. Designers should be careful to avoid unfortunate associations with historical institutional architecture, which has often been under attack for its threatening, melancholic exteriors and disorienting, overwhelming interiors (See Chapters 2 and 3). The exteriors and interiors of buildings might look different and communicate differently to those who are outside versus those who live in it. Many consider it important that a palliative facility maintain architectural uniformity with the surrounding neighbourhood (See Chapter 4). While this can be possible in a suburban area, there are complexities in urban centres where palliative units are often housed in re-purposed buildings.

- **Community Support and Involvement**

  Constructing end-of-life facilities in residential neighbourhoods may require conformance to standards and protocols laid out by local building authorities. Foresight in communication and effective planning is essential. Administrators, care staff, patients, and families need to ascertain the level of support they have from the surrounding neighbourhood.

  Access to tertiary medical, transportational, recreational and commercial resources are important factors to consider. These issues present themselves with greater urgency in suburban and rural areas, than in large urban centres, which are already set up as more efficient mixed-use areas and enjoy good connectivity to other establishments and services that might support the facility. There are, however, different challenges in busy urban centres, such as crowdedness, less access to natural landscape, noise from adjacent settings, and stress induced by the close proximity of people, vehicles, other buildings, etc.

  Involving community members from the start and throughout the process can generate knowledge about their needs, expectations and perspectives; create a platform for regular user feedback; encourage community ownership of these care locations; and inspire volunteer participation.

- **Exterior Architectural Identity**

  The exterior facade of a palliative care facility should embody its core ideals and care philosophy. There is contention among scholars, designers and medical professionals over whether these buildings should be discreetly integrated within their surroundings or not. Some believe that maintaining architectural uniformity is not only an aesthetic goal, but that it also helps in normalizing the presence of death among other locations of social life. Others argue that *hiding away* death in inconspicuously designed spaces, such as corporate buildings or residential structures, perpetuates silence around the subject.

It is important to consider each facility on a case-by-case basis, and determine what local public opinions, cultural trends, ethnic traditions, and regional expertise reflects. Designers should ultimately remember that the building's public identity has the power to evoke positive or negative reactions among staff, volunteers, families, patients and local communities at large.

- **Security and Approachability**
  Many patients and their families may be especially prone to anxiety, memory lapses, and generalized stress from their illness. It is essential to provide assurance of refuge and personal safety, especially in urban facilities, which are closer to the street. Reasonable theft-protection measures, intruder alarm systems, safe parking zones, and senior-friendly fire esape routes are obvious considerations. Other than that, sturdy assistive devices, smooth wheelchair ramps, wide staircases, secure windows, lockable storage for personal items, should be present. Visual and physical aids, such as, clear distinctions between level changes on the ground, textured grip-friendly handrails, non-skid tiling, waist-level light switches, nurse call-buttons near the bed—are additional ways to aid those who may already be undergoing immense emotional and physical trauma.

  Wayfinding, the most common point of critique in medical buildings, must be considered from the planning stages, and not as an afterthought. Too many signs, on the other hand, tend to consolidate the idea of a sprawling, unwieldy space. Palliative zones may find value in reducing the excessive use of overhead signage, and instead, concentrate on creating small-scale, easily navigable layouts, employing human assistance wherever possible.

- **Climatic Considerations**

  In locations where the weather can get too warm and humid, cross-ventilation can be achieved through open floor plans, where no major areas are locked on all sides by surrounding structures. Placing in-patient rooms along the outer edges of buildings, and creating indoor courtyards, shielded patios, high windows, air vents, sun-screens, half-covered balconies, and ceiling fans—are other ways to enable continuous air circulation. These measures help to deflect the sun's heat, without impeding natural light. Water features and garden landscaping are also effective means of cooling the premises in hot climates.

  In cold climates, compact clusters of closely-constructed buildings, with insulated walls, basements, heat-preserving materials, sunlight-directing window forms, and strategic planting of trees to create wind breaks—should be utilized. Indoor gardens, interior vine walls, or canopied porches and pavilion seating in outdoor areas provide access to nature with due consideration of the temperature. Since natural spaces provide much comfort and solace to patients, prior planning for weather conditions; local vegetation species; budget-friendly landscaping; low maintenance gardens; snow and rainwater disposal; green technology use, and energy efficient design—are crucial factors that affect how natural elements can best be integrated.

- **Sound / Sight Management**

Urban centres must employ sound buffers in order to minimize the traffic noise or other sources of industrial sounds. Thick walls, soundproof padding, extra insulation, and white noise machines may prove useful in ensuring peaceful interiors, especially for patients who already have difficulties with sleep. The positioning of windows, doors, communal spaces, garden areas can be planned so as to assist with sound management.

Some people enjoy the feeling of being immersed in everyday life outside the facility. Semi-private areas like common-use balconies with street views, trellised walking paths, separate front-facing gardens, community cafés, children's parks, etc, might offer sights and sounds to break the sense of isolation. These should be placed away from bedrooms and private zones, but close enough to walk to or access by wheelchair.

Other means of incorporating an active atmosphere include arranging small-scale events that might take place on the campus, for e.g., weekly farmer's markets, music/movie nights, baking activities. A well-planned programming schedule offers potentially limitless ways for community volunteers to engage with patients and bring ordinary pace into a facility that may become alienating for its inhabitants. In order to support such programming, needs should be anticipated and spatial provisions made for activities and events to take place in appropriately placed spots.

- **Parking Spaces / Access Routes**
  Many palliative care centres in urban areas are built adjacent to—or on the campus of—large general hospitals. Parking becomes a particularly stressful problem in these situations, especially when new patients first arrive to enquire about the centre, or are in the process of transitioning from a different medical institution.

Families and caregivers need to make frequent trips in between doctors, diagnostic centres, childcare, home, work and the palliative centre. They do not want the additional agitation of labyrinthine, mall-style, designated parking, often remote from the main building areas they wish to use.

Multiple, small-clustered, easily accessible, and disability-friendly parking is critical to the design of the palliative centre. Staff-only parking, broad walkways, wheelbed ramps, ambulance-width front driveways—are primary considerations, all of which should lead directly to the main entrance. A back entrance and separate driveway should be provided for moving furniture, transporting heavy medical equipment / supplies, and disposing of trash. Parking lots outside patient windows, prayer halls, grief counselling rooms, and quiet outdoor spaces, are to be diligently avoided.

5.1.2 ADMINISTRATIVE SPACES

The success of a palliative facility is highly reliant upon the bodily and emotional strength of staff. In their frequently unpredictable, sensitive, and stressful line of work, there is always the risk of burnout. Drawing upon an *evidence-based design* rationale (See Chapter 2), it is imperative for staff to feel physically and psychologically supported by the built environment, in order to continue to providing high patient quality care, with minimal possibilities of stress or inconvenience-induced errors.

- **Reception**

  The reception has been discussed under a subsequent category from the perspective of patients, families and visitors. It is also important to consider it from an administrative standpoint, as the central hub which leads into and connects all other parts of the facility. Clerical record storage rooms, nurse stations, medical supply areas, administrative offices, meeting rooms, and public restrooms, should all be directly accessible from the reception, enabling activities in these areas to take place without disturbing private patient zones.

- **Nurse Stations / Storage Spaces**
  While the nurse station should be accessible from the reception and outer, public domains of the facility, it should also be close to patient rooms. Accordingly, it may be placed in between the two, doubling its function as a spatial and noise buffer from external activities. As this is a place where patient and caregiver domains meet, achieving a de-institutionalized ambience through astute design decisions is encouraged. Natural lighting, artwork on walls, wide supply-cart space, uncluttered counters, and de-congested modular storage are some suggestions. The *Planetree* organization (See Introduction) has published concepts for nurse stations and medical storage that can be explored for implementation in palliative units.

- **Housekeeping**
  Constant sheet and gown changes occur with greater frequency in the palliative section. Curtains, rugs and upholstery may need regular washing as well. Most standalone hospices will normally have a laundry and linen room. Hospital-based units may send their laundry to the main site for cleaning. It would make sense to provide an independent laundry facility within the unit, with separate, commercial-grade, coin-operated laundry machines for family members to wash and iron their own clothes, rather than having to go home to do this.

- **Staff Respite Areas**
  Staff are employed in various capacities in end-of-life care—as

nurses, nurse practitioners, physicians, grief counsellors, volunteers, spiritual guides, etc. Watching patients and families struggle, dealing with losses, and resolving ethical uncertainties in the course of everyday duties, can quickly become mentally draining and physically exhausting. There should be a staff-only lounge, where they can spend some time away from the bedside, support each other, eat meals together, or get disturbance-free private moments. This room should have eating spaces, comfortable nap-friendly furniture, a television set, a music system, coffee, tea and a mini-refrigerator. Ideally, it should have its own access route to the garden and smoking spots.

- **Volunteer, Fundraising and Outreach**
  Volunteer and outreach are among the greatest strengths of the palliative care model. Volunteer offices should be positioned near the front entry, from where they can coordinate easily with representatives from local auxilliary organizations and community support groups. An archive room, communications material and printing supply storage, meeting room and workstations—should be clustered around the volunteer offices. Well-organized spaces for volunteers give due visibility, respect and credit to these very valued—and often unsung heroes—of community-based care.

5.1.3 COMMON SPACES

The palliative facility is as much a communal space as it is a private one. Much of its efficiency is dependent upon the way shared space is designed and organized. Alternative options to connect private domain with the public are worth exploring. Space allowing, small family studios may be built in clusters around common area courtyards. Borrowing from the idea of *Health Villages,* this form of layout allows the ambience of independent long-term housing, and open street views to the occupant.

Such designs are highly reliant upon the amount of real estate and budget available, and are likely most suited to suburban and semi-rural areas. Ordinarily, typical layouts arrange administrative zones around the exteriors of the building plan, with the patient zones positioned inside, shielded from high activity and the streetscape. Each facility will need to consider achieving a mix of the two—where patients do not feel too isolated, but also enjoy their privacy. Designing organically connected, easily navigable, de-institutionalized shared spaces is key.

- **Arrival Foyer / Welcome Desk**
  The point of entry—including the reception foyer, welcome desk, and the waiting area—should be warm, welcoming, friendly, and non-threatening. Hospital-based palliative care units—and less frequently, hospice-based—receptions often reflect the cold, formal environment that is associated with institutionalism. The arrival space is the first point of contact between patients and palliative professionals. As a symbolic doorway into the end-of-life care journey, initial impressions are critical in establishing trust and reassurance. The volunteer outreach office should be placed near the reception—and in many situations—it may be useful to have volunteer staff serve the reception desk, greet patients and families, give them directional assistance (or extensive site tours to first-time visitors), and connect them to other facility resources and staff.

  Discreet corner spots to sit in should be provided in addition to the main seating. A resource library, gift-shop, interactive information displays, artwork in the waiting lounge, teapots and cookie trays—are some others ideas that have previously been implemented with success in arrival space re-designs.

- **Philanthropy, Legacy, and Giving Thanks**
  Gifts and donations from community members, families, nonprofits,

and individual donors, may manifest in the form of physical artifacts. These could range from simple inobtrusive items, such as, an indoor plant or an area rug; or more space-demanding installations, like water fountains, wall murals, fireplaces, etc. Not only are these gifts helpful to the palliative facility from a budgetary perspective, but they are also thoughtful ways for people to contribute to and feel emotionally invested in the designed environment.

Conversely, it is important to incorporate gestures of thanks and remembrance within the care facility. These are commonly seen in the form of donor walls, outdoor name plaques. and commissioned art pieces. Such commemorations visibly consolidate how well-supported the palliative care building is by the neighbourhood, local organizations, volunteers, and donors. Integrating ritual and occasion in the palliative building need not be a monetary undertaking. Planting a favourite flowering tree in someone's memory or naming specific parts of the building after a patient or a donor are inexpensive, but meaningful alternatives. The design plan should anticipate spatial provisions and adaptibility for continuous legacy creation, philanthropic gestures, and objects of remembrance and gratitude.

- **Day Lounge/ Living Room**

  Close to the reception foyer, a spacious multi-purpose lounge should be designed carefully, with comfortable and variable types of seating arrangements (sofas, loveseats, adjustable height chairs, roomy window seats, individual corner seats). This room will be populated by a diverse user group—people who come for short visits, families, patients, staff members, volunteers, and others. The room will serve multiple purposes, for e.g., celebrating a special occasion, eating meals together, etc. Access to an adjoining sun-deck or large patio will provide for outdoor activities, light therapy, and smoking-designated areas. It is essential for the living room to personify a welcoming gathering space to encourage social connections and community support. Neutral design language which avoids any particular cultural affiliations, but employs universal markers of comfort and warmth are in order. Possible cues include a large fireplace, self-serve coffee and tea stands, bookshelves, reading lamps, a television set, a fish aquarium, etc. It is especially important to consider adaptability features here. Moveable partitions and half-walls can help set up zones as and when needed. The shape of the interior and the placement of things within can strike a creative balance between communal and private areas.

- **Multi-Sensory, Multi-Activity Playrooms**

  A large child-safe playroom—with ample space for toys, messy art projects, quiet reading, napping, and snacking—is essential. Large secure windows, cheerful colour schemes, child gates, uniform ground levels, child-proof electric fixtures and door knobs, and height-variable furniture are some key considerations. This room could possibly lead into an outdoor play area with swing sets, slides, sand-tables and splash pools, wherever child care or adult supervision is available. Age-appropriate zones can be created within the room, with separate space for older children and teens to read, play music, browse the internet, or play a video game.

- **Kitchen and Dining Space**

  In all cultures across the world, preparing and sharing meals together has been deemed crucial for strengthening emotional connections, facilitating social exchange and triggering community interaction. Nonetheless, eating areas should be designed to offer flexible levels of privacy, with provision for both, individual as well as communal, dining spots. Traditional dining room furniture encourages a homely atmosphere. Lightweight, movable, stackable furniture options should also be provided to serve variable uses. If possible, dining areas should open out to the gardens, so that people can take their plates outside and eat amidst natural surroundings, if they so desire.

Informal kitchen spaces with basic amenities like an oven, refrigerator, sink, and microwave—separate from the main staff kitchen—should be made available. Families can prepare a favourite meal for their loved ones here, or bake as a de-stressing activity. Coffee machines, electronic tea kettles, fruit baskets, snack bars, and cookie jars, should be placed in mutiple spots across the interior spaces. (See *Kitchenism,* Chapter 2)

- **Media Library**

  A room with internet-enabled computers and printing/scanning facilities is a common request voiced by many residents and their family members. The room can be extended into a small library with print and audiovisual resources on end-of-life issues, general interest magazines, popular fiction, poetry, and perhaps a music/video collection. Providing both, private cubicles and chair clusters around reading tables, will create a quiet, semi-private place to spend time alone or in small groups. The resource library should be positioned away from the bustling areas, preferably overlooking or having direct access to garden spaces and sunny balconies.

- **Pet Care**

  Many people derive deep joy, security, and comfort—along with a lessening of anxiety and alienation—from the company of pets and support animals. In times of trauma, vulnerability, and pain, animal therapy has been known to restore emotional wellness in human beings. Currently, many palliative wards prohibit or restrict the entry of animals for hygeine and safety reasons. Pet-safe, hygeine-compliant, environments can be planned in advance to allow patients quality time with their pets, in both indoors and outdoor designated areas, close to patient rooms.

- **Spa / Therapy / Yoga**
  Recreational activity and therapy rooms exist in many palliative facilities to support volunteer-led programming. A multipurpose room for art, music and movie activities, which can serve a number of social uses, should be planned for. A piano room is a good addition. An exercise gym for families and a yoga/pilates room for patients may help promote the de-stressing and rejuvinating benefits of physical activity. Other kinds of light exercise, such as gardening outdoors (or in an indoor greenhouse), brings cheer and a sense of accomplishment to many people. Wheelchair level flower beds, safe gardening tools and ergonomically-designed water hoses should be within reach. Safety considerations are top priority. All of these areas—whether indoor, outdoor, or combined—should be designed so that there is opportunity for individual retreat, as well as social engagement.

5.1.4 PRIVATE SPACES

The fear of death in a large, noisy ward—often without the company of loved ones, suffering the indignity of public view—was rampant during the early days of insititutionalized medicine. With the hospice movement, dying patients have been afforded separate spaces, not all of which are always completely private. Shared rooms are still quite common, with as many as four patients housed together. Relatively little research has been done on the design of rooms for terminal patients, but some main points may be highlighted.

- **Patient Bedroom**
  Space and budget permitting, each patient should have their own room. It should be designed to feel residential, but culturally neutral, and large enough for family members to gather in. Operable and secure windows that overlook garden spaces and let in plenty of sunlight are critical. Nonetheless, patients may become sensitive to light, suffer headaches, or crave darkness during daytime naps. A combination of window types, including alcoves and high windows or skylights—equipped with blinds, screens, shutters and curtains—allow the patient to adjust the amount, quality and proximity of light. Extra care must be taken to provide for continuous air circulation and temperature adjustment from the bedside. A concealed panel behind the bed keeps unsightly medical equipment away from direct view, as too many switches and tubes can be overwhelming. Likewise, the overhead lift may be concealed.

  It is essential to remember that this room signifies the patient's final abode. Correspondingly, being able to add familiar items from home promotes security and comfort, easing transition to a new place. Opportunities for personalisation allow people to re-create expressions of home and ownership, bringing them a feeling of control in their last days. Artwork and indoor plants add character and warmth, but sufficient space should be left for the patient to hang their own pictures or keep a plant that a visitor brings in. Closets are highly intimate spaces; they should be lockable, designed using high quality materials, and with ample storage options for both patient and family. The room will benefit from utilizing several surfaces (such as shelves, mantles, side-tables) for family photos, gifts, and other personal belongings. A reading lamp and power outlets to charge electronic devices should be made available at the bedside, as should the nurse call button and control switches for the television and room temperature. White noise machines are useful additions to assist with difficulties in sleeping. Care must be taken to ensure that seamless floor tiles are used inside and immediately outside patient rooms to avoid the grating sounds of pushcarts and wheelbeds.

A translucent screen or curtain between the patient-bed and the family member's side of the room can give them each the option to have some quiet time, while still being close together. Co-sleeping options for a spouse or a child should be strongly considered. In shared rooms, partitions must employ sturdy, non-translucent and noise-minimizing materials. Privacy is a major challenge and the foremost priority in such cases, as sounds and sights from adjacent sections are difficult to avoid. It is absolutely vital that no patient-section in a shared room be completely cut off from the windows or no single family be assigned a disproportionately small portion of the available area.

- **Bathrooms**
  Bathrooms are spaces that critically affect the dignity and degree of autonomy that a sick person perceives. The sterile and overbearing presence of metallic assistive devices, poster instructions on walls, and commode lifts can compound visually to aggravate anxiety. Overall, bathroom imagery risks inadvertently presenting to the dying person a measure of their physical inadequacies. Conscious design choices need to be made to avoid the bleak *clinical laboratory narrative.* Colour schemes should be cheerful and warm.

Any aiding devices should be kept in covered storage, from where they are easily retrievable. Large, properly ventilated and adequately lit bathrooms, with non-skid tiles and strategically placed handrails are primary considerations. Curtains around the commode allow the patient to be accompanied to the toilet, but still have some privacy. A small basin placed at wheelchair height, (in addition to the regular-height sink for the family) should be considered, if there is enough space.

Designers and healthcare professionals should not be quick to assume that the dying person has no interest in personal grooming, even though it may be true that any such interest could wane as the body declines. The bathroom mirror, which is usually positioned behind the basin counter, serves the family well. But it may be too far away for the patient. A separate mirrored panel, with non-breakable glass, could occupy one side of a wall, with a mounted accessory rack. This feature should not be designed to call too much attention to itself, as witnessing a decline in bodily appearance every time with every bathroom visit is unhelpful. It should, however, be discreetly available for anyone who wishes to use it.

As families spend an unpredictable amount of time in palliative care, personal grooming supplies and bathroom utilities can pile up. A lot of room through modular shelving and hanging racks can be created if planned intelligently. Medical care providers at the unit may decide that patients need to be washed in an external assisted bathing area. In that case, similar design considerations apply. However, a bath, or at minimum, a shower stall must always be available for family members who stay overnight.

If shared bathrooms are unavoidable, then providing at least two disability-accessible toilet stalls can enable simultaneous use by more than one patient. Extra ventilation in high-use bathrooms becomes even more important to reduce lingering unpleasant odours. If the shared bathroom is positioned in between two patient sections/rooms, then doorways on either side provide separate entry (See Chapter 4). While they can certainly be placed on facing walls, the doors themselves should not face each other, so as to avoid direct views into the room on the opposite end.

A cleaning space with a hand-held water jet, separate from the bathtub, should be made available to rinse anything that gets soiled. Ideally, bedpans should be cleaned in an ante-room that constructed in between private bedrooms. Cleaning them inside the patient bathroom is a hygeine concern. Nurses need a designated space and dishwasher-style machines to aid their task.

5.1.5 IN-BETWEEN SPACES

In-between spaces are those that link to the definitive zones within the palliative unit or those that perform psychological transitory functions. These are often consciously designed as repositories of emotional support, e.g., meditation rooms. Alternatively, they could be incidental in their psychological function, e.g., corridors or even walls.

- **Corridors**

  Medical buildings have historically been criticized for their endless, bleak corridors. Narrow passages that take a long time to traverse understandably exacerbate claustrophobia, heighten dread for the destination, reinforcing the idea of distance—and relatedly—large institutions. Double-loaded corridors are especially detrimental for patient privacy; they fail to distribute sights and sounds from adjacent rooms, and create ergonomic problems such as passage blockages and crowdedness (difficulties in moving medication/food carts; wheelchairs, etc). Corridors are not entirely avoidable in every type of building, but their limitations can be overcome by making them short, wide, semi-circular, or broken up into paths. Instead of monotonous blank walls, visual and tactile interest should be generated with art objects, plants, lighting and water-works. Additionally, architectural uniformity may be relieved through the placement of window views, alcoves, interesting angular transitions, and wall/ floor changes in colours, textures, and patterns.

- **Colours, Materials, Décor, Art**
  Dull neutral colour palettes, with white and cream bases, are associated with medical institutions. The dominant use of red is known to have an agitating effect on many people. There is not sufficient research on the perception of and response to colour among terminal patients. But by and large, warm colours promote intimacy and human interaction, while cool colours create an illusion of spaciousness. Busy patterns on wallpaper and the overuse of chintz upholstery are best avoided.

  Wood and stone are materials that mature and erode with time. They transform with shifting seasons and over biological/ geological processes. More luxurious, individualistic, tactile, they have long been associated with temporality and endurance in the human psyche (See Chapter 2)—and accordingly—should be used to create intimate and personable, as opposed to aloof and institutional spaces.

  The need to engage with beauty and find joy in artistic objects has been a central expression of human consciousness since time immemorial (See Chapter 3). The restorative and regenerative effects of art remain undisputed. Environmental murals, tapestries, sculptures, paintings, stained glass fixtures can all empower and inspire the spirit, disrupt visual monotony, and animate an otherwise tedious medical realm. The procurement of commissioned art should form a part of the budget at any palliative care facility. Interior layouts should actively consider and contantly create spaces for art.

- **Reflection Spaces**

  Among the most important and frequently requested spaces are those that staff, families and patients can retreat to and reflect in, without having to leave the building. These are conspicuously missing in typical hospital designs; except for the occasional chapel or prayer room. It is desirable to plan for non-denominational, accessibly-designed meditative spaces, which ideally have views—if not access to—the natural landscape. The scale of such rooms needs to be small enough to feel intimate and secure, but large enough to maintain individual privacy in the presence of multiple persons. Artwork, natural materials, stained-glasswork, and water elements are appropriate considerations. Some form of plant-life is beneficial; whether through indoor plantation or outdoor connectivity.

- **“Accidental” Privacy**

  A window booth in an unfrequented hallway is a spot to gather one’s thoughts. A surprising armchair upon turning a corner provides a much-needed place to process news from the doctor. A small patio in an unexpected place, quite importantly, affords space to cry in privacy. These strategic interventions allow people to temporarily disconnect from the stresses of a difficult situation. Although it may be assumed that sickness and death will universally trigger complex emotional responses, it is not always possible to anticipate when these moments will occur. It is the prerogative of good design to care—not only about our anticipated needs—but also our unanticipated ones. Distributed across the end-of-life unit, there should be sudden and unexpected islands of privacy, little *I-need-a-moment* withdrawal spaces. These strategic interventions will ideally bear an unintentional and unceremonial look, creating an illusion of pause, granting the user a brief suspension in the continuum of events.

- **Grieving Areas / Counselling Spaces**
  Grief precedes, continues through, and persists long after death. As families go through a difficult time, it is vital to design for ongoing processes of bereavement. There are various types of support, including private, group, family, and child and adolescent counselling. In terms of size as well as ambience, rooms should reflect the purpose they serve, ensuring privacy and security, while encouraging communicative exchange. The assurance of dignity and confidentiality is key. It is crucial that these spaces are visually and acoustically separated from high activity areas, so that it is safe to cry, express anger, or remain silent in particularly vulnerable moments. It may be of value to consider flexibility in counselling locations. People do not always find it easy or comfortable to dismantle their guard and expose their feelings just because a certain room and a specific occasion has been designated for such a purpose. Rooms that have moveable furniture arrangements, space to pace about, an alcove overlooking a garden, or if possible, a door leading outside to a quiet garden, are desirable.

5.1.6 NATURE-INTEGRATED SPACES

A flowing continuum between inside and outside spaces—built and natural environments—harnesses the therapeutic powers of gardens, and affords privacy, reflection and solace to patients (See Chapters 2 and 3). Outdoor and indoor landscaping can be used for sound buffering and spatial divisioning to bolster privacy in between different parts of the facility. Many design briefs for care centres specify that every vantage point in the building should offer views of nature, even if this might only mean a small courtyard with indoor plants. Climate, budget and real estate considerations may deter large outdoor gardens, especially in urban locations. In such cases, interior landscaping and layering of space and material is useful. Paths leading outdoors may utilize uniform tactile and colour codes, textures, and materials as subconscious directional guides. Glass facades, stone detailing and wood textures can be used as connective visual cues to seamlessly integrate points at which the building meets nature or the street (See *Theraserialization,* Chapter 2).

- **Fresh Air and Sun**
  Patient rooms should have large operable windows and/or screen doors with safety locks and adjustable shutters to change the amount of light as per preference. On upper levels, balconies, sun-decks and patios are desirable. Air quality is a key issue for patients who suffer nausea from heavy medication, strong cleaning agents, or simply as a result of debilitating disease. Constant air circulation must be planned carefully when designing inhabited spaces. Depending on local climatic conditions, windows and doors should face in appropriate directions, employ light and wind shielding devices, and overlook open sky and ground, with vegetation cover, and ideally, water elements. A meaningful view orients the patient to weather conditions and time of the day, while reducing the feeling of confinement. Being able to open windows and partake in external sights, smells and sounds empowers patients and affords them a valuable form of control over their lived environment.

- **The Private and Public Outdoors**

  Outdoor areas should employ a combination of seating styles to encourage individual contemplation as well as social connections. Single benches and discreet footpaths in hidden corners enable one to spend time alone, unnoticed and unannouced. Conversely, community gardens, parks, planted yards—with large benches, pinic tables, and wide paths—may prompt people to talk over a cup of afternoon tea. Sectional planting of person-height bushes can create private, semi-private and public zones on lawns. Trellises, gazebos, canopied walkways allow for outdoor engagement in varied weather conditions.

