# The Case for Empathy Based Design

## Ian M. Sinclair, MHA, CHE

### Principal, Vice President Healthcare, Kasian Architecture, Toronto, Canada

Over the course of my career as both a hospital executive and a planning and design consultant, I have been drawn to the notion of "empathy". Three particular experiences have profoundly influenced my personal construct of empathy. While attending a conference workshop some years ago, as delegates, we were asked to imagine a "bad news-good news" scenario. The bad news was that a massive meteor was on a collision course with earth and *in 5 days*, the earth will be destroyed. The good news was that there was a plan to evacuate everyone on earth and take them to a new planet. The proviso was that each person could take only three things with them. After a few minutes of reflection, each table began reporting what they felt were the most valuable belongings they would bring with them to the new planet. It wasn't long before it became clear that what people valued most about life on earth was not our material things and artifacts, but the more intangible or irreplaceable aspects of life on earth. One by one, each table repeatedly reported the same things of value: nature (a breeze, a hike in the mountains, the sound of a babbling brook, rain, the sun, clouds), companionship (friends, family, pets), the arts, (music, paintings, dance, theatre, art) and human emotions/senses (laughter, joy, sadness, touch, smell).

Given that many of today's admitted hospital patients are by definition, very sick, it is not uncommon for many to feel that it may be *their last* 5 days on earth. If that is **how patients feel**, then from a design perspective, have we responded appropriately when designing the spaces where they believe they may be spending their last 5 days on earth? Are we putting ourselves in their shoes? Are

we designing around their wish to feel a breeze or smell a flower, or hug a loved one, perhaps for the last time?

My second empathy-related "aha" moment occurred while visiting the Griffin Hospital in Derby, Connecticut (a Planetree Hospital). It was on that trip where I learned that all new hires, from a housekeeper to the Chief of the Medical Staff, were required to spend several days in an offsite retreat facility to **experience what it is like to be a patient**. That is, new staff members shared a room with a total stranger, fed each other, and were led blindfolded around the grounds by someone who could only use nonverbal cues to direct them. Patrick Charmel, CEO of the Griffin Hospital, noted that:

> "Patients are stripped of control, their clothes are taken away, they have little say over their schedule, and they are deliberately separated from family and friends."

He believes that if hospitals truly wish to deliver authentic, patient-centered care, then we must start from the position of **empathy.**

Thirdly, while working on a hospital master plan in Rehovot, Israel, my colleague and I were invited to attend a children's museum in Holon, just outside of Tel Aviv, called "Dialogue in the Dark". The museum was 100% pitch black dark. However, while waiting in the illuminated lobby before entering the museum exhibit, we were given a cane, shown how to move it from side to side along the ground and invited to simply follow the voice and directions of our guide while we navigated the museum. We entered a

hallway, until we experienced complete darkness. Suddenly a voice (our guide) told us when to step and when to jump. In the dark, his voice led us to a market, where we were invited to reach out, to find, feel and smell fruit that we could touch, but not see. Next, his voice led us to what was clearly intended to be a busy city intersection with all the noise, diesel fumes and confusion one would expect in any city around the world. The anxiety and fear I felt, unable to see everyday risks, was as real as the adrenaline that was making my heart pound out of my chest.

From there, his voice led us to a marina where we could hear the ocean slapping up against the pier, where sea gulls cried, circling above as fishermen gutted and cleaned freshly caught fish on the dock below. Unable to see anything in the darkness, the thought of dropping suddenly off the dock into the Mediterranean was ever present.

Finally, our guide led us to a bar, where we were invited to buy a drink and some snacks….reaching into our pockets to find money to pay, realizing only then, how difficult it was to differentiate one coin or bill from another without sight. Eventually, we followed a light, which lead us to the illuminated lobby. There we met our tour guide…who was, of course, blind. These three experiences affected me. The notion of empathy or **"walk a mile in my shoes"** in each experience offered a powerful lesson on why, perhaps, we need to revisit how we frame the design dialogue; **to begin, not from form or function, but from a place of empathy.**

## Traditional Drivers of Design

If empathy isn't the primary driver in healthcare design today, then what is?

- **"Form follows function"** (Although I think we all know that in North America at least, form actually follows parking!)