- **Water**

  Water—and images of water—hold an enduring place in human consciousness and the sense of time (See Chapter 3). Running water implies movement and passage; still water reflects our surroundings and conceals depth. Slow water is hypnotic and peaceful in its rhythms and sounds. Gushing water is powerful and drowns out other sounds, other sights. Human beings have always formed their dwellings near sources of water, and founds ways of adorning built space with water—fountains, pools, tanks, etc. Palliative unit users have repeatedly expressed the desire to sit beside an indoor fountain or walk to an outdoor waterfall or stream. Palliative units in upper level hospital buildings should have at least one indoor fountain. If open ground is available, this should be supplemented with outdoor ponds, tanks, streams, waterfalls. They do not have to be large or elaboratively designed; instead, it is more important to create recurrent points of interaction. A fish pond in the courtyard or a wall fountain in a corner is space-saving, while creating a welcome oasis in the mechanical medical sphere. Running and still water have unique benefits on the mind; there should be opportunities to engage with both. Comfortable seating and wheelchair/bed accessibility should be provided near as many of these as possible.

5.2 SUMMARY

Considering the previously discussed relationships between human experience, designed spaces and building as a time-mediating activity, it may be suggested that a *good death* requires situation in a place that can adequately enhance and support it. In this chapter, I have asserted that the designed environment can hinder experience, or alternatively, embody and help materialize some of the attributes of a good death. It has argued for the specificity of links between the designed space and human health; and identified a need to clarify our understanding of the psychosocial, physiological, and cultural aspects of end-of-life care. The next chapter will summarize the challenges of conducting such research, and stimulate questions to consider in future with regard to end-of-life contexts in modern society.

Conclusion
Moving Forward

While acknowledging that one cannot completely dissolve the stresses involved in terminal disease through environmental comforts, nor can any single conception of a *good place* to die encompass everyone's hopes and expectations, there are opportunities within the context of ageing and dying to:

- design spaces that care for some of our most important, challenging and profound life experiences;
- improve public interaction with the medical community;
- make the transition from provincial health services into specialist palliative medicine more transparent; and
- build closely integrated networks of communication and care delivery between types of medical providers and institutions.

Viewing this project through the lens of systems design, knowledge gaps manifest in two ways—in the amount of palliative expertise among healthcare professionals; and in the public's perception, accessibility and navigability of and across the palliative spectrum of services. As has been done in this research at a preliminary level, these can be identified through design thinking processes in future research. Recommendations that will arise from participant-led, design intervention workshops, feedback exercises and interview focus groups, can facilitate knowledge translation between actors in the mediscape, as seen in the case of FMC-Unit 47's experience with changing room layouts (See *Interview Synopses,* Chapter 4). Taking a step back to look at the bigger picture, some complexities in framing the limits of curative medicine, palliative care and assisted dying have emerged in the course of this study. At the micro level, these complexities relate to defining the role of individual facilities, and at the macro level, they pertain to death and dying within the country's public health system. These blurred boundaries are indicative of the rapid changes in end-of-life terminology, palliative ethics, medical standards of practice, and the sociopolitical stance on end-of-life issues. The following sections will comment broadly on what these transformations might mean for spaces of palliation in the near future.

This thesis project has explored the relationship of design to the experience of dying at sites of palliation. Situated within the context of Canada's public healthcare system, my research was conducted through an ethnographic analysis of two different types of palliative care facilities in Alberta. My readings of locations of death & dying were further extended through semi-structured interviews with people working within end-of-life care. This chapter will focus on the findings from research as they apply to:

- Challenges and Limitations in the Context of this Thesis Project
- Shifting Palliative Frameworks: The Semantics of Dying
- The Future: Re-thinking Buildings, Systems And Networks of Care

6.1 CHALLENGES & LIMITATIONS
IN THE CONTEXT OF THIS THESIS PROJECT

As I conducted my primary research, the practical difficulties of studying healthcare environments emerged as unique factors for consideration:

(i) Interviewing Health Professionals: From the start, it was extremely challenging for interviewees to work our sessions into their unpredictable and demanding schedules. They were hesitant to give me a fixed appointment in advance, as they did not know what any particular day at work might entail. When we did schedule a session, they were often interrupted by official calls, emergency situations, or other colleagues/patients who needed their attention urgently. Due to this, my interviews would sometimes begin accidentally in between their tasks for the day, and would have to be paused as and when the aforementioned disruptions occurred. To give an example, an interviewee would start talking to me in the middle of a site tour, at which time, I would not have had the prior opportunity to ask for permission to audio-record. In such a case, it would be rude to stop the interviewee just to set up audio-recording equipment, as it would cause them to lose their train of thought. As a result, I would make detailed written notes in a notebook if a spontaneous conversation started, and wait for a natural pause in the discussion to ask for permission to record. My interview with the Nurse Managers at Foothills Medical Centre began with written dialogue recorded in my notebook, followed by a mid-way switch to audio. It is also for the same reason that all interviews have abrupt endings, usually caused by the interviewee having to attend to something unforeseen.

I learnt that the nature of employment within healthcare spaces makes disturbance-free interview sessions unrealistic. It became clear to me that field research in such sites relies greatly upon my ability to quickly adapt to the situation and make on-the-spot decisions regarding how and when to record data with the flow of the scenario. Finally, ensuring that I always follow the ethics protocol of obtaining prior signed consent *before* the interview is frequently impractical. In fact, it is even seen as an annoying formality by some interviewees, who might ask to complete it at a later, more convenient, time. There are ethical implications here for the researcher, who may be caught between having to badger an already work-stressed interviewee and protecting all parties through full and informed consent procedures.

The unpredictability and chaos of these settings, in itself, offered me a glimpse into the entanglements of researching in a sensitive environment, leading me to alter my expectations as a researcher in end-of-life care.

(ii) Researcher's Objectivity: An aspect of semi-structured interviews that I had not predicted was the tangential nature of conversation, which often led to personal questions directed at me. At times, interviewees would suddenly point questions at me about my future plans or ask about my own thoughts, processes, and experiences. These may or may not have been necessarily applicable to the topic being currently researched. However, it would neither have been appropriate to evade such questions, nor always possible to stop audio-recording midway—whether to protect my own privacy or with the aim of not influencing interviewee responses. Although I have omitted irrelevant personal material from the transcripts, they do appear occasionally in audio. Most importantly, I understood that a semi-structured interview can end up dual-sided. While this is somewhat in conflict with guidelines to avoid divulgence of personal opinions to interviewees, I found that this to be a rather problematic grey area.

Professionals in end-of-life care, while intrigued by the researcher's interest, may still harbour suspicions about the kind of work being done and accordingly, withold their views, if their doubts are not resolved. One of the most important assurances they seek, and even demand to see, are signs of genuine emotional investment on the part of the researcher, who requests access to (what might be) their own workplace ethics and moral standpoints. Hence, shedding my guard and being open about myself, while generally discouraged in research interviews, proved crucial in establishing trust and authentic connections in such sensitive research.

(iii) Limitations of My Field Research: My project began with a complex ethics application, during which the ethics committee presented early concerns with protecting the particularly vulnerable interests of palliative patients. I learnt that involving patients and their families would necessitate a much more detailed and time-consuming process for obtaining permissions at various levels. In view of my master's degree timeline, I decided to focus only on the perspectives of healthcare professionals and not conduct any interviews with people receiving care. It quickly became clear to me that having ethics approval from the Health Research Ethics Board (HREB) would still need follow-up administrative approvals from each site where research would take place, in accordance with AHS-established procedures. Contact was made with several palliative care facilities in and around Edmonton through AHS-mandated platforms and policies, but the turnaround time for application processing was greatly delayed. Hence, I chose to concentrate on two sites: Red Deer Hospice, whose standalone structure eliminated need for AHS approval; and Foothills Medical Centre, which was the quickest responder to my application.

Since my study took place outside Edmonton, I was funded by a limited travel grant from the Faculty of Graduate Studies & Research (FGSR), University of Alberta, for 3 days at each site. My budget did not allow me to fully immerse myself at these sites for extended periods time. Long-term observation of care facilities may yield a more complex view of the environment and its functioning. As palliative care units are usually small and independent, even when operating out of big hospitals, I believe my sample size to be adequate for the environments being studied. Further knowledge can be gained from involving bedside nursing staff and palliative care practitioners. Both these categories of professionals follow tighter schedules than those in administrative positions and are therefore more difficult to meet during their work shifts. My ethics application states survey-questionnaires as a part of my methodology. Printed questionnaires were given to nursing staff, but owing to the factors mentioned here, I did not receive adequate responses at either site. Due to a lack of sufficient responses, this method has been omitted from the study.

This research acknowledges that:

- there is value in consulting patients and families for their insights on end-of-life care. These considerations currently fall outside its scope, but could possibly form a part of future research. My personal observations are, however, reflective of comments made by aforementioned parties, as and when they offered to speak to me (unprompted, undisclosed).
- visits to other facilities in Alberta and beyond are likely to unearth new knowledge that may not have been revealed through this project. The two facilities referenced in this study do not represent the entire landscape of palliative care in Alberta or Canada.
- the opinions of my 5 interviewees do not represent the views of all palliative care professionals in Alberta or Canada. Future research conducted over a longer time duration should consider the involvement of nursing staff and doctors. These groups currently fall outside the scope of this project.

6.2 SHIFTING PALLIATIVE FRAMEWORKS

THE SEMANTICS OF DYING

As palliative treatments advance, and choices regarding how and where we die expand, new ethical questions continue to perplex end-of-life decision-making. These questions further influence how we build future health environments to cultivate ceremony, communion and ethos in what are often seen as functional and medicalized spaces. At this point, we must concern ourselves not only with improving patient experience, but also with facilitating conversation about the limits of palliation.

In this transitioning end-of-life landscape, the spaces of palliative operation have the potential to disrupt hegemonic medical paradigms and critique social attitudes towards death.

According to medical sociologist, Allan Kellehear, modern society relies upon institutional expertise to derive its definitions and legitimize its understanding of death. He raises the commonly observed concern that dying is so often concealed from the precincts of social life, that it attains visibility mainly when experienced under medical vigil. For him, dying is a crucial existential stage in the human lifespan that might unfold over several years—rather than minutes—and therefore, calls for social occasion and status befitting its processual importance.[191] In modern times, death is no longer the existential period that Kellehear describes, but a territory of medical skill where practitioners confront and respond to a professional challenge. As the celebrated doctor Howard M. Spiro argues, "[i]n the reductionist world of physicians and nurses, death has become a purely physical process: when someone has died is no longer a matter for lay people to decide; instead it has become a highly technical and sometimes contentious judgement."[192] Indeed, contemporary life-prolonging technologies even engender new states of life/death—such as neurological or cerebral death—which may re-configure medical standards of practice and create grounds for unique ethical conflict.[193, 194]

Gendered readings of clinical locations of dying reveal what Karsoho et al have called modern medicine's paternalistic denial of human mortality.[195] The hospital is still seen as a largely masculine sphere of influence where doctors, many of whom are men, engage in the urgent business of saving lives; where resignation to terminal illness would register the defeat of science, and in some ways, imply the practitioner's failure. Palliative service, with its roots in the nursing profession and still significantly dominated by female staff, is perceived as an essentially empathy-driven, domesticized realm of care, where "[t]he emotional economy…is largely in the hands of women."[196] These gender-associated narratives in healthcare spaces reinforce existing cultures of sickness and death, and create further implications for healthcare designers, practitioners and social scientists.

Advocating for the involvement of medicine only in pain relief, the palliative model seemingly acts as a powerful counter voice to the medicalization of death. With the establishment of the first modern hospice in London in 1967, Cicely Saunders triggered a worldwide social movement committed to holistic care at life's end. She introduced the idea of *total pain*—a notion that transcended bodily distress to include emotional, social, and spiritual suffering. From this, it may be inferred that suffering must similarly be eased in multi-dimensional ways that extend beyond the physical.[197] Many end-of-life commentators opine that palliative practice has done much to address the needs of not just the diseased body, but the whole person—changing how the dying are looked at, cared for and managed in clinical environments, and ultimately, opposing the medicalization of dying.[198] In the context of what suffering means, design intervention has the same goals and may be utilized for the same purpose of serving the *whole person*.

Some, however, believe the palliative profession to be an extension of the medicalization curve, operating within institutional frameworks, and cementing society's distance from the dying.[199] There are growing concerns with whether palliation might, in fact, aggravate suffering, as technologies to prolong terminal conditions or delay remission are developed. On the one hand, using life-extension measures contradicts the code of non-interventionalism consistent with palliative ethics. But witholding such therapies—especially as they become standard procedures, financially accessible under healthcare coverage—can be interpreted as complicit in (medically preventable) death.[200] While assisted dying is normally framed as oppositional to palliative principles, the demarcation between curative, pain-relieving, and death-stalling measures is not always explicit (See *Interview Synopses,* Chapter 4). On the other hand, it has been argued that "it is simply not possible to die with dignity if the patient is wired up to machines."[201] Many places of death are still sites where values of clinical efficiency compete against the acceptance of an inevitable end. Equipped with machines to take over bodily function and prompt response protocols for emergencies, mainstream medical culture places supreme importance on 'doing everything we can' to avert death. As philosopher, Nobert Elias, has remarked, "[c]are for people sometimes lags behind care for their organs."[202]

With new medical knowledge, changing legal conditions and expanding ethical contexts, our expectations of what may constitute reasonable suffering at the end of life—and acceptable measures for alleviating such suffering—continue to shift. Some experiences of suffering may not only fall outside the bounds of palliation, but also be exacerbated by its application. In view of this, care for the dying requires acknowledgement of and attention to that existential anguish which palliative medicine cannot reach. Spaces for the end of life must be imbued with a sense of time and being, and allow for engagement with the deeper issues of ritual and occasion. Anthropologists have often commented that the purpose of all ritual is to control, subdue and order the violence of death.[203] In connection with this, *Chapter 3* has detailed how architecture and design might assist in the slowing of time, heightening of sensory experience, and embodiment of occasion. The palliative space, then, is not merely a built structure, but—as literary scholar Robert Harrison says of all architecture—a place where human time transpires.[204]

6.3 THE FUTURE: RE-THINKING BUILDINGS, SYSTEMS AND NETWORKS OF CARE

The hospice movement has historically been perceived as "white, middle class, Christian…serving a carefully selected group of patients."[205] While this legacy continues to positively inspire and influence palliative service, most people today favour a shift from religious iconography towards neutral design language. In fact, a modern secularized scheme is already seeping through a broad servicescape; concrete buildings are now giving way to an 'exploded view' format of the hospice—whether in the form of daycare facilities at community-led hospices, independent family support centres, residential palliative units in general hospitals, or extensive outreach programmes for home-based care. In-patient models are becoming an increasingly small part of the palliative communities of practice. The persona of the hospice, along with the social segment it serves, is set to be shaped by the private, public, and non-profit sectors that will drive its sources of funding, governance and innovation in the coming years.

As a building, a palliative space need no longer be a physically static, socially isolated end destination. Wilson et al, in their 2008 study assessing changing trends in Canadian locations of death, concluded that institutionalized death is on a continuing decline as more people die outside hospitals.[206] Many patients now move in and out of distributed touchpoints for accessing pain treatments and wellness therapies, to participate in recreational activities with their families, and to engage with other patients or volunteers from the community . With carefully planned support from integrative care networks, comprehensive programmes for symptom relief and overall comfort can be personalized, while keeping open the option to die at home. Finally, long-term residences for the elderly are poised to be among the most common future locations of death. The unique blend of independent living with medical support access at these sites, positions them particularly well to hold the future of end-of-life service innovation.

Studies testing the effect of hallucinogenic and mind-altering drugs on the dying experience are already underway.[207] The designers and innovators of future care spaces might question the need for building specific environments when pharmaceutical alternatives exist to alter the mental states of its occupants. Similarly, virtual reality and multisensory technologies could be used to simulate changes in the mood, lighting, and even the topography of the room in which a patient dies. During the field research for this thesis, a nurse revealed that spending last moments in the fresh outdoor air is a fairly common request. What appears to be a simple wish, is almost never possible to grant, either due to the patient's mobility issues or because the palliative unit is inside a high rise hospital building located in an urban centre. The use of future technologies could create elegant solutions for patients who desire mental states that their illness does not afford them or wish to envision a resting place other than their rooms. Nevertheless, it is unlikely that the majority of publicly funded hospitals, hospices or residential homes will be able afford the expenses of implementing and maintaining such facilities in the near future. Until then, it will remain crucial to design personable, navigable and adaptable buildings and networks for the public to access. Over the next few decades, the seamless integration of green technologies and sustainable practices will be among the foremost design considerations in all public sector architecture, including buildings for end-of-life care.

The Lien Foundation, known for commissioning the *Quality of Death Index* report every five years, collaborated with the heathcare design firm, *Fuelfor*, to release the *Hospitable Hospice Handbook (2013)*—a proposal for an open community hospice.[208] Accessible to the public, it intended to engage the neighbourhood with everyday life within the palliative sphere. The open hospice plan included shared amenities like gardens, a kindergarten, a food delivery service, a bus service, a spa, and a movie theatre. *Fuelfor* suggested the integration of a credit system within the national healthcare program, allowing the public to gain and redeem points for hospice volunteer hours against healthcare purchases. Finally, digital and print-based media materials were proposed for helping people navigate the complex processes of advance care planning. By inviting the complete age and health spectrum into its material and social fold, it encouraged normalized dialogue about death and dying.

The term *dying well* has gained a firm foothold in the conversation on enhancing quality of life for the older population. Writing of public attitudes towards ageing and death, French architect, Nils Degrémont suggests that dying outside the home can be viewed as "a death outside society—because, in a hospital environment and despite the existence of palliative care units, death is still something of which to be ashamed."[209] This shame, or discomfort, stems from the anticipated (or experienced) loss of dignity, frequently associated with disease, incapacity and pain, and too often occuring within the kind of medical space described earlier in this thesis. Degrémont's comment raises the additional question of whether death might be viewed as a subject of discomfort and embarrassment, not simply despite, but because of the presence of palliative care units, and the narratives long associated with such places. Can the dissolution of medicalized buildings in favour of open access end-of-life locations also disorient our cultural dispositions towards death? Despite our efforts to improve end-of-life architecture and health systems design, dying within an institution remains a matter fraught with social, political and ethical ambiguities. As palliative frameworks evolve, the environments within which they are implemented must constantly adapt to new social conceptions of and personal autonomies in ageing and death.

6.4 SUMMARY

This thesis has been centred on the notion that design can make meaningful contributions towards the conception, organization and management of empathic care settings at the end of life. It has highlighted that palliative architecture is, as yet, a relatively little explored area of practice and research. Interdisciplinary scholars, working professionals, and user groups from multiple fields should come together to create supportive structures around death and dying in modern society. Designers are uniquely positioned to facilitate interactions between experts of various backgrounds, and effectively combine aesthetics, spirituality, nature, and functionality for improved palliative care experiences.

Human-centred design thinking can be employed in healthcare research to expose patterns of use, movement, behaviour and social exchange, that are otherwise difficult to locate. *Participatory* and *community-based* design models grant autonomy and leadership to medical professionals to improve their workplace environments. *Narrative enquiry* and *ethnographic exercises* draw upon the rich experiences of both, care providers and patients, aiding in the identification of obscure knowledge gaps. *Evidence-based* design has already produced successful outcomes in other types of medical settings and healthcare organizations, reducing medical errors that might occur due to unsupportive environments.

With growing information about the psychological, social and biological dimensions of human health, the impact of built spaces and seamless servicescapes on our wellbeing is undeniable. In future research, it will be useful to study existing floor plans, conduct visual ethnographic analyses using photographs, and collect observational field work—to identify and amplify key problematic issues and critique current design strategies. Before building future palliative care sites, spatial thinkers and architects will benefit from research that illustrates the qualities of a sanctuary for rest, an environment of care, and a meaningful place for a *good death*. Broad studies in social science will invite new and universally transferable frameworks in end-of-life architecture—for example, by analyzing geographical concerns, national health policies, cultural heritage, and social attitudes toward death and dying—as some of the continually evolving determinants of healthcare environments. At the same time, smaller individual projects will continue to inform evidence-based practice in palliative design—by working with indigenous architectural traditions, local medical sectors, neighbourhood communities, and by uncovering fundraising and operational issues, as the additional variables that shape such projects.

Applying these frameworks to future sites of care will further the objectives of death with dignity, and have implications on medical education, gerontology, bioethics, architecture, sociology, and public health, in the years to come. Design remains a powerful—albeit underutilized—driving force in translating a diverse and evolving body of knowledge for pragmatic applications in patient-centred palliative medicine.

ENDNOTES

191: Kellehear, *A Social History of Dying,* 252.
192: Spiro et al, *Facing Death," p. xvii.*
193: Kaufman, *And a Time to Die.*
194: Kaufman, *Ordinary Medicine.*
195, 200: Karsoho et al, "Suffering and Medicalization," 190.
196, 201: Worpole, *Modern Hospice Design,* 93, 94.

197: Saunders, "Care of Patients Suffering from Terminal Illness," p. viii.

198: McNamara, "Fragile Lives," 76.

199: Broom, *quoted in* Karsoho et al, 188-196.

202: Elias, *Loneliness of the Dying,* 91.

203: Davies, *Death, Ritual, and Belief,* 16.

204: Harrison, *The Dominion of the Dead. 3.*

205: Clark, "Whither the Hospices?," 172.

206: Wilson et al, "The Rapidly Changing Location of Death," 1757.

207: Randerson, "Clinical Trials Test Potential of Hallucinogenic Drugs."

208: Parameswaran and Herczeg, "Hospitable Hospice," 1.

209: Degrémont, Nils, "Palliative Care and Architecture," 127.

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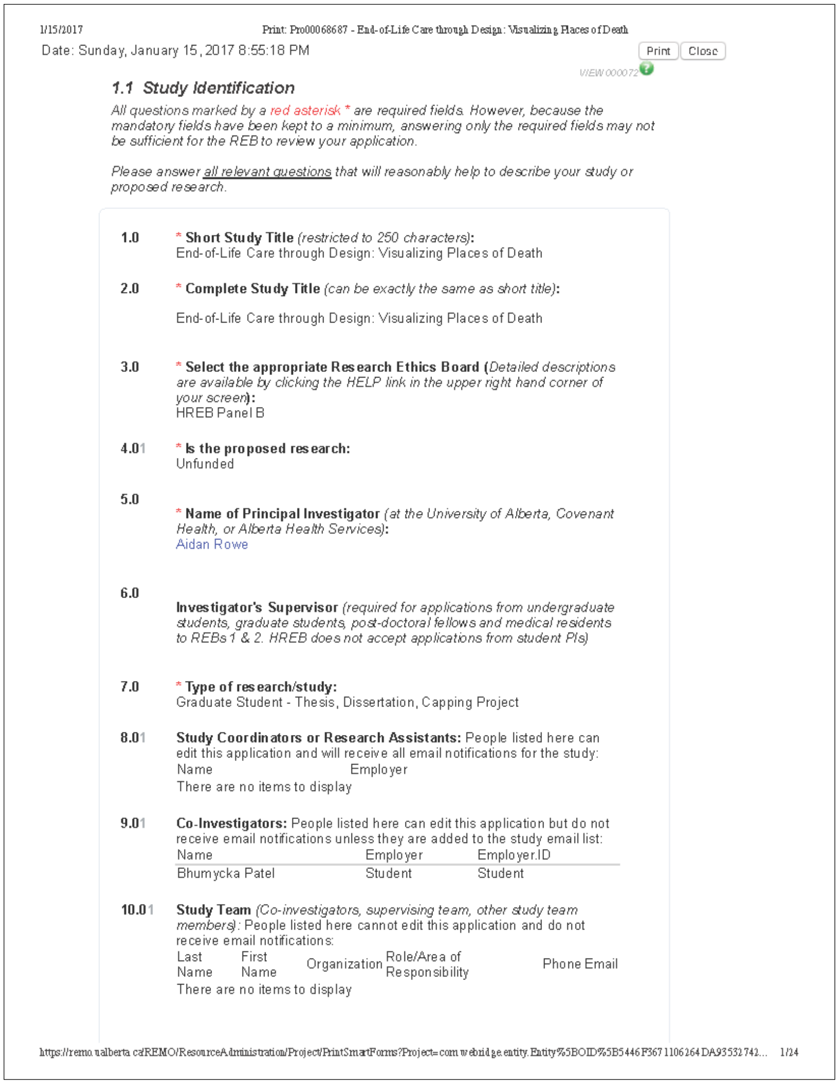
Appendices

8.1 HEALTH RESEARCH ETHICS BOARD (HREB)

RESEARCH ETHICS APPLICATION



1/15/2017 Print: Pro00068687 - End-of-Life Care through Design: Visualizing Places of Death

Date: Sunday, January 15, 2017 8:55:18 PM

1.1 Study Identification

*All questions marked by a red asterisk * are required fields. However, because the mandatory fields have been kept to a minimum, answering only the required fields may not be sufficient for the REB to review your application.*

Please answer all relevant questions that will reasonably help to describe your study or proposed research.

1.0 * **Short Study Title** *(restricted to 250 characters)*:
End-of-Life Care through Design: Visualizing Places of Death

2.0 * **Complete Study Title** *(can be exactly the same as short title)*:
End-of-Life Care through Design: Visualizing Places of Death

3.0 * **Select the appropriate Research Ethics Board** (*Detailed descriptions are available by clicking the HELP link in the upper right hand corner of your screen*):
HREB Panel B

4.0 * **Is the proposed research:**
Unfunded

5.0 * **Name of Principal Investigator** *(at the University of Alberta, Covenant Health, or Alberta Health Services)*:
Aidan Rowe

6.0 **Investigator's Supervisor** *(required for applications from undergraduate students, graduate students, post-doctoral fellows and medical residents to REBs 1 & 2. HREB does not accept applications from student PIs)*

7.0 * **Type of research/study:**
Graduate Student - Thesis, Dissertation, Capping Project

8.0 **Study Coordinators or Research Assistants:** People listed here can edit this application and will receive all email notifications for the study:

Name	Employer
There are no items to display	

9.0 **Co-Investigators:** People listed here can edit this application but do not receive email notifications unless they are added to the study email list:

Name	Employer	Employer.ID
Bhumycka Patel	Student	Student

10.0 **Study Team** *(Co-investigators, supervising team, other study team members)*: People listed here cannot edit this application and do not receive email notifications:

Last Name	First Name	Organization	Role/Area of Responsibility	Phone	Email
There are no items to display					

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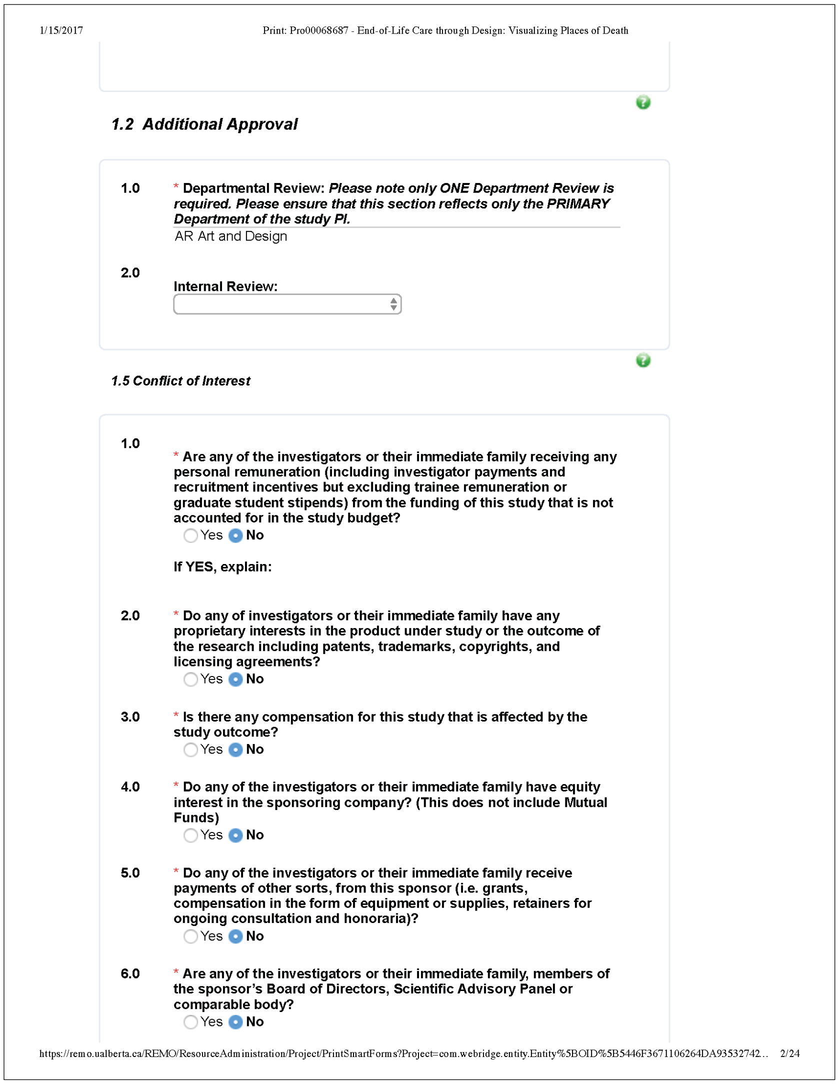


1.2 Additional Approval

1.0 * **Departmental Review:** ***Please note only ONE Department Review is required. Please ensure that this section reflects only the PRIMARY Department of the study PI.***

AR Art and Design

2.0 **Internal Review:**

1.5 Conflict of Interest

1.0 * **Are any of the investigators or their immediate family receiving any personal remuneration (including investigator payments and recruitment incentives but excluding trainee remuneration or graduate student stipends) from the funding of this study that is not accounted for in the study budget?**

○ Yes ● **No**

If YES, explain:

2.0 * **Do any of investigators or their immediate family have any proprietary interests in the product under study or the outcome of the research including patents, trademarks, copyrights, and licensing agreements?**

○ Yes ● **No**

3.0 * **Is there any compensation for this study that is affected by the study outcome?**

○ Yes ● **No**

4.0 * **Do any of the investigators or their immediate family have equity interest in the sponsoring company? (This does not include Mutual Funds)**

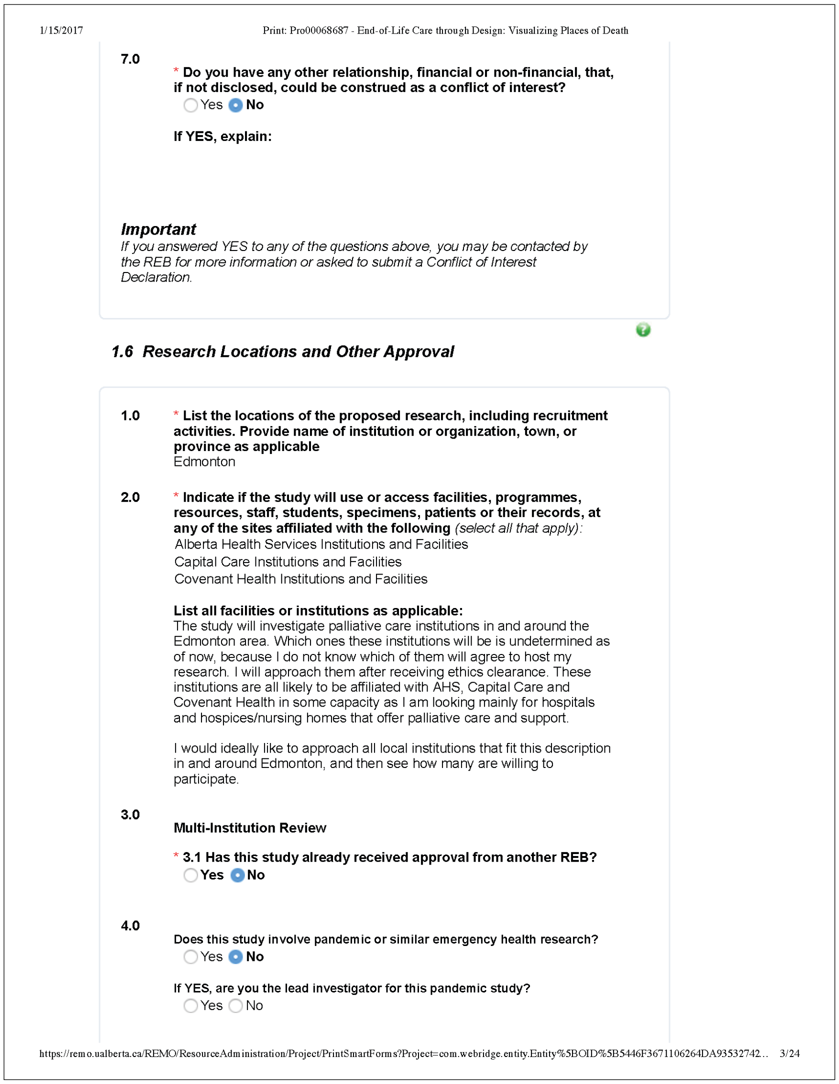
○ Yes ● **No**

5.0 * **Do any of the investigators or their immediate family receive payments of other sorts, from this sponsor (i.e. grants, compensation in the form of equipment or supplies, retainers for ongoing consultation and honoraria)?**

○ Yes ● **No**

6.0 * **Are any of the investigators or their immediate family, members of the sponsor's Board of Directors, Scientific Advisory Panel or comparable body?**

○ Yes ● **No**



1/15/2017 Print: Pro00068687 - End-of-Life Care through Design: Visualizing Places of Death

7.0

* **Do you have any other relationship, financial or non-financial, that, if not disclosed, could be construed as a conflict of interest?**
○ Yes ● **No**

If YES, explain:

Important
If you answered YES to any of the questions above, you may be contacted by the REB for more information or asked to submit a Conflict of Interest Declaration.

1.6 Research Locations and Other Approval

1.0

* **List the locations of the proposed research, including recruitment activities. Provide name of institution or organization, town, or province as applicable**
Edmonton

2.0

* **Indicate if the study will use or access facilities, programmes, resources, staff, students, specimens, patients or their records, at any of the sites affiliated with the following** *(select all that apply):*
Alberta Health Services Institutions and Facilities
Capital Care Institutions and Facilities
Covenant Health Institutions and Facilities

List all facilities or institutions as applicable:
The study will investigate palliative care institutions in and around the Edmonton area. Which ones these institutions will be is undetermined as of now, because I do not know which of them will agree to host my research. I will approach them after receiving ethics clearance. These institutions are all likely to be affiliated with AHS, Capital Care and Covenant Health in some capacity as I am looking mainly for hospitals and hospices/nursing homes that offer palliative care and support.

I would ideally like to approach all local institutions that fit this description in and around Edmonton, and then see how many are willing to participate.

3.0

Multi-Institution Review

* **3.1 Has this study already received approval from another REB?**
○ **Yes** ● **No**

4.0

Does this study involve pandemic or similar emergency health research?
○ Yes ● **No**

If YES, are you the lead investigator for this pandemic study?
○ Yes ○ No

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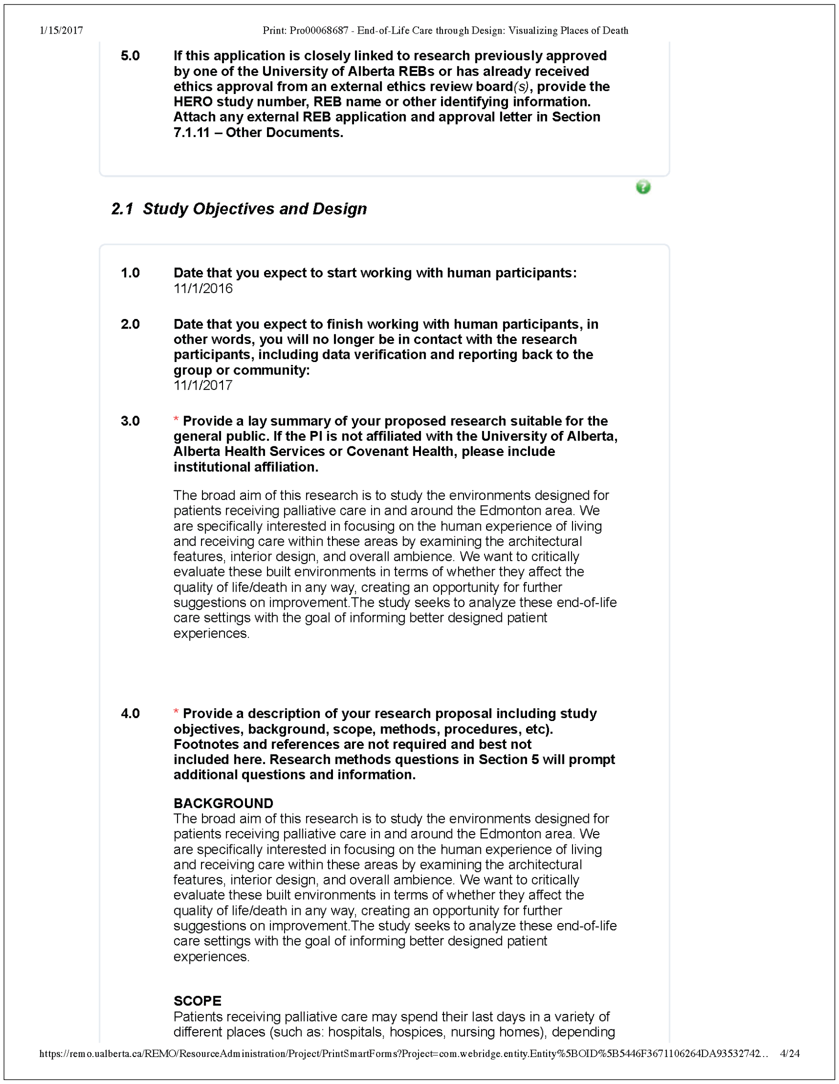


5.0 **If this application is closely linked to research previously approved by one of the University of Alberta REBs or has already received ethics approval from an external ethics review board*(s)*, provide the HERO study number, REB name or other identifying information. Attach any external REB application and approval letter in Section 7.1.11 – Other Documents.**

2.1 Study Objectives and Design

1.0 **Date that you expect to start working with human participants:**
11/1/2016

2.0 **Date that you expect to finish working with human participants, in other words, you will no longer be in contact with the research participants, including data verification and reporting back to the group or community:**
11/1/2017

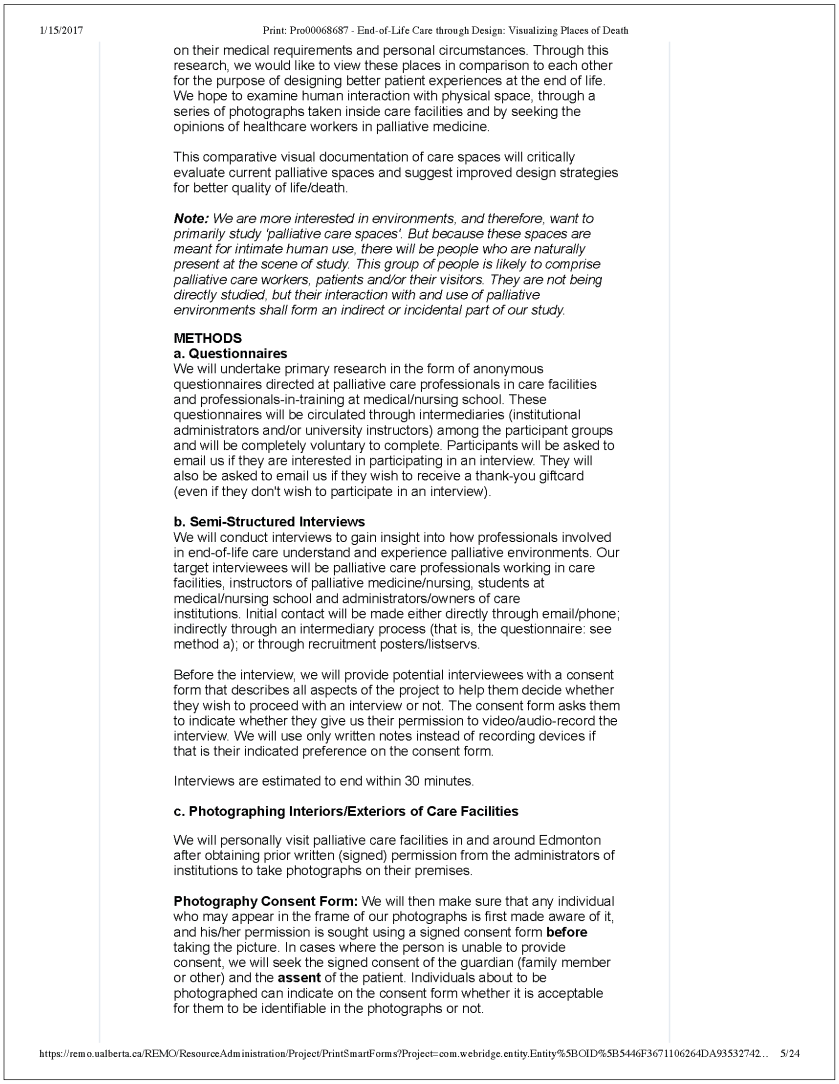
3.0 * **Provide a lay summary of your proposed research suitable for the general public. If the PI is not affiliated with the University of Alberta, Alberta Health Services or Covenant Health, please include institutional affiliation.**

The broad aim of this research is to study the environments designed for patients receiving palliative care in and around the Edmonton area. We are specifically interested in focusing on the human experience of living and receiving care within these areas by examining the architectural features, interior design, and overall ambience. We want to critically evaluate these built environments in terms of whether they affect the quality of life/death in any way, creating an opportunity for further suggestions on improvement.The study seeks to analyze these end-of-life care settings with the goal of informing better designed patient experiences.

4.0 * **Provide a description of your research proposal including study objectives, background, scope, methods, procedures, etc). Footnotes and references are not required and best not included here. Research methods questions in Section 5 will prompt additional questions and information.**

BACKGROUND
The broad aim of this research is to study the environments designed for patients receiving palliative care in and around the Edmonton area. We are specifically interested in focusing on the human experience of living and receiving care within these areas by examining the architectural features, interior design, and overall ambience. We want to critically evaluate these built environments in terms of whether they affect the quality of life/death in any way, creating an opportunity for further suggestions on improvement.The study seeks to analyze these end-of-life care settings with the goal of informing better designed patient experiences.

SCOPE
Patients receiving palliative care may spend their last days in a variety of different places (such as: hospitals, hospices, nursing homes), depending



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on their medical requirements and personal circumstances. Through this research, we would like to view these places in comparison to each other for the purpose of designing better patient experiences at the end of life. We hope to examine human interaction with physical space, through a series of photographs taken inside care facilities and by seeking the opinions of healthcare workers in palliative medicine.

This comparative visual documentation of care spaces will critically evaluate current palliative spaces and suggest improved design strategies for better quality of life/death.

***Note:** We are more interested in environments, and therefore, want to primarily study 'palliative care spaces'. But because these spaces are meant for intimate human use, there will be people who are naturally present at the scene of study. This group of people is likely to comprise palliative care workers, patients and/or their visitors. They are not being directly studied, but their interaction with and use of palliative environments shall form an indirect or incidental part of our study.*

METHODS
a. Questionnaires
We will undertake primary research in the form of anonymous questionnaires directed at palliative care professionals in care facilities and professionals-in-training at medical/nursing school. These questionnaires will be circulated through intermediaries (institutional administrators and/or university instructors) among the participant groups and will be completely voluntary to complete. Participants will be asked to email us if they are interested in participating in an interview. They will also be asked to email us if they wish to receive a thank-you giftcard (even if they don't wish to participate in an interview).

b. Semi-Structured Interviews
We will conduct interviews to gain insight into how professionals involved in end-of-life care understand and experience palliative environments. Our target interviewees will be palliative care professionals working in care facilities, instructors of palliative medicine/nursing, students at medical/nursing school and administrators/owners of care institutions. Initial contact will be made either directly through email/phone; indirectly through an intermediary process (that is, the questionnaire: see method a); or through recruitment posters/listservs.

Before the interview, we will provide potential interviewees with a consent form that describes all aspects of the project to help them decide whether they wish to proceed with an interview or not. The consent form asks them to indicate whether they give us their permission to video/audio-record the interview. We will use only written notes instead of recording devices if that is their indicated preference on the consent form.

Interviews are estimated to end within 30 minutes.

c. Photographing Interiors/Exteriors of Care Facilities

We will personally visit palliative care facilities in and around Edmonton after obtaining prior written (signed) permission from the administrators of institutions to take photographs on their premises.

Photography Consent Form: We will then make sure that any individual who may appear in the frame of our photographs is first made aware of it, and his/her permission is sought using a signed consent form **before** taking the picture. In cases where the person is unable to provide consent, we will seek the signed consent of the guardian (family member or other) and the **assent** of the patient. Individuals about to be photographed can indicate on the consent form whether it is acceptable for them to be identifiable in the photographs or not.

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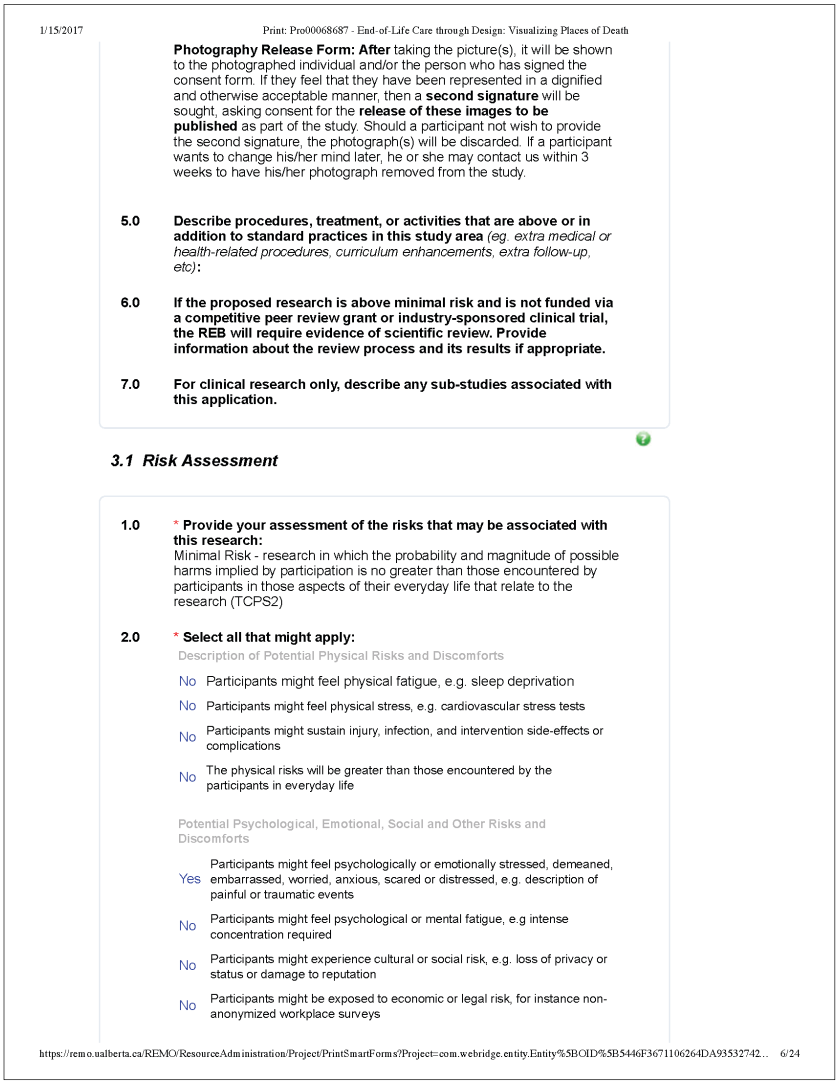


Photography Release Form: After taking the picture(s), it will be shown to the photographed individual and/or the person who has signed the consent form. If they feel that they have been represented in a dignified and otherwise acceptable manner, then a **second signature** will be sought, asking consent for the **release of these images to be published** as part of the study. Should a participant not wish to provide the second signature, the photograph(s) will be discarded. If a participant wants to change his/her mind later, he or she may contact us within 3 weeks to have his/her photograph removed from the study.

5.0 **Describe procedures, treatment, or activities that are above or in addition to standard practices in this study area** *(eg. extra medical or health-related procedures, curriculum enhancements, extra follow-up, etc)***:**

6.0 **If the proposed research is above minimal risk and is not funded via a competitive peer review grant or industry-sponsored clinical trial, the REB will require evidence of scientific review. Provide information about the review process and its results if appropriate.**

7.0 **For clinical research only, describe any sub-studies associated with this application.**

3.1 Risk Assessment

1.0 * **Provide your assessment of the risks that may be associated with this research:**
Minimal Risk - research in which the probability and magnitude of possible harms implied by participation is no greater than those encountered by participants in those aspects of their everyday life that relate to the research (TCPS2)

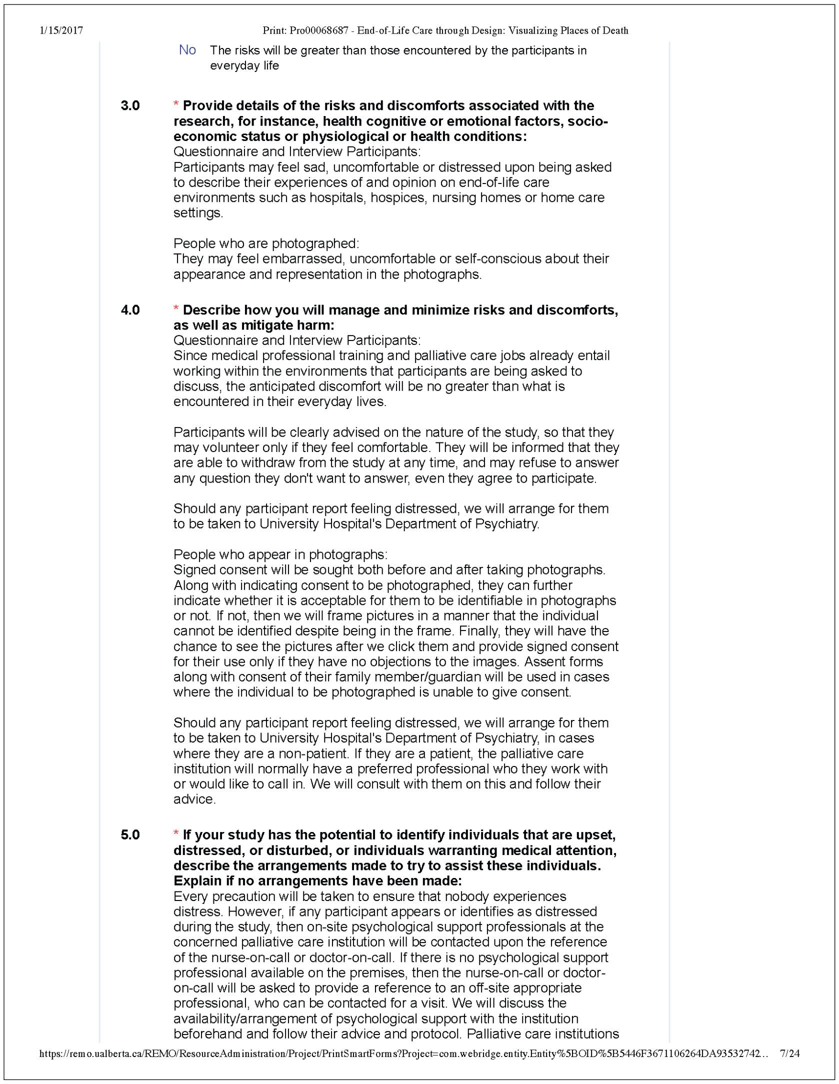
2.0 * **Select all that might apply:**

Description of Potential Physical Risks and Discomforts

No	Participants might feel physical fatigue, e.g. sleep deprivation
No	Participants might feel physical stress, e.g. cardiovascular stress tests
No	Participants might sustain injury, infection, and intervention side-effects or complications
No	The physical risks will be greater than those encountered by the participants in everyday life

Potential Psychological, Emotional, Social and Other Risks and Discomforts

Yes	Participants might feel psychologically or emotionally stressed, demeaned, embarrassed, worried, anxious, scared or distressed, e.g. description of painful or traumatic events
No	Participants might feel psychological or mental fatigue, e.g intense concentration required
No	Participants might experience cultural or social risk, e.g. loss of privacy or status or damage to reputation
No	Participants might be exposed to economic or legal risk, for instance non-anonymized workplace surveys



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No The risks will be greater than those encountered by the participants in everyday life

3.0 * **Provide details of the risks and discomforts associated with the research, for instance, health cognitive or emotional factors, socio-economic status or physiological or health conditions:**

Questionnaire and Interview Participants:
Participants may feel sad, uncomfortable or distressed upon being asked to describe their experiences of and opinion on end-of-life care environments such as hospitals, hospices, nursing homes or home care settings.

People who are photographed:
They may feel embarrassed, uncomfortable or self-conscious about their appearance and representation in the photographs.

4.0 * **Describe how you will manage and minimize risks and discomforts, as well as mitigate harm:**

Questionnaire and Interview Participants:
Since medical professional training and palliative care jobs already entail working within the environments that participants are being asked to discuss, the anticipated discomfort will be no greater than what is encountered in their everyday lives.

Participants will be clearly advised on the nature of the study, so that they may volunteer only if they feel comfortable. They will be informed that they are able to withdraw from the study at any time, and may refuse to answer any question they don't want to answer, even they agree to participate.

Should any participant report feeling distressed, we will arrange for them to be taken to University Hospital's Department of Psychiatry.

People who appear in photographs:
Signed consent will be sought both before and after taking photographs. Along with indicating consent to be photographed, they can further indicate whether it is acceptable for them to be identifiable in photographs or not. If not, then we will frame pictures in a manner that the individual cannot be identified despite being in the frame. Finally, they will have the chance to see the pictures after we click them and provide signed consent for their use only if they have no objections to the images. Assent forms along with consent of their family member/guardian will be used in cases where the individual to be photographed is unable to give consent.

Should any participant report feeling distressed, we will arrange for them to be taken to University Hospital's Department of Psychiatry, in cases where they are a non-patient. If they are a patient, the palliative care institution will normally have a preferred professional who they work with or would like to call in. We will consult with them on this and follow their advice.