- **A design brief or a program** that projects space requirements and key adjacencies driven by **patient volume or activity**, **demographic forces**, **incidence of disease**, changing **technology a**nd **clinical practice models**.
- **LEED** or **sustainability targets** to support the most **efficient operational practices**.
- **Life cycle costing** decisions to ensure **material durability** and **maintainability**.
- The **latest planning standards or building codes.**
- "**Future proofing"** to help ensure the facility is flexible and adaptable over time.

## Evolution of the Design Process from user-centered design to co-design

According to Liz Sanders, (IIT Institute of Design) in the 1980's, the design process was characterized as "Expert Driven". That is, we designed **"for"** people with users assuming a more passive posture in the process. This approach evolved toward a "user-centered approach" in the 90's, where we employed research but still with the mindset of designer as lead expert. In a user-centered design approach, Sanders states that the user (or patient) is still a passive object of study but where the researcher brings "expert knowledge" from theories and develops more knowledge through observation and interviews. And then in the 2000's, we moved toward the Scandinavian model of co-design or **"co-creation"** where **users are partners in the process** where we design "**with them", not "for them**". In **co-design**, the person, who will eventually be served through the design process, is given the position of expert of his/her experience and plays a significant role in knowledge development, idea generation and concept development.(IIT Design Research Conference @ https://vimeo.com/11278500).

## Evolution of the Design Process

| 1980's | 1990's | 2000's | Today |
|---|---|---|---|
| "Expert Driven" | "User-Centered" | "Co-Design/Co-Creation" | Empathy Based Design/ Design Thinking? |
| • Design "for" people<br>• Designer as expert<br>• Passive role of client | • Designer still as "expert" but employs research<br>• User as passive object of study<br>• Designer brings expert knowledge from theory and develops more knowledge through observation and interviews<br>• Focus on user likes and dislikes | • Design "with them", not "for them"<br>• End user is given position as "the expert", not the designer.<br>• User experience informs concept development | • Designer starts with understanding user needs in terms of their emotional human-centered needs<br>• Designer uses storytelling as research tool to unpack user emotions.<br>• Documents emotions and feeling on empathy map |

Figure 1: Evolution Chart

User or patient-centered design, therefore, leverages information garnered on the **likes** and **dislikes** in order to inform the design response. However, if we were to begin the design process based on empathy, we would not start the conversation with what a patient likes or dislikes, but instead, we could start by developing an "empathy map" by asking for example, "**How did you feel at a moment in time?  What were your thoughts?  How did you respond?  What emotions dominated you and when?**"
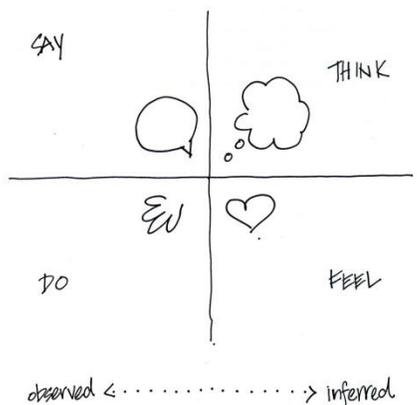


Figure 2: Empathy Map

All of these approaches to design are still relevant in healthcare, however, the key is to know which to use and when.  For me, the notion of **empathy – *the ability to understand and share the feelings and emotions of another*, or more simply, "putting yourself in the shoes of the patient"** – defines the construct of patient-centered care more intuitively, with more clarity and with more meaning.

## Sympathy vs. Empathy

It is important that we do not confuse sympathy with empathy.  For example, imagine that you are walking along the sidewalk on your way to work and you see a homeless person jangling a cup with a few coins.  What is your response?  The sympathy response would be to toss him a coin and feel a bit sorry for him.

In contrast, according to the social philosopher, Roman Krznaric, the author of *Empathy: Why It Matters and how to Get It?*, the empathy response would be to really try to imagine **what it might be like to be him**; to feel his pain when having to sleep outside on a cold winter's night; to feel his hunger, or to imagine how he must feel when people walk right past him without looking him in the eye.

Being empathetic is not about being nice to people or being friendly.  **It is about feeling what others are feeling**, imagining what they might be feeling and fostering that sense of being connected to one another.  Acting on empathy has become an important topic in the healthcare sector and is increasingly viewed as an essential skill for caregivers to build trust with patients and promote healing.  Empathy is now being taught, for example, at many medical schools around the world (Grotto, Glimcher, Nov 2013).