5.0 * **If your study has the potential to identify individuals that are upset, distressed, or disturbed, or individuals warranting medical attention, describe the arrangements made to try to assist these individuals. Explain if no arrangements have been made:**

Every precaution will be taken to ensure that nobody experiences distress. However, if any participant appears or identifies as distressed during the study, then on-site psychological support professionals at the concerned palliative care institution will be contacted upon the reference of the nurse-on-call or doctor-on-call. If there is no psychological support professional available on the premises, then the nurse-on-call or doctor-on-call will be asked to provide a reference to an off-site appropriate professional, who can be contacted for a visit. We will discuss the availability/arrangement of psychological support with the institution beforehand and follow their advice and protocol. Palliative care institutions

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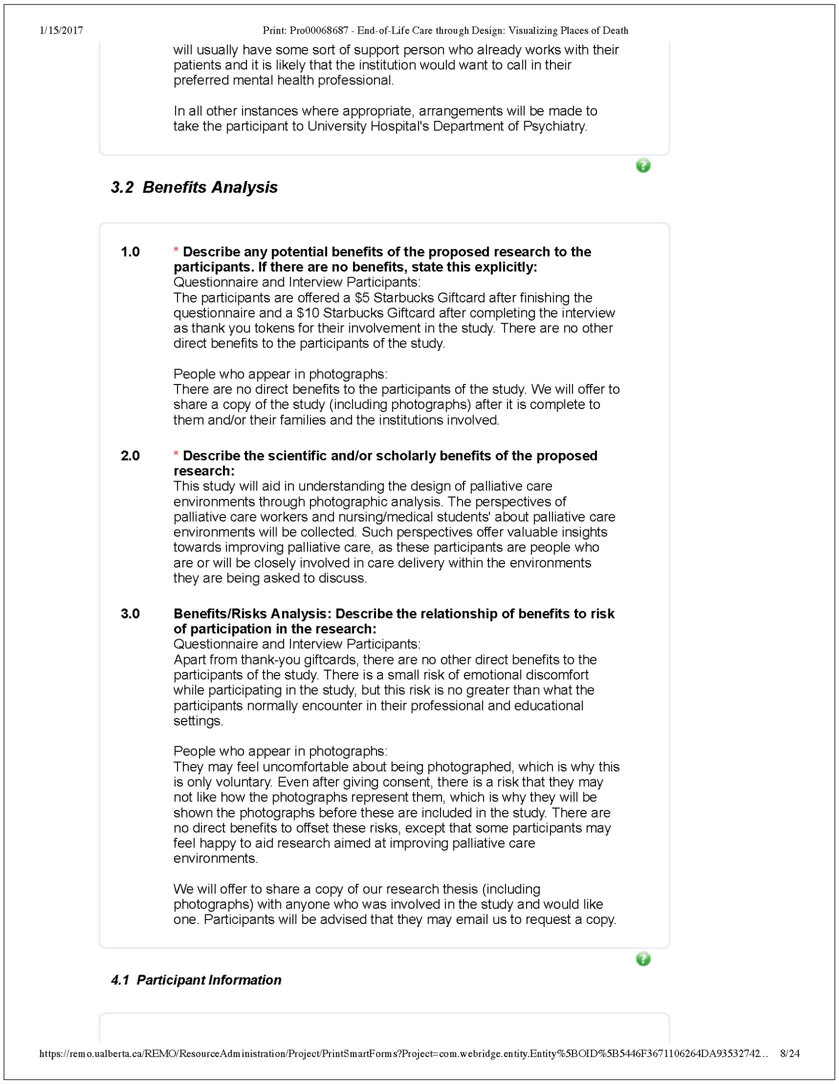

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will usually have some sort of support person who already works with their patients and it is likely that the institution would want to call in their preferred mental health professional.

In all other instances where appropriate, arrangements will be made to take the participant to University Hospital's Department of Psychiatry.

3.2 Benefits Analysis

1.0 * **Describe any potential benefits of the proposed research to the participants. If there are no benefits, state this explicitly:**

Questionnaire and Interview Participants:
The participants are offered a $5 Starbucks Giftcard after finishing the questionnaire and a $10 Starbucks Giftcard after completing the interview as thank you tokens for their involvement in the study. There are no other direct benefits to the participants of the study.

People who appear in photographs:
There are no direct benefits to the participants of the study. We will offer to share a copy of the study (including photographs) after it is complete to them and/or their families and the institutions involved.

2.0 * **Describe the scientific and/or scholarly benefits of the proposed research:**

This study will aid in understanding the design of palliative care environments through photographic analysis. The perspectives of palliative care workers and nursing/medical students' about palliative care environments will be collected. Such perspectives offer valuable insights towards improving palliative care, as these participants are people who are or will be closely involved in care delivery within the environments they are being asked to discuss.

3.0 **Benefits/Risks Analysis: Describe the relationship of benefits to risk of participation in the research:**

Questionnaire and Interview Participants:
Apart from thank-you giftcards, there are no other direct benefits to the participants of the study. There is a small risk of emotional discomfort while participating in the study, but this risk is no greater than what the participants normally encounter in their professional and educational settings.

People who appear in photographs:
They may feel uncomfortable about being photographed, which is why this is only voluntary. Even after giving consent, there is a risk that they may not like how the photographs represent them, which is why they will be shown the photographs before these are included in the study. There are no direct benefits to offset these risks, except that some participants may feel happy to aid research aimed at improving palliative care environments.

We will offer to share a copy of our research thesis (including photographs) with anyone who was involved in the study and would like one. Participants will be advised that they may email us to request a copy.

4.1 Participant Information

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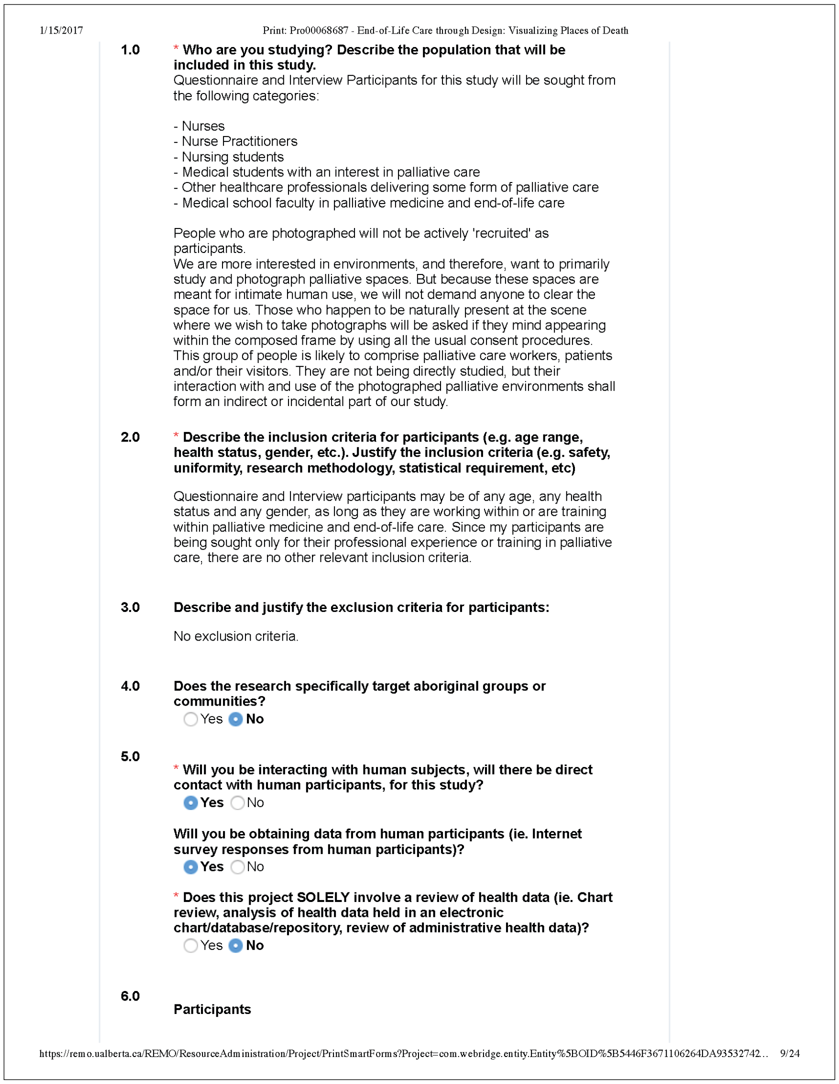

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1.0 *** Who are you studying? Describe the population that will be included in this study.**

Questionnaire and Interview Participants for this study will be sought from the following categories:

- Nurses
- Nurse Practitioners
- Nursing students
- Medical students with an interest in palliative care
- Other healthcare professionals delivering some form of palliative care
- Medical school faculty in palliative medicine and end-of-life care

People who are photographed will not be actively 'recruited' as participants.
We are more interested in environments, and therefore, want to primarily study and photograph palliative spaces. But because these spaces are meant for intimate human use, we will not demand anyone to clear the space for us. Those who happen to be naturally present at the scene where we wish to take photographs will be asked if they mind appearing within the composed frame by using all the usual consent procedures. This group of people is likely to comprise palliative care workers, patients and/or their visitors. They are not being directly studied, but their interaction with and use of the photographed palliative environments shall form an indirect or incidental part of our study.

2.0 *** Describe the inclusion criteria for participants (e.g. age range, health status, gender, etc.). Justify the inclusion criteria (e.g. safety, uniformity, research methodology, statistical requirement, etc)**

Questionnaire and Interview participants may be of any age, any health status and any gender, as long as they are working within or are training within palliative medicine and end-of-life care. Since my participants are being sought only for their professional experience or training in palliative care, there are no other relevant inclusion criteria.

3.0 **Describe and justify the exclusion criteria for participants:**

No exclusion criteria.

4.0 **Does the research specifically target aboriginal groups or communities?**
○ Yes ● **No**

5.0

*** Will you be interacting with human subjects, will there be direct contact with human participants, for this study?**
● **Yes** ○ No

Will you be obtaining data from human participants (ie. Internet survey responses from human participants)?
● **Yes** ○ No

*** Does this project SOLELY involve a review of health data (ie. Chart review, analysis of health data held in an electronic chart/database/repository, review of administrative health data)?**
○ Yes ● **No**

6.0

Participants

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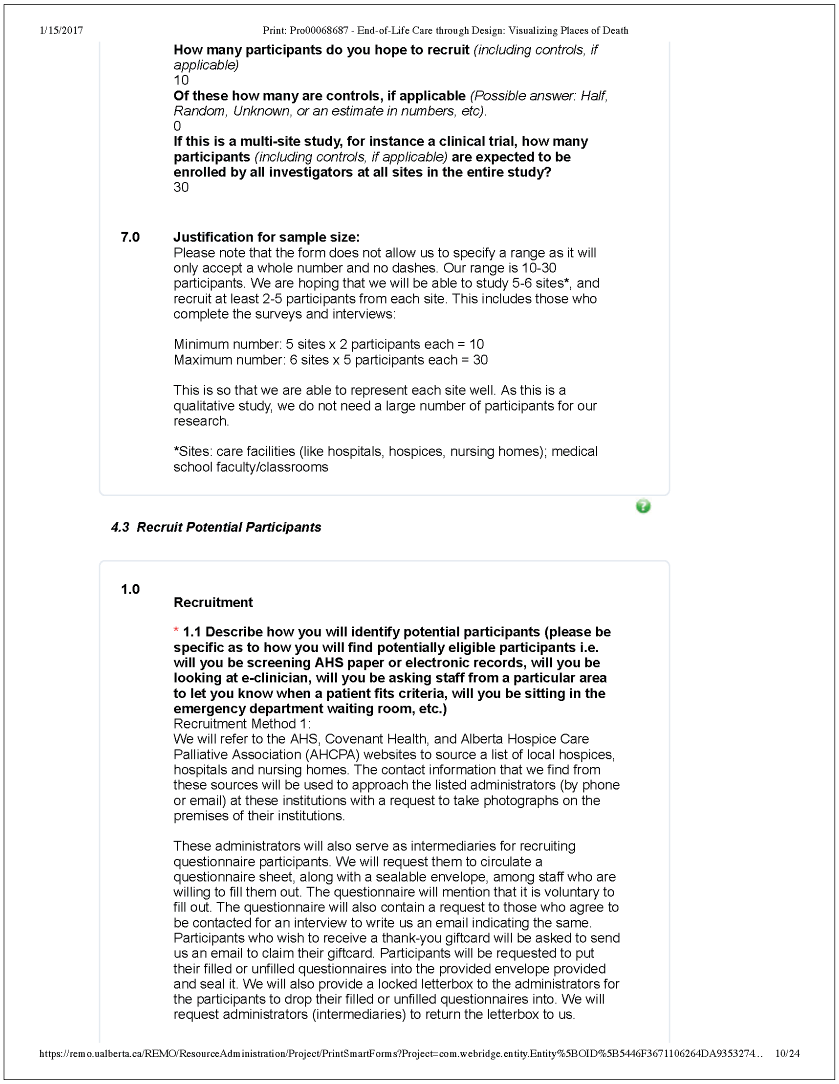

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How many participants do you hope to recruit *(including controls, if applicable)*
10
Of these how many are controls, if applicable *(Possible answer: Half, Random, Unknown, or an estimate in numbers, etc).*
0
If this is a multi-site study, for instance a clinical trial, how many participants *(including controls, if applicable)* **are expected to be enrolled by all investigators at all sites in the entire study?**
30

7.0 Justification for sample size:
Please note that the form does not allow us to specify a range as it will only accept a whole number and no dashes. Our range is 10-30 participants. We are hoping that we will be able to study 5-6 sites*, and recruit at least 2-5 participants from each site. This includes those who complete the surveys and interviews:

Minimum number: 5 sites x 2 participants each = 10
Maximum number: 6 sites x 5 participants each = 30

This is so that we are able to represent each site well. As this is a qualitative study, we do not need a large number of participants for our research.

*Sites: care facilities (like hospitals, hospices, nursing homes); medical school faculty/classrooms

4.3 Recruit Potential Participants

1.0

Recruitment

* **1.1 Describe how you will identify potential participants (please be specific as to how you will find potentially eligible participants i.e. will you be screening AHS paper or electronic records, will you be looking at e-clinician, will you be asking staff from a particular area to let you know when a patient fits criteria, will you be sitting in the emergency department waiting room, etc.)**
Recruitment Method 1:
We will refer to the AHS, Covenant Health, and Alberta Hospice Care Palliative Association (AHCPA) websites to source a list of local hospices, hospitals and nursing homes. The contact information that we find from these sources will be used to approach the listed administrators (by phone or email) at these institutions with a request to take photographs on the premises of their institutions.

These administrators will also serve as intermediaries for recruiting questionnaire participants. We will request them to circulate a questionnaire sheet, along with a sealable envelope, among staff who are willing to fill them out. The questionnaire will mention that it is voluntary to fill out. The questionnaire will also contain a request to those who agree to be contacted for an interview to write us an email indicating the same. Participants who wish to receive a thank-you giftcard will be asked to send us an email to claim their giftcard. Participants will be requested to put their filled or unfilled questionnaires into the provided envelope provided and seal it. We will also provide a locked letterbox to the administrators for the participants to drop their filled or unfilled questionnaires into. We will request administrators (intermediaries) to return the letterbox to us.

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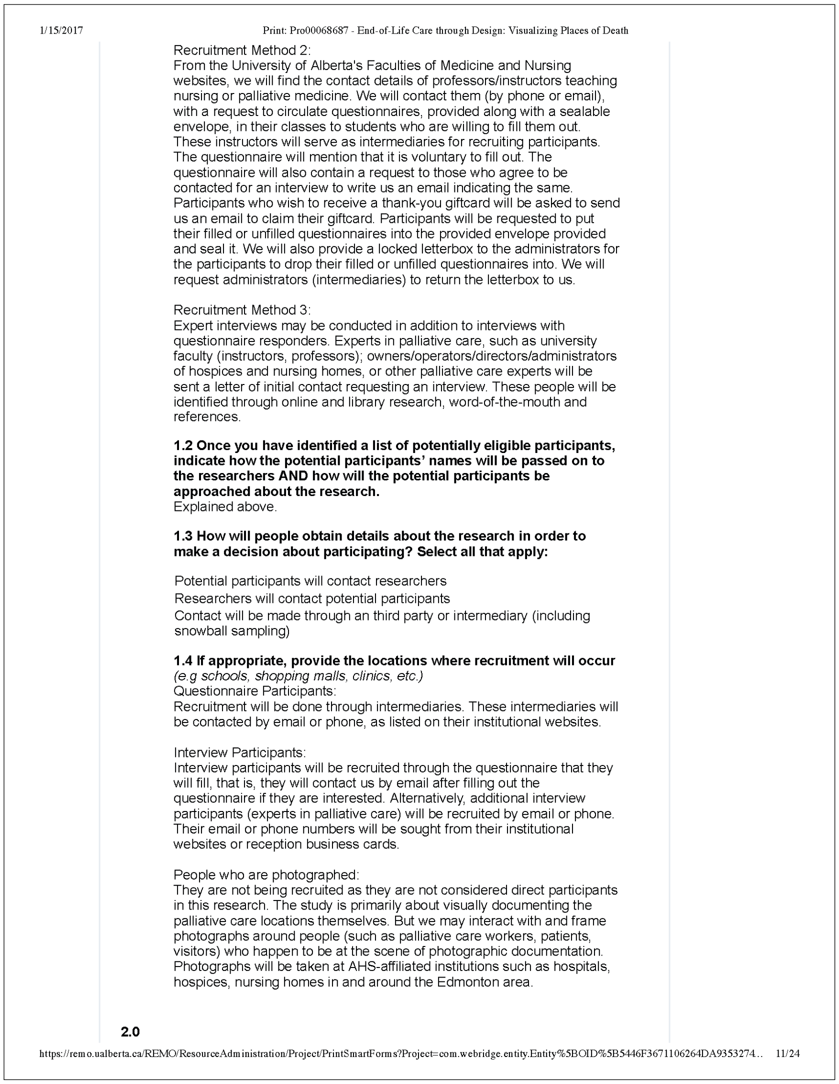

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Recruitment Method 2:
From the University of Alberta's Faculties of Medicine and Nursing websites, we will find the contact details of professors/instructors teaching nursing or palliative medicine. We will contact them (by phone or email), with a request to circulate questionnaires, provided along with a sealable envelope, in their classes to students who are willing to fill them out. These instructors will serve as intermediaries for recruiting participants. The questionnaire will mention that it is voluntary to fill out. The questionnaire will also contain a request to those who agree to be contacted for an interview to write us an email indicating the same. Participants who wish to receive a thank-you giftcard will be asked to send us an email to claim their giftcard. Participants will be requested to put their filled or unfilled questionnaires into the provided envelope provided and seal it. We will also provide a locked letterbox to the administrators for the participants to drop their filled or unfilled questionnaires into. We will request administrators (intermediaries) to return the letterbox to us.

Recruitment Method 3:
Expert interviews may be conducted in addition to interviews with questionnaire responders. Experts in palliative care, such as university faculty (instructors, professors); owners/operators/directors/administrators of hospices and nursing homes, or other palliative care experts will be sent a letter of initial contact requesting an interview. These people will be identified through online and library research, word-of-the-mouth and references.

1.2 Once you have identified a list of potentially eligible participants, indicate how the potential participants' names will be passed on to the researchers AND how will the potential participants be approached about the research.
Explained above.

1.3 How will people obtain details about the research in order to make a decision about participating? Select all that apply:

Potential participants will contact researchers
Researchers will contact potential participants
Contact will be made through an third party or intermediary (including snowball sampling)

1.4 If appropriate, provide the locations where recruitment will occur
(e.g schools, shopping malls, clinics, etc.)
Questionnaire Participants:
Recruitment will be done through intermediaries. These intermediaries will be contacted by email or phone, as listed on their institutional websites.

Interview Participants:
Interview participants will be recruited through the questionnaire that they will fill, that is, they will contact us by email after filling out the questionnaire if they are interested. Alternatively, additional interview participants (experts in palliative care) will be recruited by email or phone. Their email or phone numbers will be sought from their institutional websites or reception business cards.

People who are photographed:
They are not being recruited as they are not considered direct participants in this research. The study is primarily about visually documenting the palliative care locations themselves. But we may interact with and frame photographs around people (such as palliative care workers, patients, visitors) who happen to be at the scene of photographic documentation. Photographs will be taken at AHS-affiliated institutions such as hospitals, hospices, nursing homes in and around the Edmonton area.

2.0

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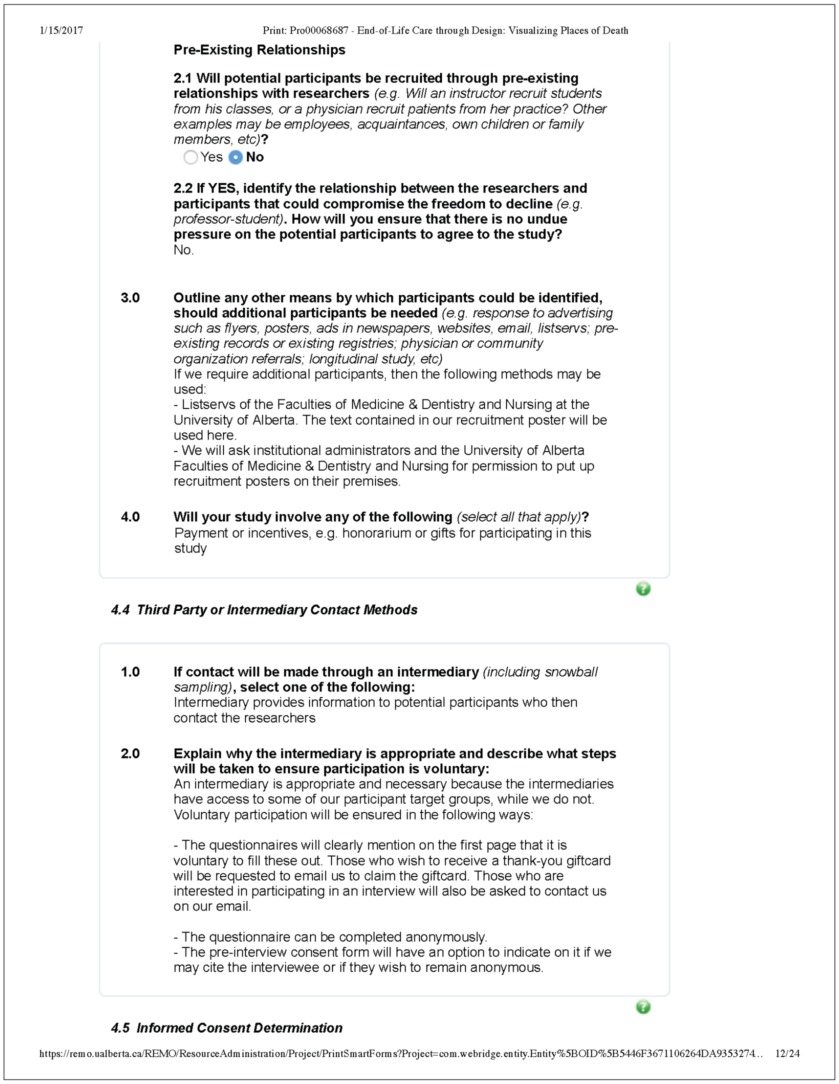

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Pre-Existing Relationships

2.1 Will potential participants be recruited through pre-existing relationships with researchers *(e.g. Will an instructor recruit students from his classes, or a physician recruit patients from her practice? Other examples may be employees, acquaintances, own children or family members, etc)***?**

○ Yes ● **No**

2.2 If YES, identify the relationship between the researchers and participants that could compromise the freedom to decline *(e.g. professor-student)***. How will you ensure that there is no undue pressure on the potential participants to agree to the study?**
No.

3.0 **Outline any other means by which participants could be identified, should additional participants be needed** *(e.g. response to advertising such as flyers, posters, ads in newspapers, websites, email, listservs; pre-existing records or existing registries; physician or community organization referrals; longitudinal study, etc)*
If we require additional participants, then the following methods may be used:
- Listservs of the Faculties of Medicine & Dentistry and Nursing at the University of Alberta. The text contained in our recruitment poster will be used here.
- We will ask institutional administrators and the University of Alberta Faculties of Medicine & Dentistry and Nursing for permission to put up recruitment posters on their premises.

4.0 **Will your study involve any of the following** *(select all that apply)***?**
Payment or incentives, e.g. honorarium or gifts for participating in this study

4.4 Third Party or Intermediary Contact Methods

1.0 **If contact will be made through an intermediary** *(including snowball sampling)***, select one of the following:**
Intermediary provides information to potential participants who then contact the researchers

2.0 **Explain why the intermediary is appropriate and describe what steps will be taken to ensure participation is voluntary:**
An intermediary is appropriate and necessary because the intermediaries have access to some of our participant target groups, while we do not. Voluntary participation will be ensured in the following ways:

- The questionnaires will clearly mention on the first page that it is voluntary to fill these out. Those who wish to receive a thank-you giftcard will be requested to email us to claim the giftcard. Those who are interested in participating in an interview will also be asked to contact us on our email.

- The questionnaire can be completed anonymously.
- The pre-interview consent form will have an option to indicate on it if we may cite the interviewee or if they wish to remain anonymous.

4.5 Informed Consent Determination

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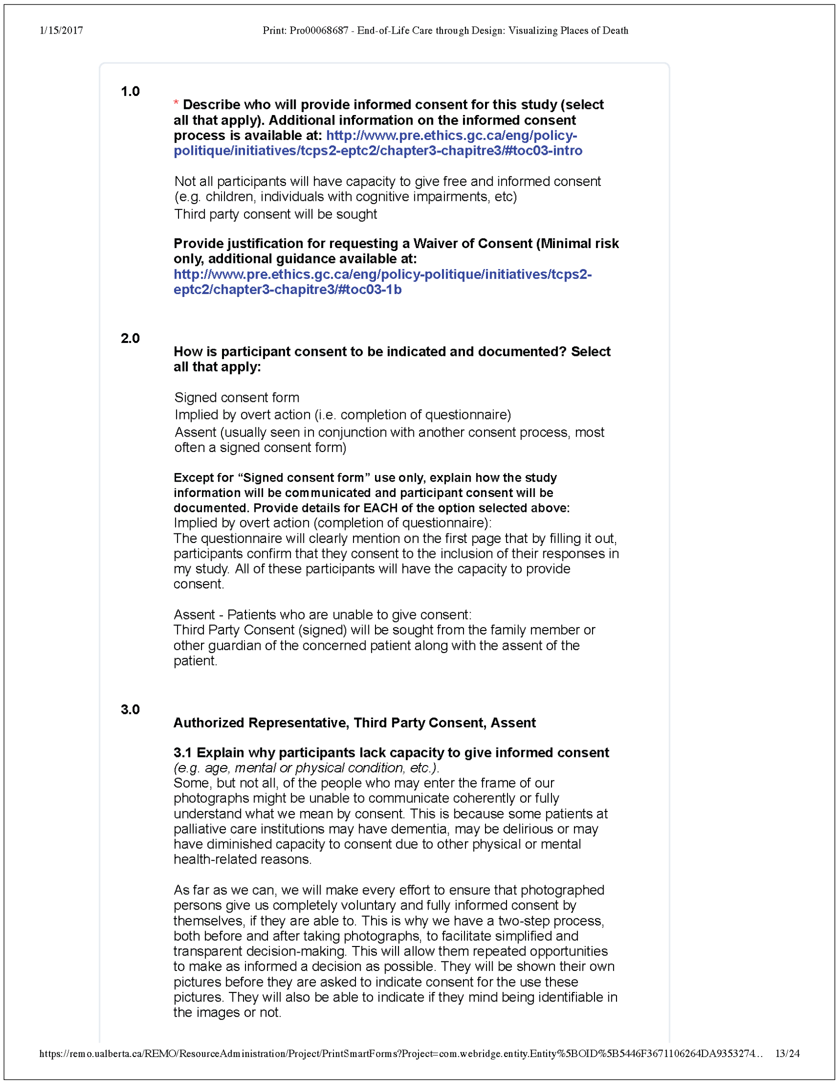

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1.0

* **Describe who will provide informed consent for this study (select all that apply). Additional information on the informed consent process is available at: http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter3-chapitre3/#toc03-intro**

Not all participants will have capacity to give free and informed consent (e.g. children, individuals with cognitive impairments, etc)

Third party consent will be sought

Provide justification for requesting a Waiver of Consent (Minimal risk only, additional guidance available at: http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/chapter3-chapitre3/#toc03-1b

2.0

How is participant consent to be indicated and documented? Select all that apply:

Signed consent form

Implied by overt action (i.e. completion of questionnaire)

Assent (usually seen in conjunction with another consent process, most often a signed consent form)

Except for "Signed consent form" use only, explain how the study information will be communicated and participant consent will be documented. Provide details for EACH of the option selected above:

Implied by overt action (completion of questionnaire):

The questionnaire will clearly mention on the first page that by filling it out, participants confirm that they consent to the inclusion of their responses in my study. All of these participants will have the capacity to provide consent.

Assent - Patients who are unable to give consent:

Third Party Consent (signed) will be sought from the family member or other guardian of the concerned patient along with the assent of the patient.

3.0

Authorized Representative, Third Party Consent, Assent

3.1 Explain why participants lack capacity to give informed consent *(e.g. age, mental or physical condition, etc.).*

Some, but not all, of the people who may enter the frame of our photographs might be unable to communicate coherently or fully understand what we mean by consent. This is because some patients at palliative care institutions may have dementia, may be delirious or may have diminished capacity to consent due to other physical or mental health-related reasons.

As far as we can, we will make every effort to ensure that photographed persons give us completely voluntary and fully informed consent by themselves, if they are able to. This is why we have a two-step process, both before and after taking photographs, to facilitate simplified and transparent decision-making. This will allow them repeated opportunities to make as informed a decision as possible. They will be shown their own pictures before they are asked to indicate consent for the use these pictures. They will also be able to indicate if they mind being identifiable in the images or not.

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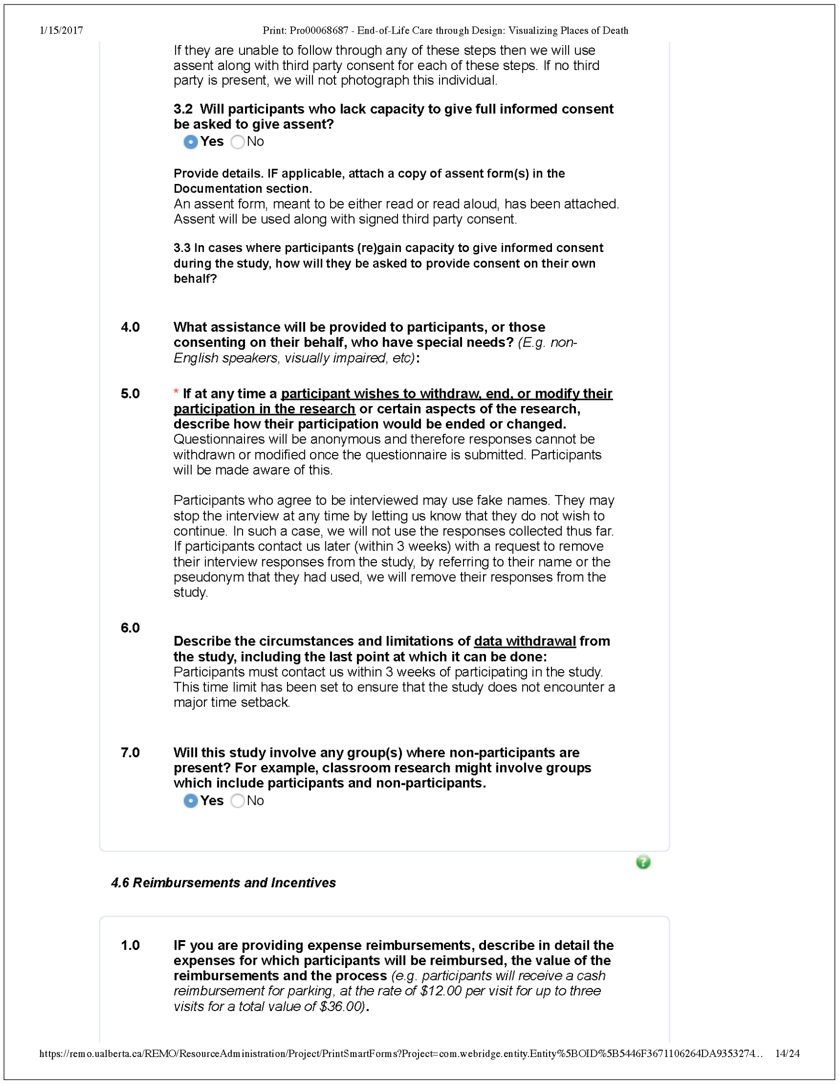

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If they are unable to follow through any of these steps then we will use assent along with third party consent for each of these steps. If no third party is present, we will not photograph this individual.

3.2 Will participants who lack capacity to give full informed consent be asked to give assent?

● **Yes** ○ No

Provide details. IF applicable, attach a copy of assent form(s) in the Documentation section.

An assent form, meant to be either read or read aloud, has been attached. Assent will be used along with signed third party consent.

3.3 In cases where participants (re)gain capacity to give informed consent during the study, how will they be asked to provide consent on their own behalf?

4.0 **What assistance will be provided to participants, or those consenting on their behalf, who have special needs?** *(E.g. non-English speakers, visually impaired, etc)***:**

5.0 * **If at any time a participant wishes to withdraw, end, or modify their participation in the research or certain aspects of the research, describe how their participation would be ended or changed.**

Questionnaires will be anonymous and therefore responses cannot be withdrawn or modified once the questionnaire is submitted. Participants will be made aware of this.

Participants who agree to be interviewed may use fake names. They may stop the interview at any time by letting us know that they do not wish to continue. In such a case, we will not use the responses collected thus far. If participants contact us later (within 3 weeks) with a request to remove their interview responses from the study, by referring to their name or the pseudonym that they had used, we will remove their responses from the study.

6.0

Describe the circumstances and limitations of data withdrawal from the study, including the last point at which it can be done:

Participants must contact us within 3 weeks of participating in the study. This time limit has been set to ensure that the study does not encounter a major time setback.

7.0 **Will this study involve any group(s) where non-participants are present? For example, classroom research might involve groups which include participants and non-participants.**

● **Yes** ○ No

4.6 Reimbursements and Incentives

1.0 **IF you are providing expense reimbursements, describe in detail the expenses for which participants will be reimbursed, the value of the reimbursements and the process** *(e.g. participants will receive a cash reimbursement for parking, at the rate of $12.00 per visit for up to three visits for a total value of $36.00)***.**

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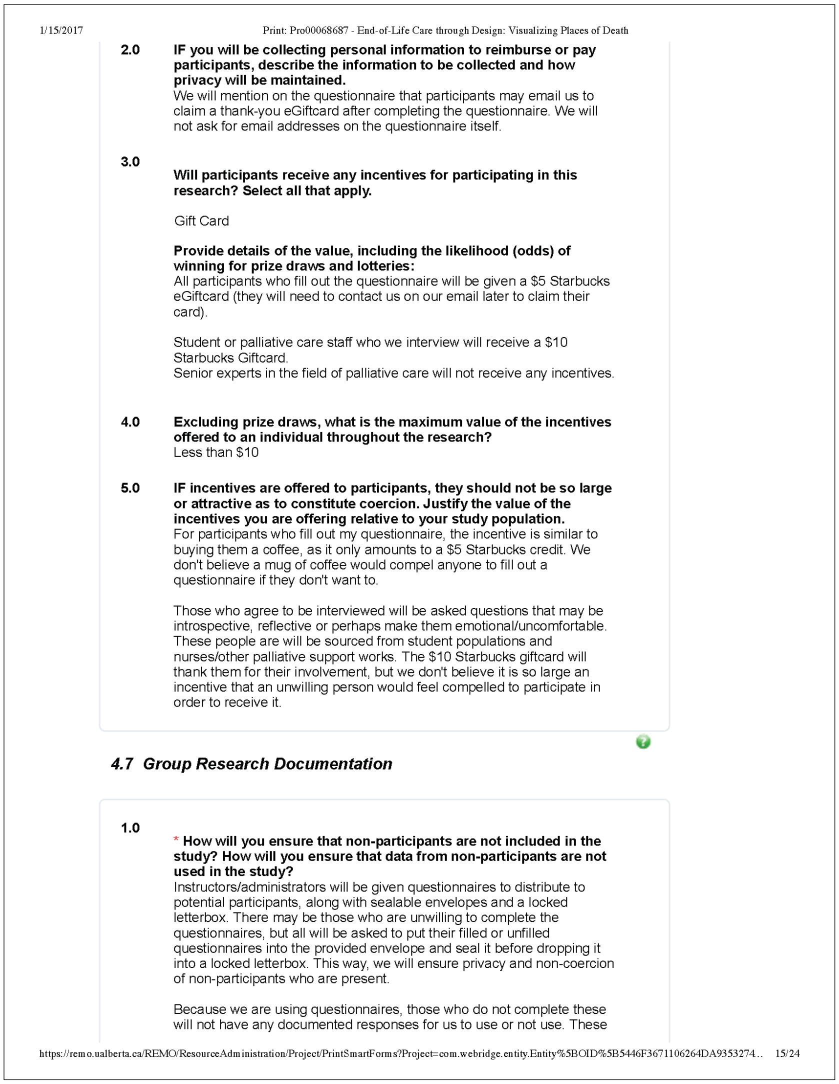

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2.0 **IF you will be collecting personal information to reimburse or pay participants, describe the information to be collected and how privacy will be maintained.**
We will mention on the questionnaire that participants may email us to claim a thank-you eGiftcard after completing the questionnaire. We will not ask for email addresses on the questionnaire itself.

3.0 **Will participants receive any incentives for participating in this research? Select all that apply.**

Gift Card

Provide details of the value, including the likelihood (odds) of winning for prize draws and lotteries:
All participants who fill out the questionnaire will be given a $5 Starbucks eGiftcard (they will need to contact us on our email later to claim their card).

Student or palliative care staff who we interview will receive a $10 Starbucks Giftcard.
Senior experts in the field of palliative care will not receive any incentives.

4.0 **Excluding prize draws, what is the maximum value of the incentives offered to an individual throughout the research?**
Less than $10

5.0 **IF incentives are offered to participants, they should not be so large or attractive as to constitute coercion. Justify the value of the incentives you are offering relative to your study population.**
For participants who fill out my questionnaire, the incentive is similar to buying them a coffee, as it only amounts to a $5 Starbucks credit. We don't believe a mug of coffee would compel anyone to fill out a questionnaire if they don't want to.

Those who agree to be interviewed will be asked questions that may be introspective, reflective or perhaps make them emotional/uncomfortable. These people are will be sourced from student populations and nurses/other palliative support works. The $10 Starbucks giftcard will thank them for their involvement, but we don't believe it is so large an incentive that an unwilling person would feel compelled to participate in order to receive it.

4.7 Group Research Documentation

1.0 * **How will you ensure that non-participants are not included in the study? How will you ensure that data from non-participants are not used in the study?**
Instructors/administrators will be given questionnaires to distribute to potential participants, along with sealable envelopes and a locked letterbox. There may be those who are unwilling to complete the questionnaires, but all will be asked to put their filled or unfilled questionnaires into the provided envelope and seal it before dropping it into a locked letterbox. This way, we will ensure privacy and non-coercion of non-participants who are present.

Because we are using questionnaires, those who do not complete these will not have any documented responses for us to use or not use. These

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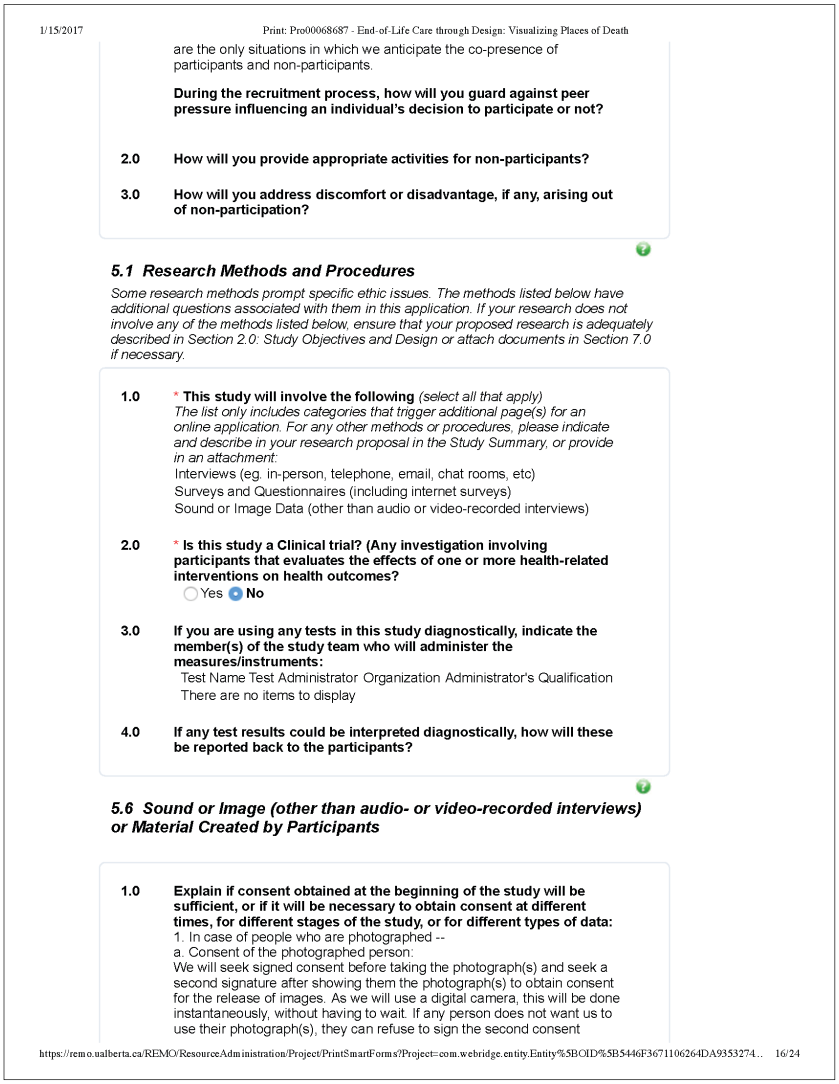

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are the only situations in which we anticipate the co-presence of participants and non-participants.

During the recruitment process, how will you guard against peer pressure influencing an individual's decision to participate or not?

2.0 **How will you provide appropriate activities for non-participants?**

3.0 **How will you address discomfort or disadvantage, if any, arising out of non-participation?**

5.1 Research Methods and Procedures

Some research methods prompt specific ethic issues. The methods listed below have additional questions associated with them in this application. If your research does not involve any of the methods listed below, ensure that your proposed research is adequately described in Section 2.0: Study Objectives and Design or attach documents in Section 7.0 if necessary.

1.0 * **This study will involve the following** *(select all that apply)*
The list only includes categories that trigger additional page(s) for an online application. For any other methods or procedures, please indicate and describe in your research proposal in the Study Summary, or provide in an attachment:
Interviews (eg. in-person, telephone, email, chat rooms, etc)
Surveys and Questionnaires (including internet surveys)
Sound or Image Data (other than audio or video-recorded interviews)

2.0 * **Is this study a Clinical trial? (Any investigation involving participants that evaluates the effects of one or more health-related interventions on health outcomes?**
○ Yes ● **No**

3.0 **If you are using any tests in this study diagnostically, indicate the member(s) of the study team who will administer the measures/instruments:**
Test Name Test Administrator Organization Administrator's Qualification
There are no items to display

4.0 **If any test results could be interpreted diagnostically, how will these be reported back to the participants?**

5.6 Sound or Image (other than audio- or video-recorded interviews) or Material Created by Participants

1.0 **Explain if consent obtained at the beginning of the study will be sufficient, or if it will be necessary to obtain consent at different times, for different stages of the study, or for different types of data:**
1. In case of people who are photographed --
a. Consent of the photographed person:
We will seek signed consent before taking the photograph(s) and seek a second signature after showing them the photograph(s) to obtain consent for the release of images. As we will use a digital camera, this will be done instantaneously, without having to wait. If any person does not want us to use their photograph(s), they can refuse to sign the second consent

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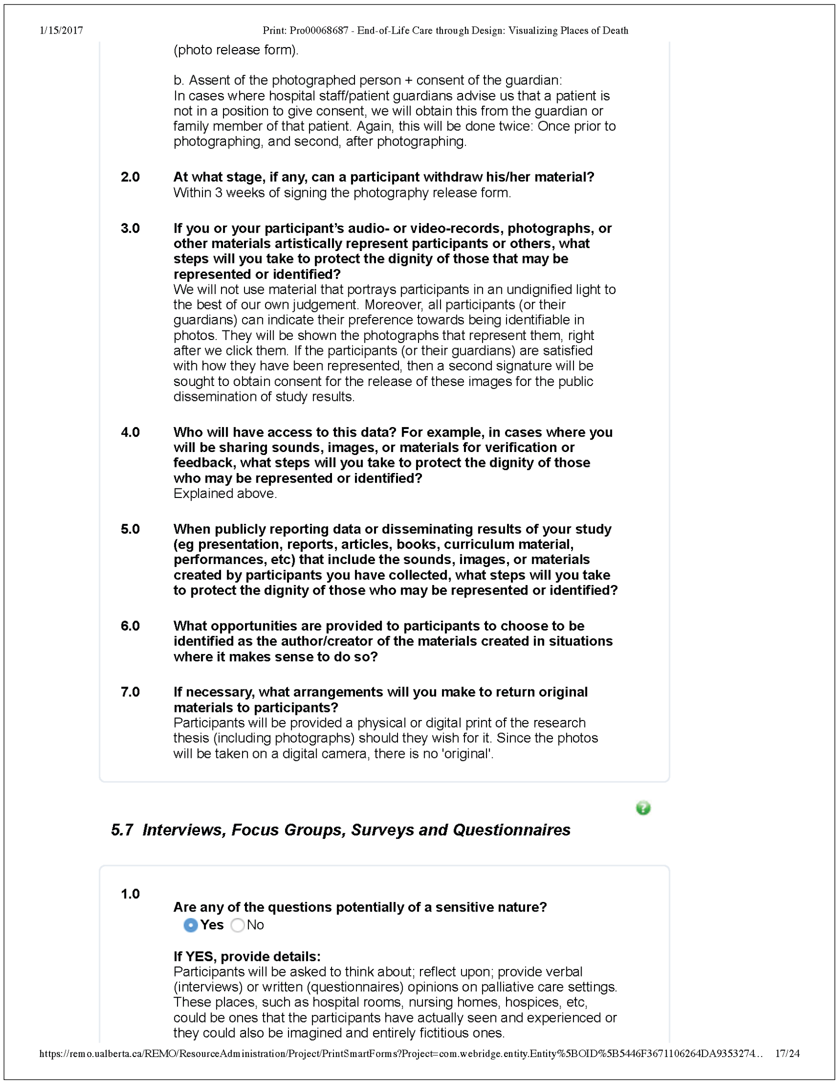

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(photo release form).

b. Assent of the photographed person + consent of the guardian:
In cases where hospital staff/patient guardians advise us that a patient is not in a position to give consent, we will obtain this from the guardian or family member of that patient. Again, this will be done twice: Once prior to photographing, and second, after photographing.

2.0 **At what stage, if any, can a participant withdraw his/her material?**
Within 3 weeks of signing the photography release form.

3.0 **If you or your participant's audio- or video-records, photographs, or other materials artistically represent participants or others, what steps will you take to protect the dignity of those that may be represented or identified?**
We will not use material that portrays participants in an undignified light to the best of our own judgement. Moreover, all participants (or their guardians) can indicate their preference towards being identifiable in photos. They will be shown the photographs that represent them, right after we click them. If the participants (or their guardians) are satisfied with how they have been represented, then a second signature will be sought to obtain consent for the release of these images for the public dissemination of study results.

4.0 **Who will have access to this data? For example, in cases where you will be sharing sounds, images, or materials for verification or feedback, what steps will you take to protect the dignity of those who may be represented or identified?**
Explained above.

5.0 **When publicly reporting data or disseminating results of your study (eg presentation, reports, articles, books, curriculum material, performances, etc) that include the sounds, images, or materials created by participants you have collected, what steps will you take to protect the dignity of those who may be represented or identified?**

6.0 **What opportunities are provided to participants to choose to be identified as the author/creator of the materials created in situations where it makes sense to do so?**

7.0 **If necessary, what arrangements will you make to return original materials to participants?**
Participants will be provided a physical or digital print of the research thesis (including photographs) should they wish for it. Since the photos will be taken on a digital camera, there is no 'original'.

5.7 Interviews, Focus Groups, Surveys and Questionnaires

1.0 **Are any of the questions potentially of a sensitive nature?**
● **Yes** ○ No

If YES, provide details:
Participants will be asked to think about; reflect upon; provide verbal (interviews) or written (questionnaires) opinions on palliative care settings. These places, such as hospital rooms, nursing homes, hospices, etc, could be ones that the participants have actually seen and experienced or they could also be imagined and entirely fictitious ones.

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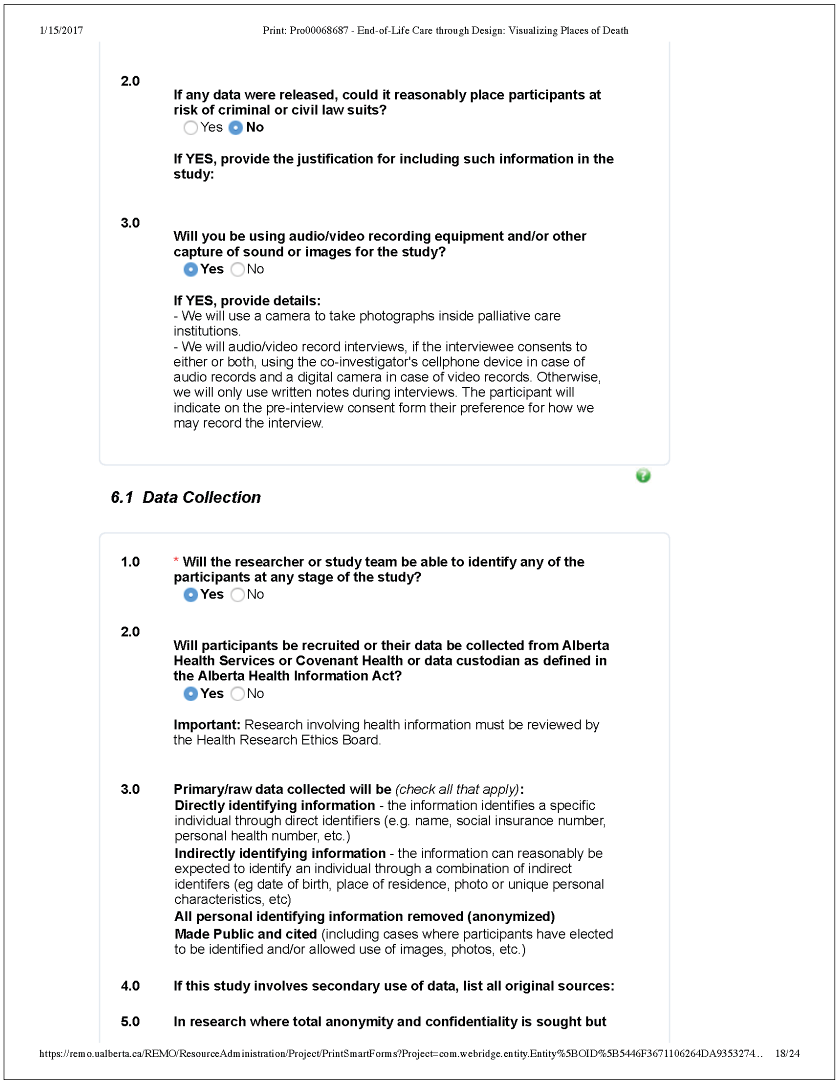

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2.0 **If any data were released, could it reasonably place participants at risk of criminal or civil law suits?**

○ Yes ● **No**

If YES, provide the justification for including such information in the study:

3.0 **Will you be using audio/video recording equipment and/or other capture of sound or images for the study?**

● **Yes** ○ No

If YES, provide details:

- We will use a camera to take photographs inside palliative care institutions.
- We will audio/video record interviews, if the interviewee consents to either or both, using the co-investigator's cellphone device in case of audio records and a digital camera in case of video records. Otherwise, we will only use written notes during interviews. The participant will indicate on the pre-interview consent form their preference for how we may record the interview.

6.1 Data Collection

1.0 * **Will the researcher or study team be able to identify any of the participants at any stage of the study?**

● **Yes** ○ No

2.0 **Will participants be recruited or their data be collected from Alberta Health Services or Covenant Health or data custodian as defined in the Alberta Health Information Act?**

● **Yes** ○ No

Important: Research involving health information must be reviewed by the Health Research Ethics Board.

3.0 **Primary/raw data collected will be** *(check all that apply)***:**

Directly identifying information - the information identifies a specific individual through direct identifiers (e.g. name, social insurance number, personal health number, etc.)

Indirectly identifying information - the information can reasonably be expected to identify an individual through a combination of indirect identifers (eg date of birth, place of residence, photo or unique personal characteristics, etc)

All personal identifying information removed (anonymized)

Made Public and cited (including cases where participants have elected to be identified and/or allowed use of images, photos, etc.)