## What does the Research say about Empathy?

Research shows that the capacity to put ourselves into someone else's shoes is crucial to our ability to live among and relate to others. Studies show that "empathy can especially make a difference in healthcare notably among patients who suffer from chronic and or life threatening disease." (Empathy by Design: Healing the body while caring for the mind (Cleveland Clinic), Dana Brown, Jan 4, 2017.) Research shows that empathetic care by clinicians can result in improved patient outcomes. A 2012 study of primary care physicians with different levels of empathy showed that the most empathetic group had more patients with fewer diabetic complications. In another study, patients with colds were seen either by doctors in a standard visit or by doctors who had received special training to make direct eye contact, touch patients, and spend more time with them. The people who rated their doctors as the most empathetic recovered from their colds sooner than the rest of the group (Antonio M. Gotto, Jr. MD, DPhil, Laurie H. Glimcher, MD, Teaching Empathy in Medical School, Huffington post, Nov 4, 2013). Empathy has been proven to be an essential component of any healing process (Kzarnic).

## Design Thinking: the application of empathy

Design thinking is a way to take on design challenges by applying empathy. It is a framework for a human-centered approach to strategic innovation and a new management paradigm for value creation in a world of radically changing networks and disruptive technology. Design thinking today, is popular among educators and social entrepreneurs for social innovation because it approaches problem solving **from the point of view of the end user** and calls for creative solutions by developing a deep understanding of unmet needs within the context and constraints of a particular situation (Design Thinking for Strategic Innovation, Idris Mootee, Wiley 2013).

In his book, *Design Thinking for Strategic Innovation*, **Idris Mootee** states that we *need to evolve from Human Centered design to Emotion Centered Design by starting with empathy.* **"Good Design is only as good as its ability to connect and forge relationships with the people who ultimately use it."** Therefore, the first task of great design is to understand the *cultural touch points* to humanization that make such relationships possible. "Design thinking Promotes Empathy" (Mootee). By promoting empathy, you put users at the core of everything. It encourages the use of tools to help us communicate with people to better understand their behaviors, expectations, values, motivations, and the needs that drive them and can help improve their lives. Design thinkers, he says, "are sensitive to *the human touch points* that encourage and foster such emotions as profound moments of attachment to a product, service or brand" (Mootee).

The move toward empathy as a driver, however, conflicts with another common design driver, **standardization**. Standardization has become a prevalent driving force to inform efficiency and predictability. **Standardization demands detachment** much like a physician who is trained to detach from patients in medical school. However, the lack of humanization in experiences is not always purposeful, but tends to occur when standardization takes hold.

Knowing that there is a place for standardization in business and process definition, we must recognize nonetheless, that it is the *human touch points* that resonate most in real-life patient experience to give environments true value and meaning. Employing design thinking to understand how to best design a space, we must **unpack the emotional context that defines a person's experience in that space**. Design thinking seeks to reinsert humanization opportunities that can introduce new meaning by using real talk about the personal histories, dreams, fears, desires, hopes aspirations that define the experience.

## Where is empathy informed design most applicable?

So, in exploring this notion of empathy, I thought about all the different healthcare facilities and the illnesses that are typically treated in each. I then decided that the notion of empathy, although valid and applicable in all healthcare settings, is most salient and most applicable in one particular type of healthcare facility: **Cancer Centres.**

A Cancer Centre is not just another health care building. It is a place for those with a very unique disease—**unlike any other illness**. The journey of every cancer patient is personal; no two patients or diagnoses are exactly alike. Although mortality rates trend downward and the number of cancer survivors increases, a cancer diagnosis, **unlike any other diagnosis**, is often experienced as a **death sentence**. Even after patients are treated and move into remission, the most salient worry among these patients is the **fear of re-occurrence** (Armes, Jo et al, Patients' supportive care needs beyond end of treatment, Journal of Clinical Oncology, 2009,(36) 6172-9).

In general, cancer has no bias to age, ethnicity or gender and levies a devastating toll upon the normal life of patients and families. Treatments often feel worse than the disease itself, often causing weakness and compromise the immune system increasing susceptibility to viruses that can disrupt the healing process. For many, these treatments and medications trigger nausea, gastro intestinal problems, hair loss, scars, changes in skin colour, weight loss or gain, heightened sensitivity to smell and temperature, loss of muscle tone increasing risk of falls, memory loss; all impacting the activities of daily life we all take for granted. More often today, cancer patients also suffer other chronic conditions including diabetes, heart disease, autoimmune disorders, thyroid disorders, chronic viral and bacterial disorders and the effects of stroke. Emotionally, the treatment journey can be a roller coaster of progress and setback that evokes a loss of control, uncertainty and fear for both the patient and the family.