4.0 **If this study involves secondary use of data, list all original sources:**

5.0 **In research where total anonymity and confidentiality is sought but**

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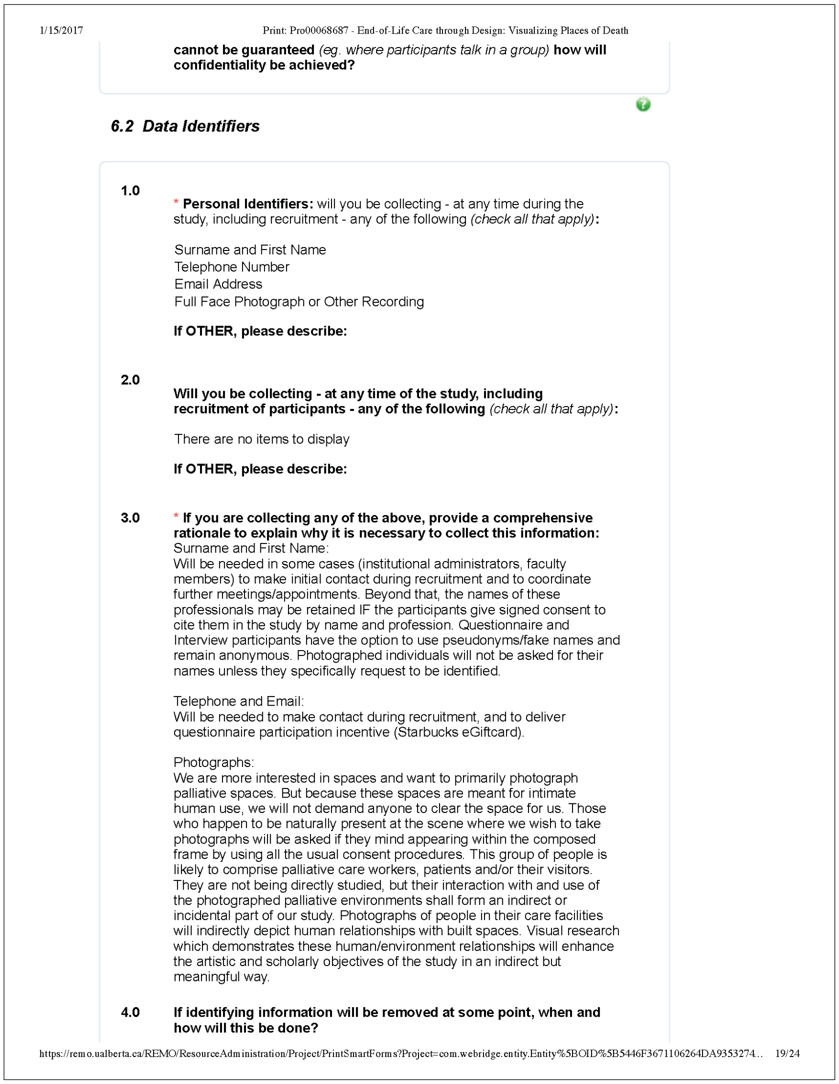

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cannot be guaranteed *(eg. where participants talk in a group)* **how will confidentiality be achieved?**

6.2 Data Identifiers

1.0

* **Personal Identifiers:** will you be collecting - at any time during the study, including recruitment - any of the following *(check all that apply)*:

Surname and First Name
Telephone Number
Email Address
Full Face Photograph or Other Recording

If OTHER, please describe:

2.0

Will you be collecting - at any time of the study, including recruitment of participants - any of the following *(check all that apply)*:

There are no items to display

If OTHER, please describe:

3.0

* **If you are collecting any of the above, provide a comprehensive rationale to explain why it is necessary to collect this information:**
Surname and First Name:
Will be needed in some cases (institutional administrators, faculty members) to make initial contact during recruitment and to coordinate further meetings/appointments. Beyond that, the names of these professionals may be retained IF the participants give signed consent to cite them in the study by name and profession. Questionnaire and Interview participants have the option to use pseudonyms/fake names and remain anonymous. Photographed individuals will not be asked for their names unless they specifically request to be identified.

Telephone and Email:
Will be needed to make contact during recruitment, and to deliver questionnaire participation incentive (Starbucks eGiftcard).

Photographs:
We are more interested in spaces and want to primarily photograph palliative spaces. But because these spaces are meant for intimate human use, we will not demand anyone to clear the space for us. Those who happen to be naturally present at the scene where we wish to take photographs will be asked if they mind appearing within the composed frame by using all the usual consent procedures. This group of people is likely to comprise palliative care workers, patients and/or their visitors. They are not being directly studied, but their interaction with and use of the photographed palliative environments shall form an indirect or incidental part of our study. Photographs of people in their care facilities will indirectly depict human relationships with built spaces. Visual research which demonstrates these human/environment relationships will enhance the artistic and scholarly objectives of the study in an indirect but meaningful way.

4.0

If identifying information will be removed at some point, when and how will this be done?

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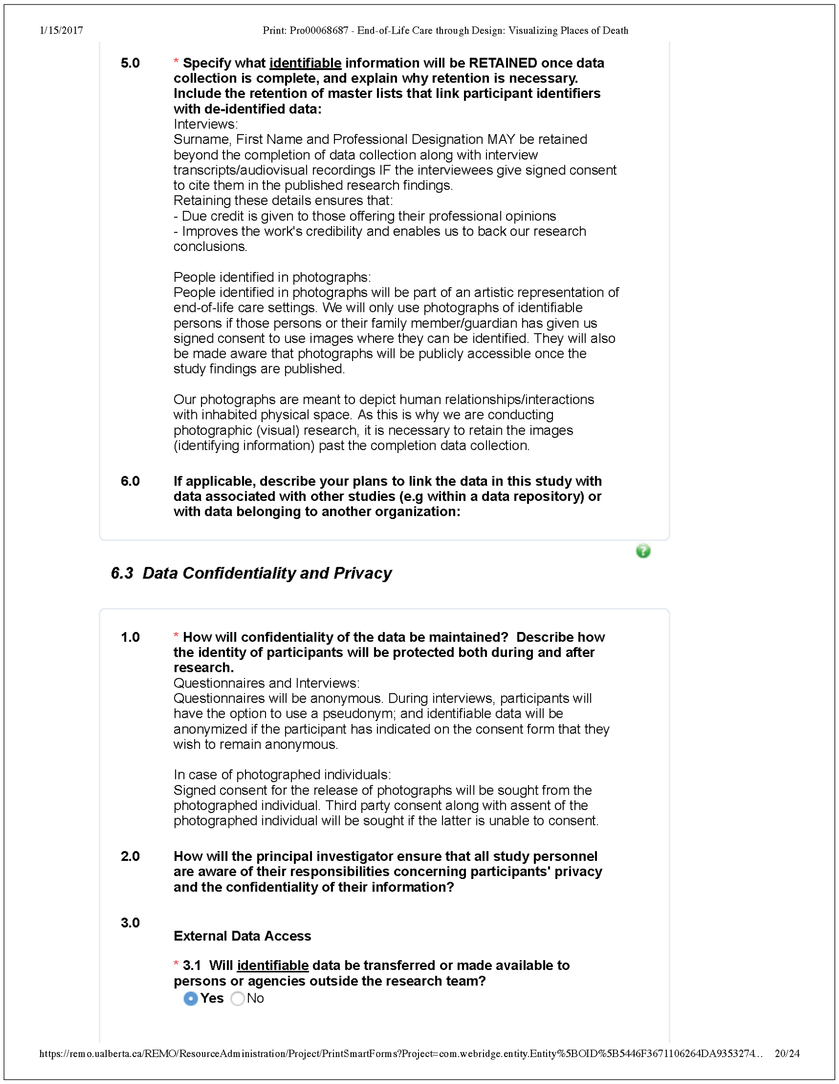

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5.0 * **Specify what identifiable information will be RETAINED once data collection is complete, and explain why retention is necessary. Include the retention of master lists that link participant identifiers with de-identified data:**

Interviews:
Surname, First Name and Professional Designation MAY be retained beyond the completion of data collection along with interview transcripts/audiovisual recordings IF the interviewees give signed consent to cite them in the published research findings.
Retaining these details ensures that:
- Due credit is given to those offering their professional opinions
- Improves the work's credibility and enables us to back our research conclusions.

People identified in photographs:
People identified in photographs will be part of an artistic representation of end-of-life care settings. We will only use photographs of identifiable persons if those persons or their family member/guardian has given us signed consent to use images where they can be identified. They will also be made aware that photographs will be publicly accessible once the study findings are published.

Our photographs are meant to depict human relationships/interactions with inhabited physical space. As this is why we are conducting photographic (visual) research, it is necessary to retain the images (identifying information) past the completion data collection.

6.0 **If applicable, describe your plans to link the data in this study with data associated with other studies (e.g within a data repository) or with data belonging to another organization:**

6.3 Data Confidentiality and Privacy

1.0 * **How will confidentiality of the data be maintained? Describe how the identity of participants will be protected both during and after research.**

Questionnaires and Interviews:
Questionnaires will be anonymous. During interviews, participants will have the option to use a pseudonym; and identifiable data will be anonymized if the participant has indicated on the consent form that they wish to remain anonymous.

In case of photographed individuals:
Signed consent for the release of photographs will be sought from the photographed individual. Third party consent along with assent of the photographed individual will be sought if the latter is unable to consent.

2.0 **How will the principal investigator ensure that all study personnel are aware of their responsibilities concerning participants' privacy and the confidentiality of their information?**

3.0

External Data Access

* **3.1 Will identifiable data be transferred or made available to persons or agencies outside the research team?**
● **Yes** ○ No

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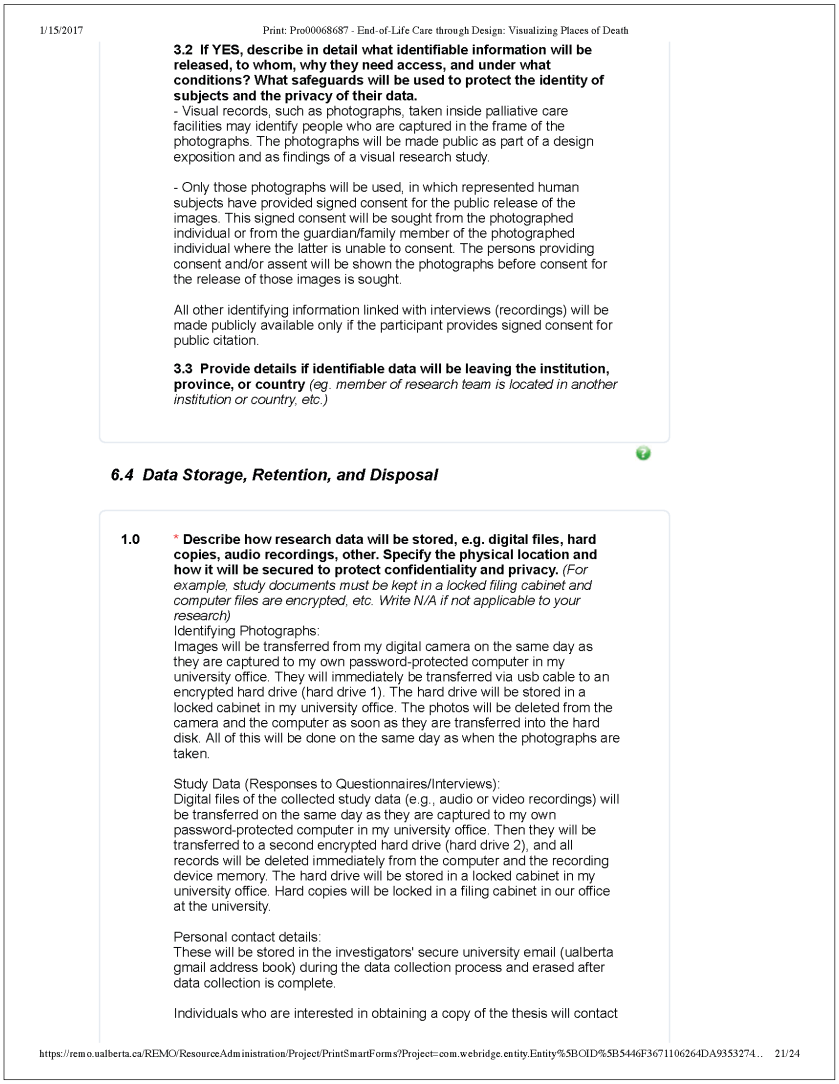


3.2 If YES, describe in detail what identifiable information will be released, to whom, why they need access, and under what conditions? What safeguards will be used to protect the identity of subjects and the privacy of their data.
- Visual records, such as photographs, taken inside palliative care facilities may identify people who are captured in the frame of the photographs. The photographs will be made public as part of a design exposition and as findings of a visual research study.

- Only those photographs will be used, in which represented human subjects have provided signed consent for the public release of the images. This signed consent will be sought from the photographed individual or from the guardian/family member of the photographed individual where the latter is unable to consent. The persons providing consent and/or assent will be shown the photographs before consent for the release of those images is sought.

All other identifying information linked with interviews (recordings) will be made publicly available only if the participant provides signed consent for public citation.

3.3 Provide details if identifiable data will be leaving the institution, province, or country *(eg. member of research team is located in another institution or country, etc.)*

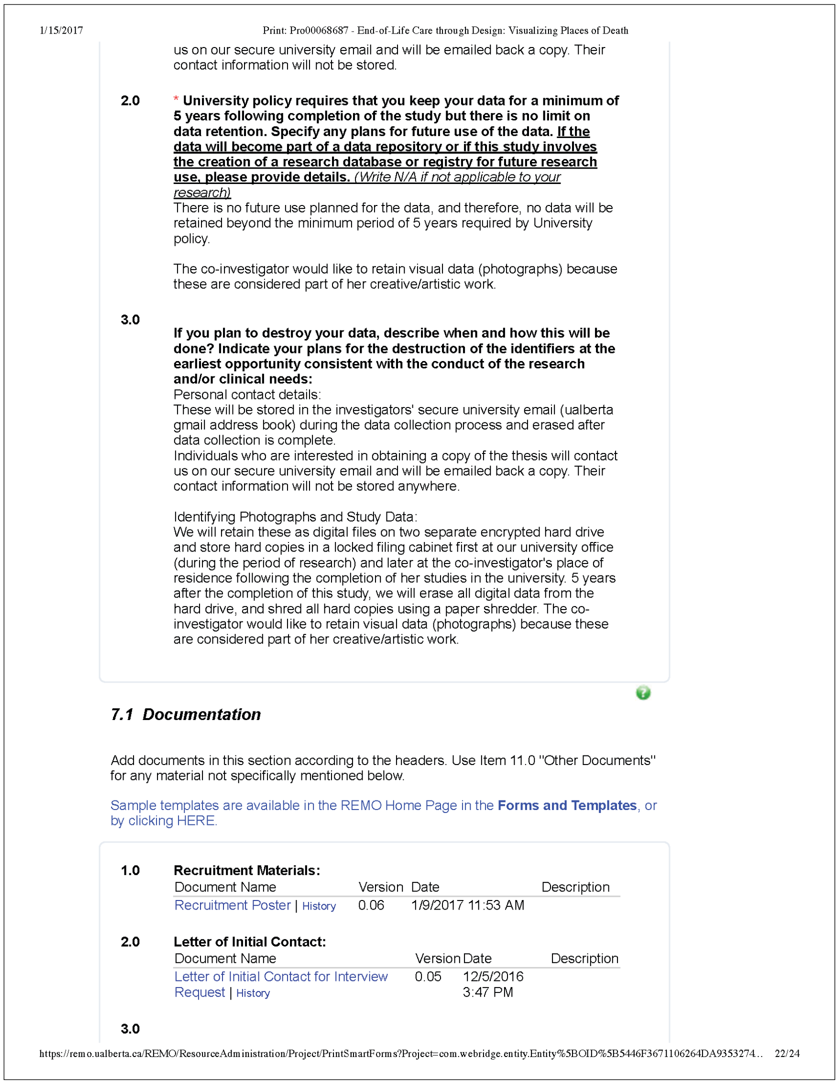
6.4 Data Storage, Retention, and Disposal

1.0 * **Describe how research data will be stored, e.g. digital files, hard copies, audio recordings, other. Specify the physical location and how it will be secured to protect confidentiality and privacy.** *(For example, study documents must be kept in a locked filing cabinet and computer files are encrypted, etc. Write N/A if not applicable to your research)*
Identifying Photographs:
Images will be transferred from my digital camera on the same day as they are captured to my own password-protected computer in my university office. They will immediately be transferred via usb cable to an encrypted hard drive (hard drive 1). The hard drive will be stored in a locked cabinet in my university office. The photos will be deleted from the camera and the computer as soon as they are transferred into the hard disk. All of this will be done on the same day as when the photographs are taken.

Study Data (Responses to Questionnaires/Interviews):
Digital files of the collected study data (e.g., audio or video recordings) will be transferred on the same day as they are captured to my own password-protected computer in my university office. Then they will be transferred to a second encrypted hard drive (hard drive 2), and all records will be deleted immediately from the computer and the recording device memory. The hard drive will be stored in a locked cabinet in my university office. Hard copies will be locked in a filing cabinet in our office at the university.

Personal contact details:
These will be stored in the investigators' secure university email (ualberta gmail address book) during the data collection process and erased after data collection is complete.

Individuals who are interested in obtaining a copy of the thesis will contact



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us on our secure university email and will be emailed back a copy. Their contact information will not be stored.

2.0 * **University policy requires that you keep your data for a minimum of 5 years following completion of the study but there is no limit on data retention. Specify any plans for future use of the data. If the data will become part of a data repository or if this study involves the creation of a research database or registry for future research use, please provide details.** *(Write N/A if not applicable to your research)*

There is no future use planned for the data, and therefore, no data will be retained beyond the minimum period of 5 years required by University policy.

The co-investigator would like to retain visual data (photographs) because these are considered part of her creative/artistic work.

3.0 **If you plan to destroy your data, describe when and how this will be done? Indicate your plans for the destruction of the identifiers at the earliest opportunity consistent with the conduct of the research and/or clinical needs:**

Personal contact details:
These will be stored in the investigators' secure university email (ualberta gmail address book) during the data collection process and erased after data collection is complete.
Individuals who are interested in obtaining a copy of the thesis will contact us on our secure university email and will be emailed back a copy. Their contact information will not be stored anywhere.

Identifying Photographs and Study Data:
We will retain these as digital files on two separate encrypted hard drive and store hard copies in a locked filing cabinet first at our university office (during the period of research) and later at the co-investigator's place of residence following the completion of her studies in the university. 5 years after the completion of this study, we will erase all digital data from the hard drive, and shred all hard copies using a paper shredder. The co-investigator would like to retain visual data (photographs) because these are considered part of her creative/artistic work.

7.1 Documentation

Add documents in this section according to the headers. Use Item 11.0 "Other Documents" for any material not specifically mentioned below.

Sample templates are available in the REMO Home Page in the **Forms and Templates**, or by clicking HERE.

1.0 **Recruitment Materials:**

Document Name	Version	Date	Description
Recruitment Poster | History	0.06	1/9/2017 11:53 AM	

2.0 **Letter of Initial Contact:**

Document Name	Version	Date	Description
Letter of Initial Contact for Interview Request | History	0.05	12/5/2016 3:47 PM	

3.0

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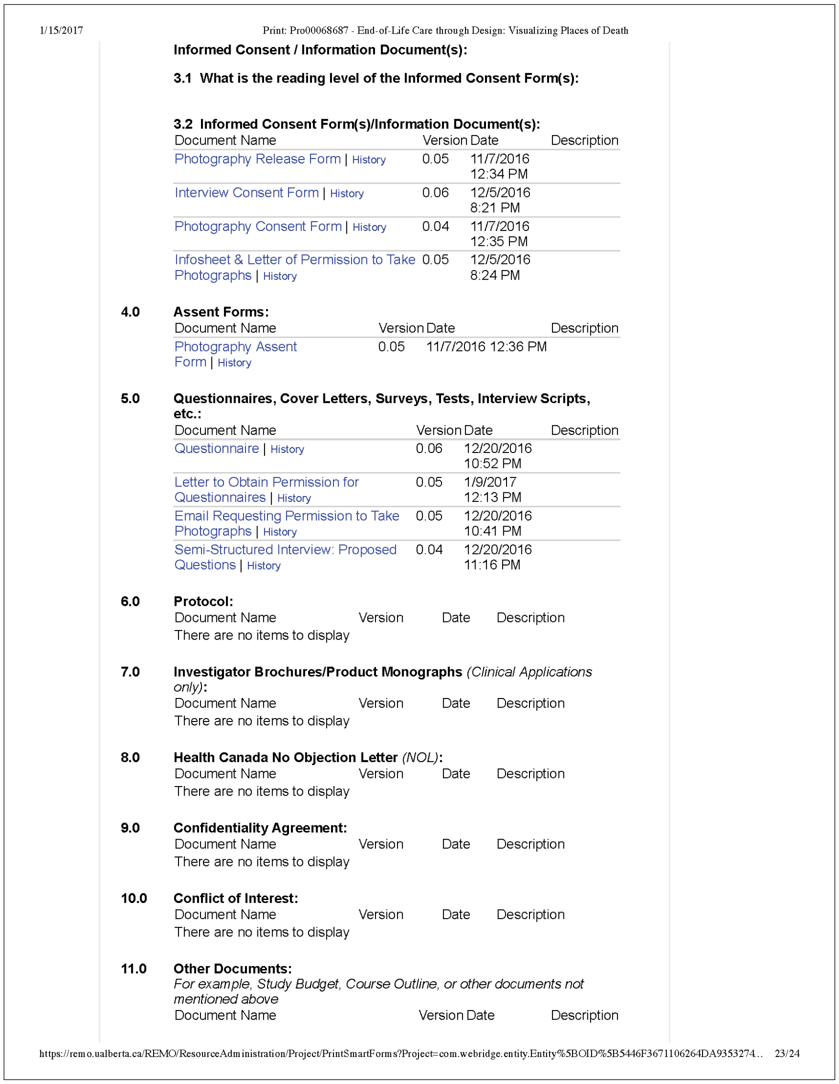

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Informed Consent / Information Document(s):

3.1 What is the reading level of the Informed Consent Form(s):

3.2 Informed Consent Form(s)/Information Document(s):

Document Name	Version	Date	Description
Photography Release Form | History	0.05	11/7/2016 12:34 PM	
Interview Consent Form | History	0.06	12/5/2016 8:21 PM	
Photography Consent Form | History	0.04	11/7/2016 12:35 PM	
Infosheet & Letter of Permission to Take Photographs | History	0.05	12/5/2016 8:24 PM	

4.0 Assent Forms:

Document Name	Version	Date	Description
Photography Assent Form | History	0.05	11/7/2016 12:36 PM	

5.0 Questionnaires, Cover Letters, Surveys, Tests, Interview Scripts, etc.:

Document Name	Version	Date	Description
Questionnaire | History	0.06	12/20/2016 10:52 PM	
Letter to Obtain Permission for Questionnaires | History	0.05	1/9/2017 12:13 PM	
Email Requesting Permission to Take Photographs | History	0.05	12/20/2016 10:41 PM	
Semi-Structured Interview: Proposed Questions | History	0.04	12/20/2016 11:16 PM	

6.0 Protocol:

Document Name Version Date Description

There are no items to display

7.0 Investigator Brochures/Product Monographs *(Clinical Applications only)***:**

Document Name Version Date Description

There are no items to display

8.0 Health Canada No Objection Letter *(NOL)***:**

Document Name Version Date Description

There are no items to display

9.0 Confidentiality Agreement:

Document Name Version Date Description

There are no items to display

10.0 Conflict of Interest:

Document Name Version Date Description

There are no items to display

11.0 Other Documents:

For example, Study Budget, Course Outline, or other documents not mentioned above

Document Name Version Date Description

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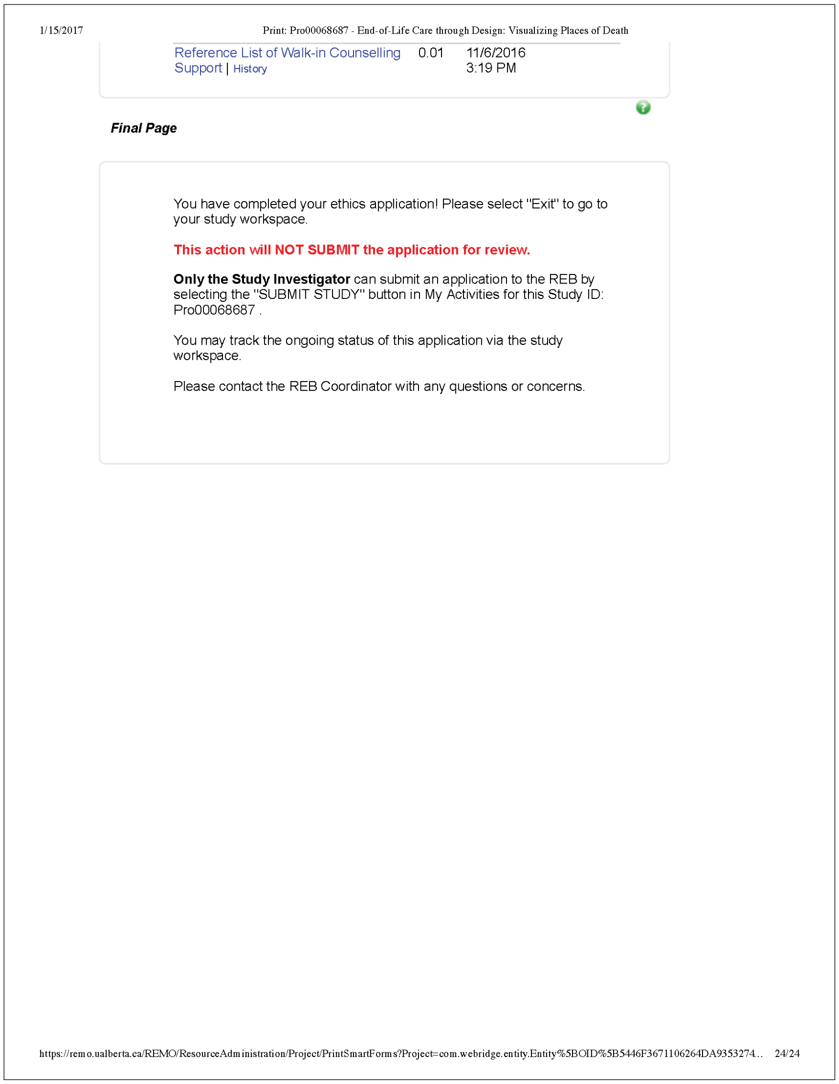

Reference List of Walk-in Counselling Support | History 0.01 11/6/2016 3:19 PM

Final Page

You have completed your ethics application! Please select "Exit" to go to your study workspace.

This action will NOT SUBMIT the application for review.

Only the Study Investigator can submit an application to the REB by selecting the "SUBMIT STUDY" button in My Activities for this Study ID: Pro00068687 .

You may track the ongoing status of this application via the study workspace.

Please contact the REB Coordinator with any questions or concerns.

8.2 ETHICS APPLICATION SUPPORT DOCUMENTS

Study Information Sheet and Photography Permission Form

UNIVERSITY OF ALBERTA

FACULTY OF ARTS
DEPARTMENT OF ART & DESIGN

Fine Arts Building
Edmonton, Alberta, Canada T6G 2C9
Tel: 780.492.3261
Fax: 780.492.7870
aidan.rowe@ualberta.ca
www.ualberta.ca/art-design

INFO-SHEET & LETTER OF PERMISSION TO TAKE PHOTOGRAPHS

Thank you for your interest in this study. Please read the following information carefully. You are strongly advised to retain this information sheet with yourself for future reference.

BACKGROUND
My research aims to study the environments designed for patients receiving palliative care in and around the Edmonton area. The results of this study will be used in support of my master's degree thesis.

I am requesting you for permission to take photographs of inner and outer spaces belonging to [name of the institution] **to help me obtain a visual record of the spaces I am studying**.

How I have obtained your contact details: I have obtained your contact details from your institutional website at [name of healthcare facility or organization], with which you are associated as [name of professional designation or other role at this place]. [Alternatively: I have obtained your contact details from the business card at your office reception.]

PURPOSE
This study is being conducted to support my master's degree thesis. I am studying the design of end-of-life care environments and human relationships with these physical spaces in relation to quality of life and death.
I will use my research findings to critically analyze present environments and outline suggestions for improving the design of these spaces, with the aim of creating better patient experiences at the end of life.

STUDY PROCEDURES
The entire process of my research is estimated to take at least one academic year, which is the minimum remaining duration of my master's degree. The time spent taking photographs on your institutional premises is not pre-determined as I may need to return for more photographs. I would like to request you permission to conduct my research over a period of four weeks. This time period is being requested so that I may have the chance to observe various parts of the building better, and take well-considered photographs. Four weeks will also provide me with sufficient time to return for more photographs, if I feel the need to do so, or if there are practical hinderances to photographing particular location on some days. I will do everything I can to make sure I do not cause any interruptions in the daily activities of your staff, residents, their visitors or anyone else. I will be as unobtrusive as possible, and will make sure not to get in the way of the usual running of your institution. **Please read the section on risks, inconveniences and confidentiality carefully.**

STUDY TITLE End-of-Life Care through Design: Visualizing Places of Death	**DATE** Dec 5th, 2016
INFORMATION SHEET Sent to Palliative Institutions Admins to Request Permission for Photographic Research	**PAGE** 1/4

UNIVERSITY OF ALBERTA

FACULTY OF ARTS
DEPARTMENT OF ART & DESIGN

Fine Arts Building
Edmonton, Alberta, Canada T6G 2C9
Tel: 780.492.3261
Fax: 780.492.7870
aidan.rowe@ualberta.ca
www.ualberta.ca/art-design

BENEFITS

Benefits to you: We are happy to share a copy of the research thesis including photographs with you. There are no other direct benefits to you.

Benefits to society: Your institution's support will contribute towards improving designs of spatial environments for patients receiving palliative care.

RISKS

No significant distress or disturbance greater to anyone at [name of the institution] is anticipated, although people may not wish to be photographed or they may not wish to be identified in photographs. They will not be photographed without their signed consent (or assent + third party consent in case of incapacity to consent). The photographs I take will be shown to the photographed person and/or the person who signed consent on their behalf. If they have no objection to the use of the photograph in relation to my research, only then will they indicate so with a signature on the Photography Release Form. They may also withdraw their *consent within 3 wee*ks after signing the photography release. This time period has been set to ensure that my study does not suffer a major time setback**.**

INCONVENIENCES: REQUEST FOR ACCESS

If I have your permission, then I may need to ask staff/security for directions or for assistance to let me through to certain areas if these are not normally accessible to non-residents. **Some staff/security members might consider this to be an inconvenience. I understand that it may not be possible for you to allow me to go into some parts of the building at all.** If you prefer to have any special arrangements (such as temporary access cards, door codes, prior intimation of security or staff) to facilitate ease of access and to ensure least disturbance to your staff-on-duty, then I would appreciate the chance to discuss these with you. At this stage, I would like to assure you that I **do not** need entry into any administrative areas/staff-only areas. I only request access to areas which patients or their visitors use (whether for medical, semi-medical or non-medical purposes). We can **mutually work out a plan** for accessing these areas, discuss which areas are out-of-bounds and make note of any limitations/conditions regarding my access even to those places where I am allowed to go to.

PRIVACY AND CONFIDENTIALITY

The photographs I take will be used to support my master's degree thesis. **Photographs** in which [name of the insitution] or people at [name of the institution] are represented **may appear publicly** in the researcher's thesis, academic research articles, academic conference presentations, or web postings on other academic platforms. Those who I wish to photograph will be asked prior permission through **a signed consent and/or assent form.** This consent form will allow people to indicate if they mind being **identifiable in pictures** or not. If not, I will frame pictures so that they are not identifiable even if they are within the frame. The consent form only allows me to take pictures, but not to use them. After taking a picture, **I must show it to the photographed individual** and/or to the person who signed consent on their behalf. At this point, they may freely choose whether or not to **sign a Photography Release Form,** allowing me to use these pictures in my study. *(contd next page)*

STUDY TITLE
End-of-Life Care through Design: Visualizing Places of Death

DATE
Dec 5th, 2016

INFORMATION SHEET
Sent to Palliative Institutions Admins to Request Permission for Photographic Research

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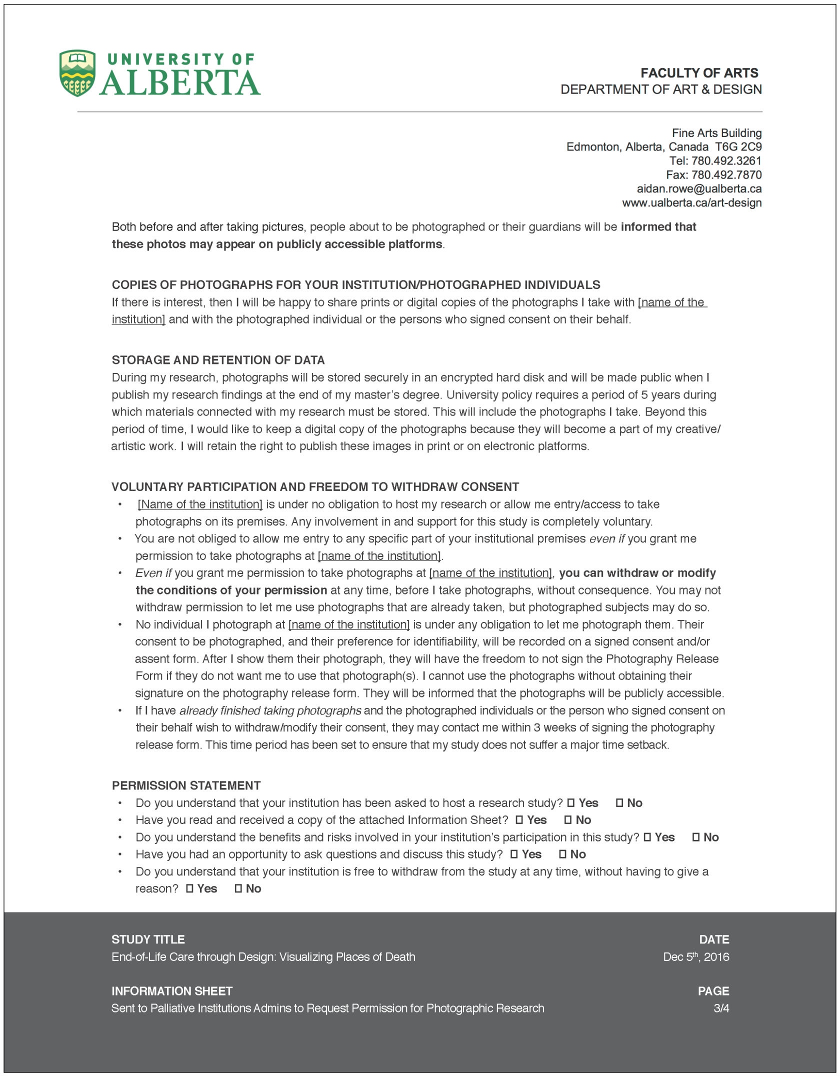

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Both before and after taking pictures, people about to be photographed or their guardians will be **informed that these photos may appear on publicly accessible platforms**.

COPIES OF PHOTOGRAPHS FOR YOUR INSTITUTION/PHOTOGRAPHED INDIVIDUALS

If there is interest, then I will be happy to share prints or digital copies of the photographs I take with [name of the institution] and with the photographed individual or the persons who signed consent on their behalf.

STORAGE AND RETENTION OF DATA

During my research, photographs will be stored securely in an encrypted hard disk and will be made public when I publish my research findings at the end of my master's degree. University policy requires a period of 5 years during which materials connected with my research must be stored. This will include the photographs I take. Beyond this period of time, I would like to keep a digital copy of the photographs because they will become a part of my creative/artistic work. I will retain the right to publish these images in print or on electronic platforms.

VOLUNTARY PARTICIPATION AND FREEDOM TO WITHDRAW CONSENT

- [Name of the institution] is under no obligation to host my research or allow me entry/access to take photographs on its premises. Any involvement in and support for this study is completely voluntary.
- You are not obliged to allow me entry to any specific part of your institutional premises *even if* you grant me permission to take photographs at [name of the institution].
- *Even if* you grant me permission to take photographs at [name of the institution], **you can withdraw or modify the conditions of your permission** at any time, before I take photographs, without consequence. You may not withdraw permission to let me use photographs that are already taken, but photographed subjects may do so.
- No individual I photograph at [name of the institution] is under any obligation to let me photograph them. Their consent to be photographed, and their preference for identifiability, will be recorded on a signed consent and/or assent form. After I show them their photograph, they will have the freedom to not sign the Photography Release Form if they do not want me to use that photograph(s). I cannot use the photographs without obtaining their signature on the photography release form. They will be informed that the photographs will be publicly accessible.
- If I have *already finished taking photographs* and the photographed individuals or the person who signed consent on their behalf wish to withdraw/modify their consent, they may contact me within 3 weeks of signing the photography release form. This time period has been set to ensure that my study does not suffer a major time setback.

PERMISSION STATEMENT

- Do you understand that your institution has been asked to host a research study? ☐ **Yes** ☐ **No**
- Have you read and received a copy of the attached Information Sheet? ☐ **Yes** ☐ **No**
- Do you understand the benefits and risks involved in your institution's participation in this study? ☐ **Yes** ☐ **No**
- Have you had an opportunity to ask questions and discuss this study? ☐ **Yes** ☐ **No**
- Do you understand that your institution is free to withdraw from the study at any time, without having to give a reason? ☐ **Yes** ☐ **No**

STUDY TITLE
End-of-Life Care through Design: Visualizing Places of Death

DATE
Dec 5th, 2016

INFORMATION SHEET
Sent to Palliative Institutions Admins to Request Permission for Photographic Research

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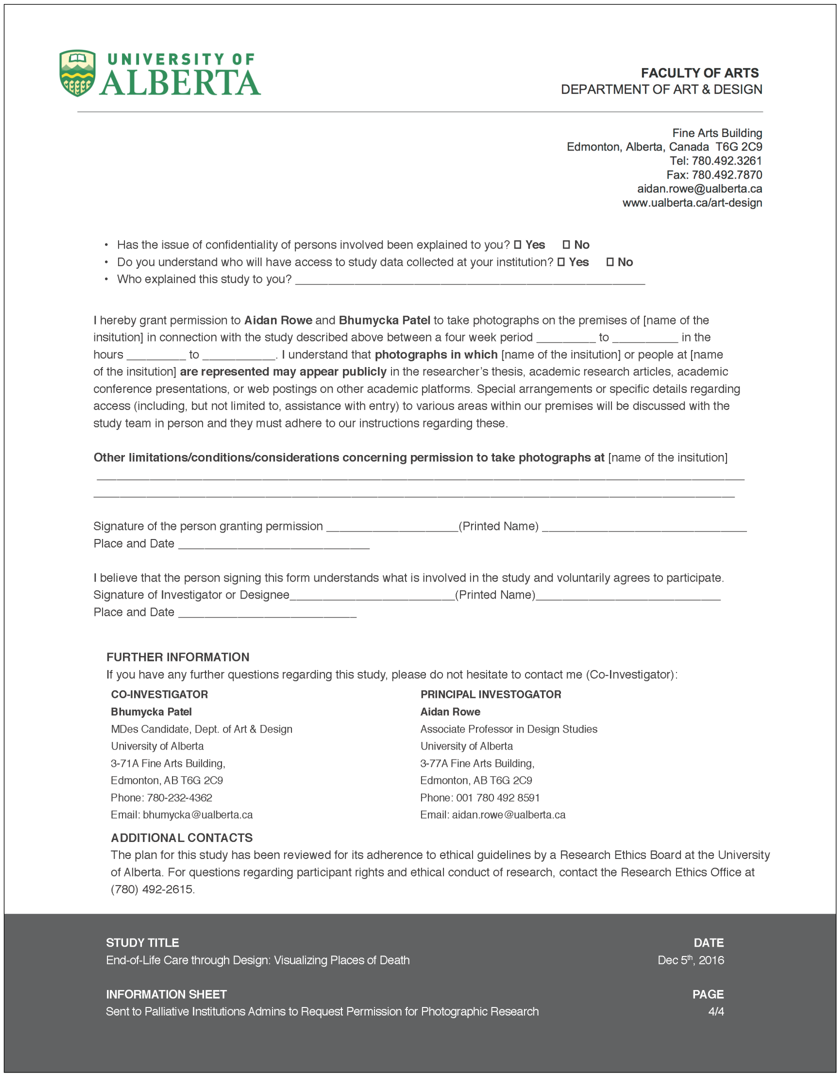

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- Has the issue of confidentiality of persons involved been explained to you? ☐ **Yes** ☐ **No**
- Do you understand who will have access to study data collected at your institution? ☐ **Yes** ☐ **No**
- Who explained this study to you? ____

I hereby grant permission to **Aidan Rowe** and **Bhumycka Patel** to take photographs on the premises of [name of the insitution] in connection with the study described above between a four week period _________ to __________ in the hours _________ to ___________. I understand that **photographs in which** [name of the insitution] or people at [name of the insitution] **are represented may appear publicly** in the researcher's thesis, academic research articles, academic conference presentations, or web postings on other academic platforms. Special arrangements or specific details regarding access (including, but not limited to, assistance with entry) to various areas within our premises will be discussed with the study team in person and they must adhere to our instructions regarding these.

Other limitations/conditions/considerations concerning permission to take photographs at [name of the insitution]
____
____

Signature of the person granting permission ____________________(Printed Name) ______________________________
Place and Date ____________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Signature of Investigator or Designee________________________(Printed Name)____________________________
Place and Date __________________________

FURTHER INFORMATION
If you have any further questions regarding this study, please do not hesitate to contact me (Co-Investigator):

CO-INVESTIGATOR	**PRINCIPAL INVESTOGATOR**
Bhumycka Patel	**Aidan Rowe**
MDes Candidate, Dept. of Art & Design	Associate Professor in Design Studies
University of Alberta	University of Alberta
3-71A Fine Arts Building,	3-77A Fine Arts Building,
Edmonton, AB T6G 2C9	Edmonton, AB T6G 2C9
Phone: 780-232-4362	Phone: 001 780 492 8591
Email: bhumycka@ualberta.ca	Email: aidan.rowe@ualberta.ca

ADDITIONAL CONTACTS
The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

STUDY TITLE End-of-Life Care through Design: Visualizing Places of Death	**DATE** Dec 5th, 2016
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Photography Consent Form

STUDY TITLE
End-of-Life Care through Design: Visualizing Places of Death

DATE
Nov 5th, 2016

CO-INVESTIGATOR
Bhumycka Patel
MDes Candidate, Dept. of Art & Design
University of Alberta
3-71A Fine Arts Building,
Edmonton, AB T6G 2C9
Phone: 780-232-4362
Email: bhumycka@ualberta.ca

PRINCIPAL INVESTIGATOR
Aidan Rowe
Associate Professor in Design Studies
University of Alberta
3-77A Fine Arts Building,
Edmonton, AB T6G 2C9
Phone: 001 780 492 8591
Email: aidan.rowe@ualberta.ca

CONSENT TO BE PHOTOGRAPHED

I hereby grant permission to **Aidan Rowe** and **Bhumycka Patel** to take photographs of ______________________ (self/family member/ward) in connection with their research project, *End-of-Life Care through Design: Visualizing Places of Death.*

I understand that **these images may appear publicly** in the researcher's thesis, academic research articles, academic conference presentations, or web postings on other academic platforms. I have been informed that **I will be shown the photographs** after they are taken. After seeing the photographs, if I have no objection to their use, then I will sign a separate photography release form, indicating my consent for their use. If I have any objections at this point, then I will not sign the photography release form and may ask for the photographs to be destroyed. I will also retain the right to withdraw my consent for photography release up until 3 weeks after signing the photography release form. I will receive a copy of this consent form after I sign it.

I am indicating below whether images showing the identity of the photographed person are permissible for use in the study or not:

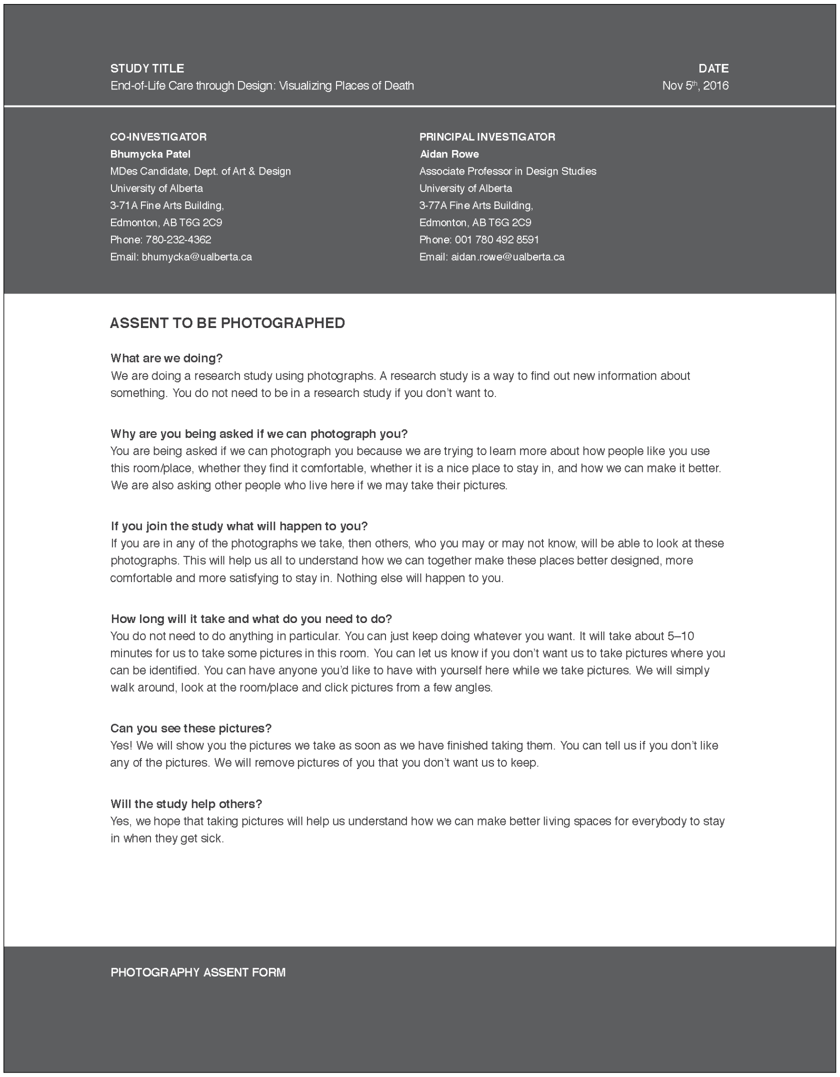
☐ You may use photos where ______________________ (self/family member/ward) is identifiable after I sign the photo release form.
☐ You may **only** use photos where ______________________(self/family member/ward) is **not** identifiable after I sign the photo release form.

Name (printed) and Signature of the Participant	Place and Date
Name (printed) and Signature of Family Member/Guardian	Place and Date
Name (printed) and Signature of Person Obtaining Consent	Place and Date

ADDITIONAL CONTACTS
The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

PHOTOGRAPHY CONSENT FORM

Photography Assent Form



STUDY TITLE
End-of-Life Care through Design: Visualizing Places of Death

DATE
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Bhumycka Patel
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ASSENT TO BE PHOTOGRAPHED

What are we doing?
We are doing a research study using photographs. A research study is a way to find out new information about something. You do not need to be in a research study if you don't want to.

Why are you being asked if we can photograph you?
You are being asked if we can photograph you because we are trying to learn more about how people like you use this room/place, whether they find it comfortable, whether it is a nice place to stay in, and how we can make it better. We are also asking other people who live here if we may take their pictures.

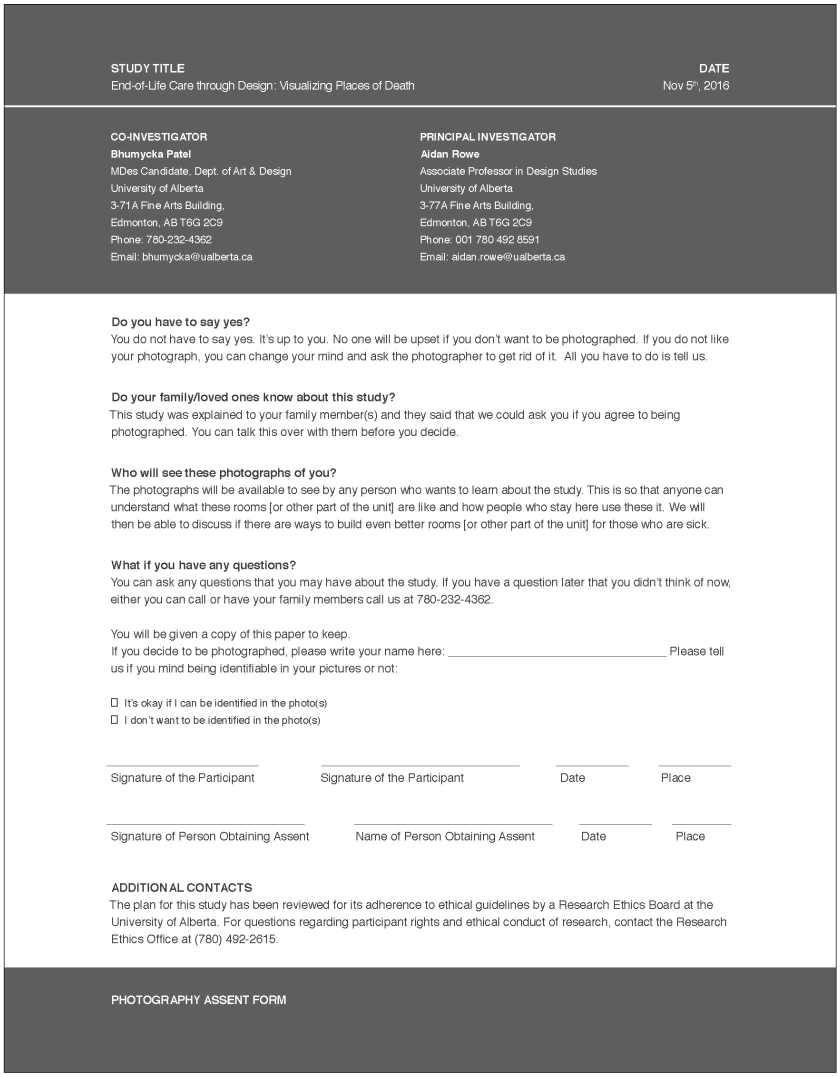
If you join the study what will happen to you?
If you are in any of the photographs we take, then others, who you may or may not know, will be able to look at these photographs. This will help us all to understand how we can together make these places better designed, more comfortable and more satisfying to stay in. Nothing else will happen to you.

How long will it take and what do you need to do?
You do not need to do anything in particular. You can just keep doing whatever you want. It will take about 5–10 minutes for us to take some pictures in this room. You can let us know if you don't want us to take pictures where you can be identified. You can have anyone you'd like to have with yourself here while we take pictures. We will simply walk around, look at the room/place and click pictures from a few angles.

Can you see these pictures?
Yes! We will show you the pictures we take as soon as we have finished taking them. You can tell us if you don't like any of the pictures. We will remove pictures of you that you don't want us to keep.

Will the study help others?
Yes, we hope that taking pictures will help us understand how we can make better living spaces for everybody to stay in when they get sick.

PHOTOGRAPHY ASSENT FORM



STUDY TITLE
End-of-Life Care through Design: Visualizing Places of Death

DATE
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Bhumycka Patel
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Do you have to say yes?
You do not have to say yes. It's up to you. No one will be upset if you don't want to be photographed. If you do not like your photograph, you can change your mind and ask the photographer to get rid of it. All you have to do is tell us.

Do your family/loved ones know about this study?
This study was explained to your family member(s) and they said that we could ask you if you agree to being photographed. You can talk this over with them before you decide.

Who will see these photographs of you?
The photographs will be available to see by any person who wants to learn about the study. This is so that anyone can understand what these rooms [or other part of the unit] are like and how people who stay here use these it. We will then be able to discuss if there are ways to build even better rooms [or other part of the unit] for those who are sick.

What if you have any questions?
You can ask any questions that you may have about the study. If you have a question later that you didn't think of now, either you can call or have your family members call us at 780-232-4362.

You will be given a copy of this paper to keep.
If you decide to be photographed, please write your name here: ______________________________ Please tell us if you mind being identifiable in your pictures or not:

☐ It's okay if I can be identified in the photo(s)
☐ I don't want to be identified in the photo(s)

Signature of the Participant	Signature of the Participant	Date	Place
Signature of Person Obtaining Assent	Name of Person Obtaining Assent	Date	Place

ADDITIONAL CONTACTS
The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

PHOTOGRAPHY ASSENT FORM

Photography Release Form

STUDY TITLE
End-of-Life Care through Design: Visualizing Places of Death

DATE
Nov 5th, 2016

CO-INVESTIGATOR
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PHOTOGRAPHY RELEASE FORM [after seeing the photographs**]**

Permission to Use Images:

I hereby grant to **Aidan Rowe** and **Bhumycka Patel**, carrying out the "*End-of-Life Care through Design: Visualizing Places of Death"* research project, the right to use photographs/images of ______________________________(self/family member/ward) in connection with this research project. The photographer has shown me these image(s) and I have no objection to their use in the study. I understand that **these images may appear publicly** in the researcher's thesis, academic research articles, academic conference presentations, or web postings on other academic platforms.

I authorize the researchers to use and publish the same in print and/or electronically. I will retain the right to withdraw my consent for photography release up until 3 weeks after signing this photography release form. I will receive a copy of this release form after I sign it.

____
Name (printed) and Signature of the Participant

____
Place and Date

____
Name (printed) and Signature of Family Member/Guardian

____
Place and Date

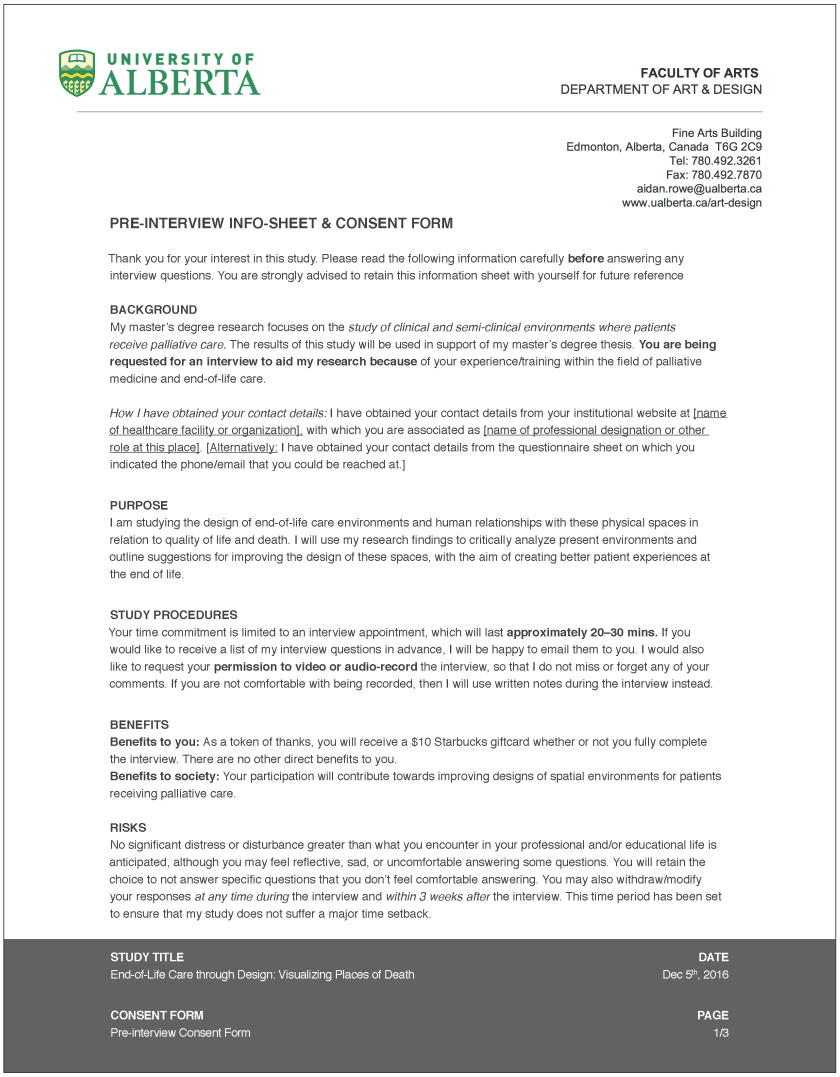
____
Name (printed) and Signature of Person Obtaining Consent

____
Place and Date

ADDITIONAL CONTACTS
The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

PHOTOGRAPHY RELEASE FORM

Interview Consent Form



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PRE-INTERVIEW INFO-SHEET & CONSENT FORM

Thank you for your interest in this study. Please read the following information carefully **before** answering any interview questions. You are strongly advised to retain this information sheet with yourself for future reference

BACKGROUND

My master's degree research focuses on the *study of clinical and semi-clinical environments where patients receive palliative care.* The results of this study will be used in support of my master's degree thesis. **You are being requested for an interview to aid my research because** of your experience/training within the field of palliative medicine and end-of-life care.

How I have obtained your contact details: I have obtained your contact details from your institutional website at [name of healthcare facility or organization], with which you are associated as [name of professional designation or other role at this place]. [Alternatively: I have obtained your contact details from the questionnaire sheet on which you indicated the phone/email that you could be reached at.]

PURPOSE

I am studying the design of end-of-life care environments and human relationships with these physical spaces in relation to quality of life and death. I will use my research findings to critically analyze present environments and outline suggestions for improving the design of these spaces, with the aim of creating better patient experiences at the end of life.

STUDY PROCEDURES

Your time commitment is limited to an interview appointment, which will last **approximately 20–30 mins.** If you would like to receive a list of my interview questions in advance, I will be happy to email them to you. I would also like to request your **permission to video or audio-record** the interview, so that I do not miss or forget any of your comments. If you are not comfortable with being recorded, then I will use written notes during the interview instead.

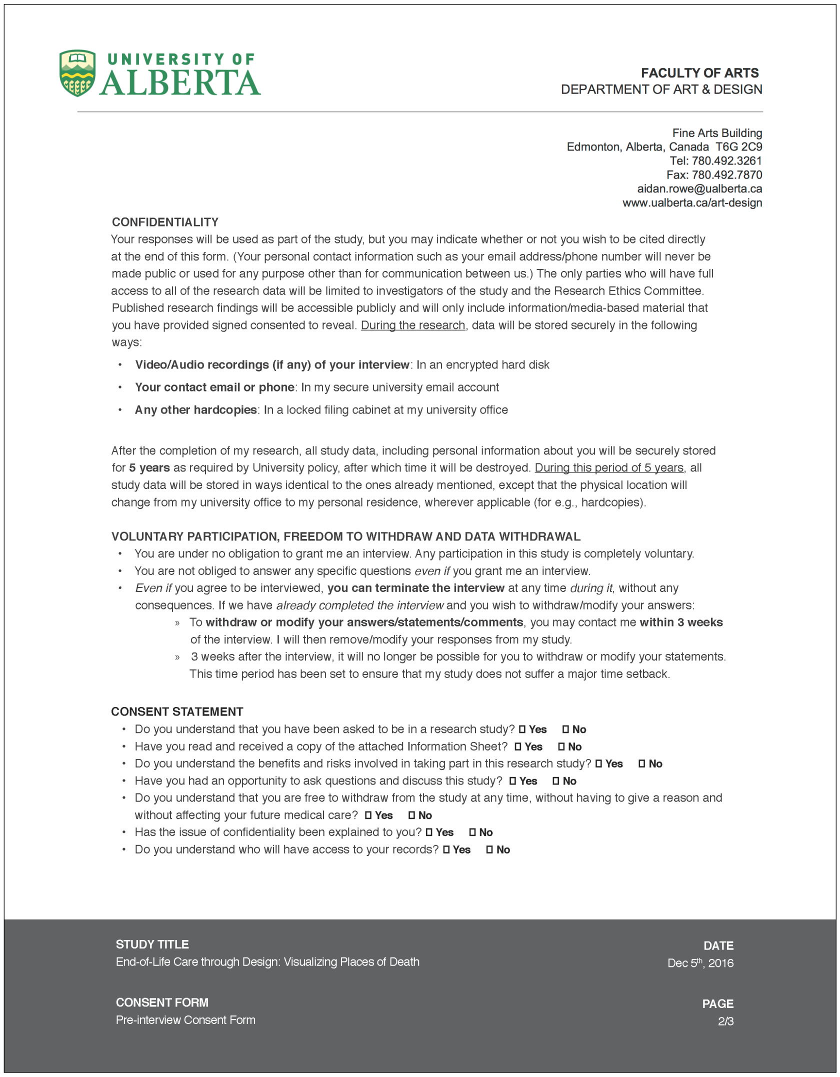
BENEFITS

Benefits to you: As a token of thanks, you will receive a $10 Starbucks giftcard whether or not you fully complete the interview. There are no other direct benefits to you.
Benefits to society: Your participation will contribute towards improving designs of spatial environments for patients receiving palliative care.

RISKS

No significant distress or disturbance greater than what you encounter in your professional and/or educational life is anticipated, although you may feel reflective, sad, or uncomfortable answering some questions. You will retain the choice to not answer specific questions that you don't feel comfortable answering. You may also withdraw/modify your responses *at any time during* the interview and *within 3 weeks after* the interview. This time period has been set to ensure that my study does not suffer a major time setback.

STUDY TITLE End-of-Life Care through Design: Visualizing Places of Death	**DATE** Dec 5th, 2016
CONSENT FORM Pre-interview Consent Form	**PAGE** 1/3



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CONFIDENTIALITY

Your responses will be used as part of the study, but you may indicate whether or not you wish to be cited directly at the end of this form. (Your personal contact information such as your email address/phone number will never be made public or used for any purpose other than for communication between us.) The only parties who will have full access to all of the research data will be limited to investigators of the study and the Research Ethics Committee. Published research findings will be accessible publicly and will only include information/media-based material that you have provided signed consented to reveal. During the research, data will be stored securely in the following ways:

- **Video/Audio recordings (if any) of your interview**: In an encrypted hard disk
- **Your contact email or phone**: In my secure university email account
- **Any other hardcopies**: In a locked filing cabinet at my university office

After the completion of my research, all study data, including personal information about you will be securely stored for **5 years** as required by University policy, after which time it will be destroyed. During this period of 5 years, all study data will be stored in ways identical to the ones already mentioned, except that the physical location will change from my university office to my personal residence, wherever applicable (for e.g., hardcopies).

VOLUNTARY PARTICIPATION, FREEDOM TO WITHDRAW AND DATA WITHDRAWAL

- You are under no obligation to grant me an interview. Any participation in this study is completely voluntary.
- You are not obliged to answer any specific questions *even if* you grant me an interview.
- *Even if* you agree to be interviewed, **you can terminate the interview** at any time *during it*, without any consequences. If we have *already completed the interview* and you wish to withdraw/modify your answers:
    - » To **withdraw or modify your answers/statements/comments**, you may contact me **within 3 weeks** of the interview. I will then remove/modify your responses from my study.
    - » 3 weeks after the interview, it will no longer be possible for you to withdraw or modify your statements. This time period has been set to ensure that my study does not suffer a major time setback.

CONSENT STATEMENT

- Do you understand that you have been asked to be in a research study? ☐ **Yes** ☐ **No**
- Have you read and received a copy of the attached Information Sheet? ☐ **Yes** ☐ **No**
- Do you understand the benefits and risks involved in taking part in this research study? ☐ **Yes** ☐ **No**
- Have you had an opportunity to ask questions and discuss this study? ☐ **Yes** ☐ **No**
- Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your future medical care? ☐ **Yes** ☐ **No**
- Has the issue of confidentiality been explained to you? ☐ **Yes** ☐ **No**
- Do you understand who will have access to your records? ☐ **Yes** ☐ **No**

STUDY TITLE
End-of-Life Care through Design: Visualizing Places of Death

DATE
Dec 5th, 2016

CONSENT FORM
Pre-interview Consent Form

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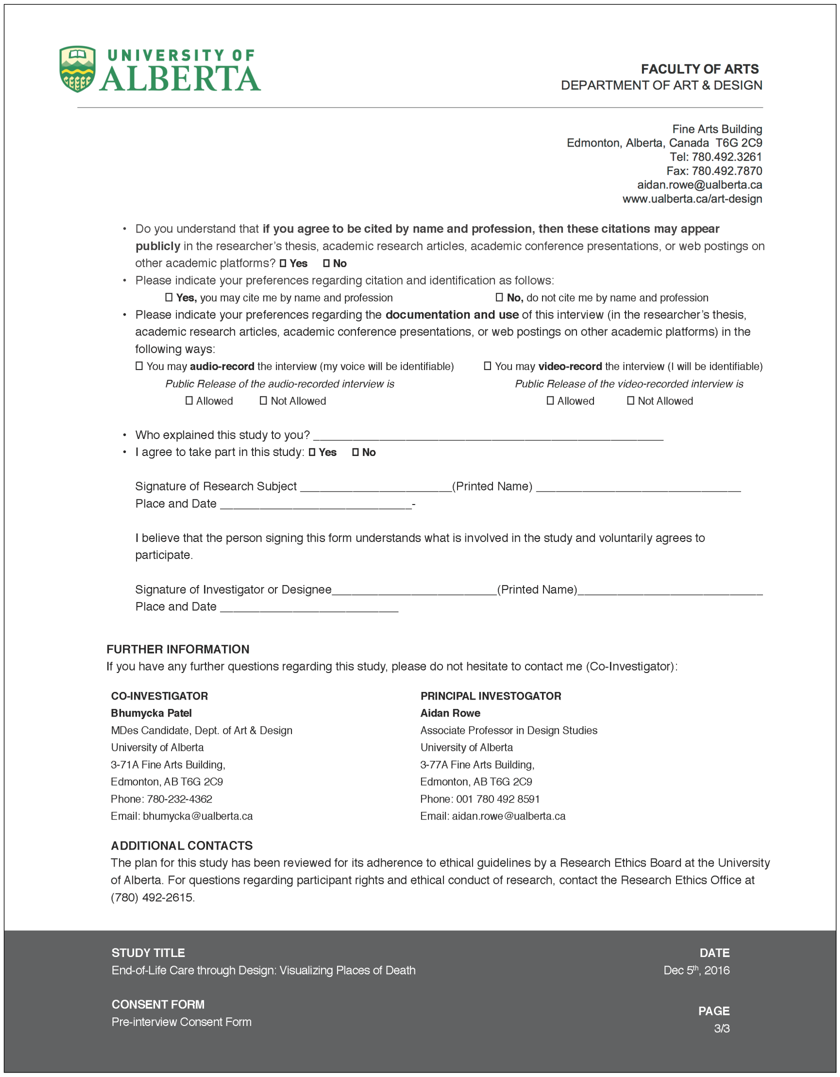

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www.ualberta.ca/art-design

- Do you understand that **if you agree to be cited by name and profession, then these citations may appear publicly** in the researcher's thesis, academic research articles, academic conference presentations, or web postings on other academic platforms? ☐ **Yes** ☐ **No**
- Please indicate your preferences regarding citation and identification as follows:
  ☐ **Yes,** you may cite me by name and profession ☐ **No,** do not cite me by name and profession
- Please indicate your preferences regarding the **documentation and use** of this interview (in the researcher's thesis, academic research articles, academic conference presentations, or web postings on other academic platforms) in the following ways:

☐ You may **audio-record** the interview (my voice will be identifiable)
Public Release of the audio-recorded interview is
☐ Allowed ☐ Not Allowed

☐ You may **video-record** the interview (I will be identifiable)
Public Release of the video-recorded interview is
☐ Allowed ☐ Not Allowed

- Who explained this study to you? ____
- I agree to take part in this study: ☐ **Yes** ☐ **No**

Signature of Research Subject _______________________(Printed Name) _______________________________
Place and Date _____________________________-

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee_________________________(Printed Name)____________________________
Place and Date ___________________________

FURTHER INFORMATION
If you have any further questions regarding this study, please do not hesitate to contact me (Co-Investigator):

CO-INVESTIGATOR	**PRINCIPAL INVESTOGATOR**
Bhumycka Patel	**Aidan Rowe**
MDes Candidate, Dept. of Art & Design	Associate Professor in Design Studies
University of Alberta	University of Alberta
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CONSENT FORM
Pre-interview Consent Form

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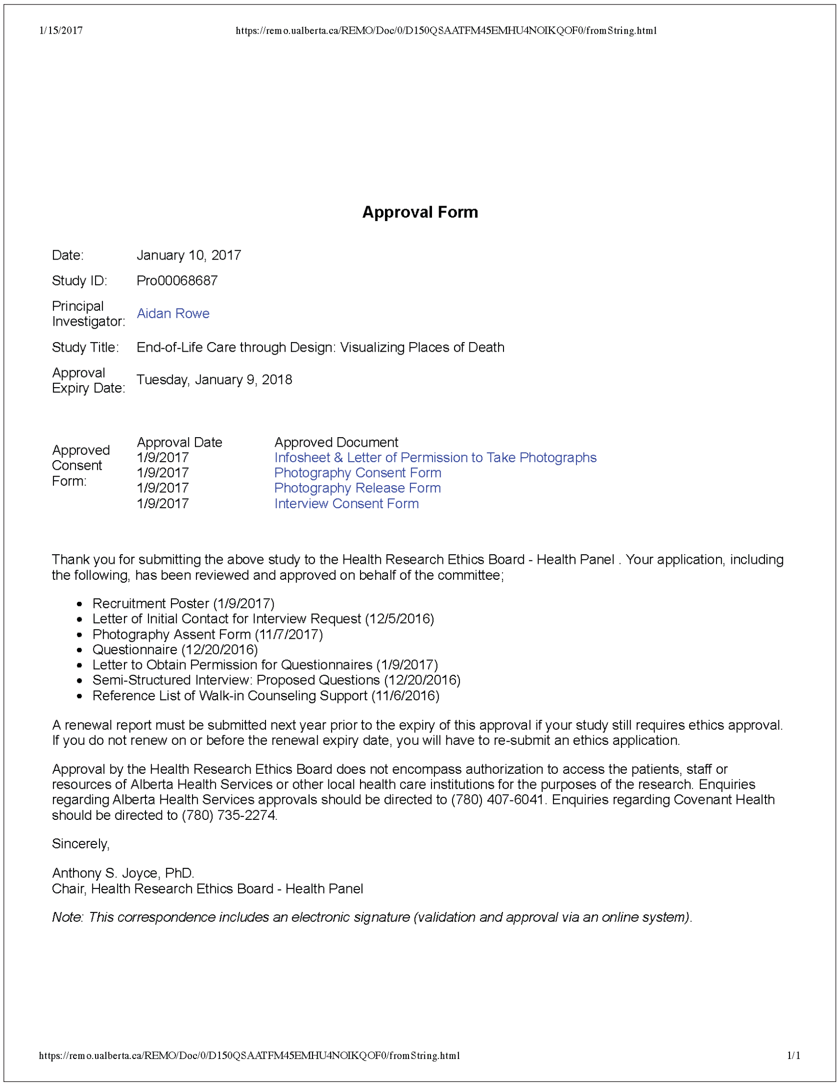
8.3 HEALTH RESEARCH ETHICS BOARD (HREB)

STUDY APPROVAL LETTER



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Approval Form

Date: January 10, 2017

Study ID: Pro00068687

Principal Investigator: Aidan Rowe

Study Title: End-of-Life Care through Design: Visualizing Places of Death

Approval Expiry Date: Tuesday, January 9, 2018

	Approval Date	Approved Document
Approved Consent Form:	1/9/2017	Infosheet & Letter of Permission to Take Photographs
	1/9/2017	Photography Consent Form
	1/9/2017	Photography Release Form
	1/9/2017	Interview Consent Form

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel . Your application, including the following, has been reviewed and approved on behalf of the committee;

- Recruitment Poster (1/9/2017)
- Letter of Initial Contact for Interview Request (12/5/2016)
- Photography Assent Form (11/7/2017)
- Questionnaire (12/20/2016)
- Letter to Obtain Permission for Questionnaires (1/9/2017)
- Semi-Structured Interview: Proposed Questions (12/20/2016)
- Reference List of Walk-in Counseling Support (11/6/2016)

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health Services approvals should be directed to (780) 407-6041. Enquiries regarding Covenant Health should be directed to (780) 735-2274.

Sincerely,

Anthony S. Joyce, PhD.
Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).

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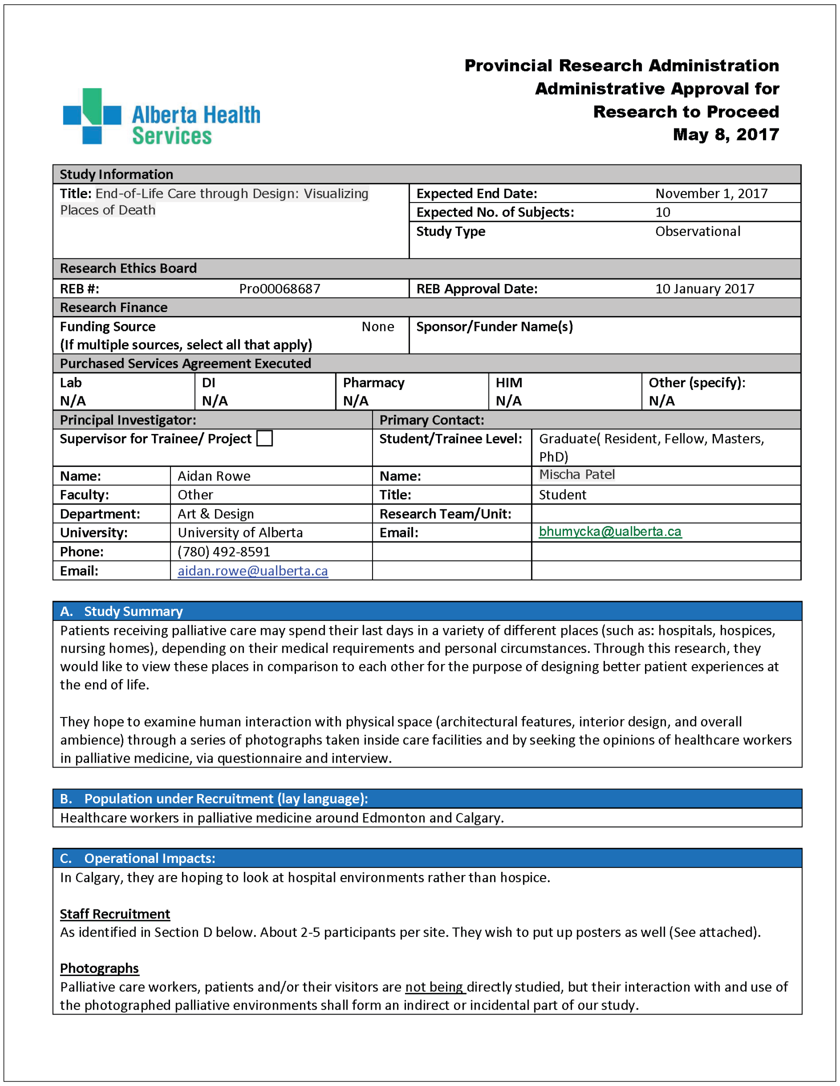
8.4 ALBERTA HEALTH SERVICES

ADMINISTRATIVE APPROVAL



Alberta Health Services

Provincial Research Administration
Administrative Approval for
Research to Proceed
May 8, 2017

Study Information			
Title: End-of-Life Care through Design: Visualizing Places of Death		**Expected End Date:**	November 1, 2017
		Expected No. of Subjects:	10
		Study Type	Observational
Research Ethics Board			
REB #:	Pro00068687	**REB Approval Date:**	10 January 2017
Research Finance			
Funding Source **(If multiple sources, select all that apply)**	None	**Sponsor/Funder Name(s)**	

Purchased Services Agreement Executed				
Lab **N/A**	**DI** **N/A**	**Pharmacy** **N/A**	**HIM** **N/A**	**Other (specify):** **N/A**

Principal Investigator:		**Primary Contact:**	
Supervisor for Trainee/ Project ☐		**Student/Trainee Level:**	Graduate(Resident, Fellow, Masters, PhD)
Name:	Aidan Rowe	**Name:**	Mischa Patel
Faculty:	Other	**Title:**	Student
Department:	Art & Design	**Research Team/Unit:**	
University:	University of Alberta	**Email:**	bhumycka@ualberta.ca
Phone:	(780) 492-8591		
Email:	aidan.rowe@ualberta.ca		

A. Study Summary

Patients receiving palliative care may spend their last days in a variety of different places (such as: hospitals, hospices, nursing homes), depending on their medical requirements and personal circumstances. Through this research, they would like to view these places in comparison to each other for the purpose of designing better patient experiences at the end of life.

They hope to examine human interaction with physical space (architectural features, interior design, and overall ambience) through a series of photographs taken inside care facilities and by seeking the opinions of healthcare workers in palliative medicine, via questionnaire and interview.

B. Population under Recruitment (lay language):

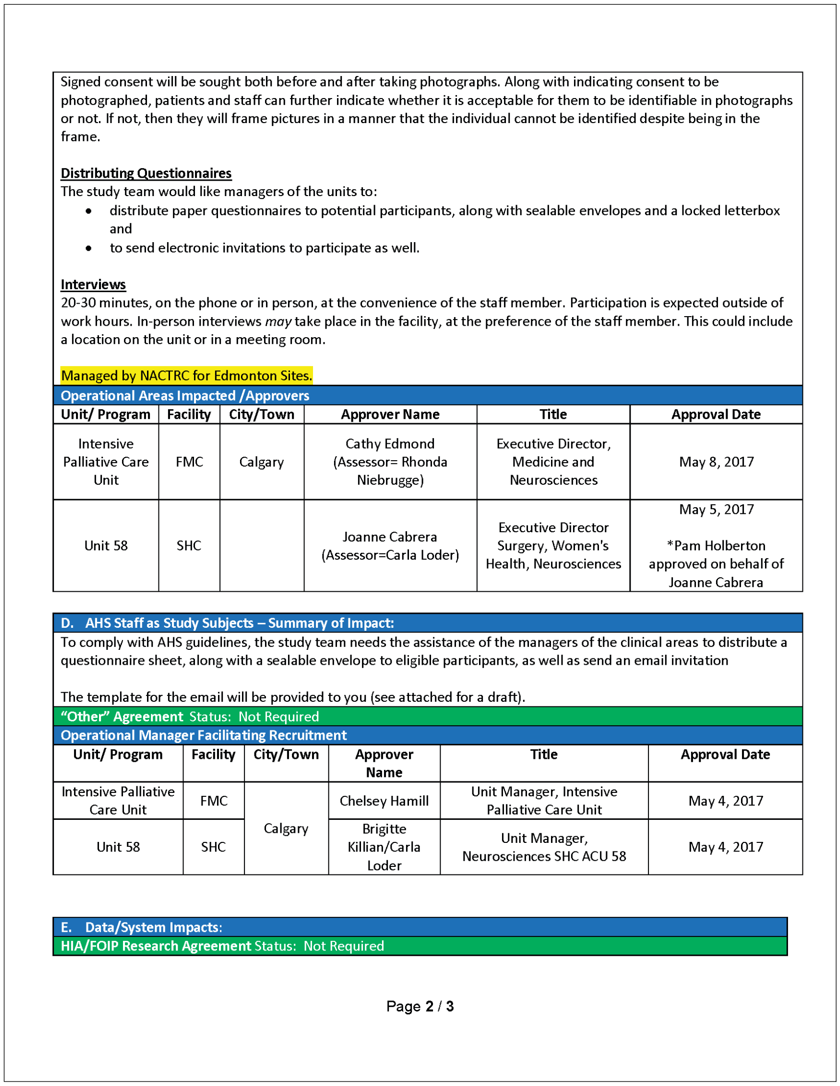
Healthcare workers in palliative medicine around Edmonton and Calgary.

C. Operational Impacts:

In Calgary, they are hoping to look at hospital environments rather than hospice.

Staff Recruitment
As identified in Section D below. About 2-5 participants per site. They wish to put up posters as well (See attached).

Photographs
Palliative care workers, patients and/or their visitors are not being directly studied, but their interaction with and use of the photographed palliative environments shall form an indirect or incidental part of our study.



Signed consent will be sought both before and after taking photographs. Along with indicating consent to be photographed, patients and staff can further indicate whether it is acceptable for them to be identifiable in photographs or not. If not, then they will frame pictures in a manner that the individual cannot be identified despite being in the frame.

Distributing Questionnaires

The study team would like managers of the units to:

- distribute paper questionnaires to potential participants, along with sealable envelopes and a locked letterbox and
- to send electronic invitations to participate as well.

Interviews

20-30 minutes, on the phone or in person, at the convenience of the staff member. Participation is expected outside of work hours. In-person interviews *may* take place in the facility, at the preference of the staff member. This could include a location on the unit or in a meeting room.

Managed by NACTRC for Edmonton Sites.

Operational Areas Impacted /Approvers

Unit/ Program	Facility	City/Town	Approver Name	Title	Approval Date
Intensive Palliative Care Unit	FMC	Calgary	Cathy Edmond (Assessor= Rhonda Niebrugge)	Executive Director, Medicine and Neurosciences	May 8, 2017
Unit 58	SHC		Joanne Cabrera (Assessor=Carla Loder)	Executive Director Surgery, Women's Health, Neurosciences	May 5, 2017 *Pam Holberton approved on behalf of Joanne Cabrera

D. AHS Staff as Study Subjects – Summary of Impact:

To comply with AHS guidelines, the study team needs the assistance of the managers of the clinical areas to distribute a questionnaire sheet, along with a sealable envelope to eligible participants, as well as send an email invitation

The template for the email will be provided to you (see attached for a draft).

"Other" Agreement Status: Not Required

Operational Manager Facilitating Recruitment

Unit/ Program	Facility	City/Town	Approver Name	Title	Approval Date
Intensive Palliative Care Unit	FMC	Calgary	Chelsey Hamill	Unit Manager, Intensive Palliative Care Unit	May 4, 2017
Unit 58	SHC		Brigitte Killian/Carla Loder	Unit Manager, Neurosciences SHC ACU 58	May 4, 2017

E. Data/System Impacts:

HIA/FOIP Research Agreement Status: Not Required

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// ALBERTA HEALTH SERVICES APPROVAL

F. Transfer of AHS Data:
Data Transfer Agreement Status: Not Required

AHS Administrative Approval (All Zones Except Edmonton):			
Date Issued	**Name of Approver**	**Title**	**Approved**
May 8, 2017	Amanda Cunningham	Research Administration Advisor	Alberta Health Services PROVINCIAL RESEARCH ADMINISTRATION ADMINISTRATIVE APPROVAL

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8.5 THESIS EXPOSITION

FINE ARTS BUILDING, UNIVERSITY OF ALBERTA