The Chairman of the Cleveland Clinic Taussig Cancer Institute, Brian Bolwell, MC, says that:

> "Patients with cancer are scared **more than any other diagnosis**. It's life changing…shatters your world…and nothing else can hold a candle to it. It is impossible to get away from. It dominates your thoughts. It's hard for anyone to get it unless they have **walked in your shoes**" (Empathy by Design: Healing the body while caring for the mind (Cleveland Clinic), Dana Brown, Jan 4, 2017).

Unlike other diseases, no single cancer care provider owns the disease. For example, a typical cancer patient will interact with a large mix of caregivers including surgical, medical and radiation oncologists, a geneticist, residents, internists, physicists, oncology nurses, techs, radiation therapists, pharmacists, phlebotomists, social workers, chaplains, psychotherapists, massage therapists, researchers, geneticists as well as family and friends. Each one of these patient interactions with these caregivers has the potential to make or break the healing process. Cancer treatment, unlike any other disease, can be viewed as a series of important **human touch points** within a process of disease management by multi-disciplinary specialists.

The cumulative result of invasive treatments typical to each of these oncologic specialists takes its toll on cancer patients in ways other patients rarely experience. Salvatore Ianconesi, a survivor who open sourced his brain cancer diagnosis, said, "with a cancer diagnosis you become a disease on legs".

Finally, in addition to the impact of the treatment on their physical and emotional states, the typical cancer journey can result in an **assault on human dignity**. For cancer patients, the requirement to repeatedly undress and gown, exposing your body to the many probing treatments, evaluations and consultations by complete strangers that include physicians, nurses, technicians, and students can be

humiliating and de-humanizing (Jason Schrooer and Carol Kartje, Fundamentals Of cancer Centre Design: The patient, Healthcare design, January, 13, 2014). Simply put, cancer is an evil and insidious disease.

## What does the Research say about the emotions of most Cancer Patients?

Various studies have demonstrated that cancer patients and families are overwhelmed by at least 13 different emotions of devastation characterized by: pain, loneliness, worry, anxiety, helplessness, anger, dread, despair, darkness and unfairness, confusion, danger and guilt (At home in hospital? Interaction and stigma in people affected by cancer. Social Science & Medicine 62 (2006) 1616–1627. Emotions and Cancer, Cancer Council, NSW, April 2013). If these emotions are typical of all cancer patients and we accept empathy as our design driver, what then, are the design responses that will serve as a **counterpoint to these powerful emotions**? Specifically what are the design considerations for well-being, love, calmness, tranquility, control, happiness, bravery, hope, illumination, fairness, clarity, safety and security and blamelessness? As designers, therefore, are we not compelled to place ourselves in the shoes of patients, families and caregivers, to feel these emotions, to truly be empathetic, to be able to design a facility that truly responds to these powerful human emotions?

How can design best offer a counterpoint to fear, anxiety, loss of control and loss of dignity? How can design offer simplicity and clarity in the face of care system characterized by an unfamiliar medical language within a system whose navigation is an anxiety provoking experience? How can design respond to the patient's insatiable thirst for information on their disease and treatment options? How can design counteract the extreme interface with imposing technology faced by most patients?

Assuming that there is a general agreement that patients with a cancer diagnosis are different than almost any other patient, then **the criteria typically**

**used to inform cancer centre design must, in my view, be different.** This paper argues that the most important and appropriate design criterion for a cancer centre, above and beyond form and function, **is human empathy**. Efficient, flexible, and operationally sustainable design should simply be a given. The greater the degree to which a design team can internalize and empathize with these constituents, the more responsive and supportive the environment, the more successful the solution and the better the patient outcomes.

## How do we understand what a patient feels?

Applying an approach common to design thinking, the key to better understanding the emotional impact of sickness is to let it unfold in stories. Whether in a patient's main complaint or a family member's saga of surgery, the events of illness unfurl and accrue meaning by being told. "Equipping health professionals with the wherewithal to recognize and absorb and be moved by the stories patients tell, might go a long way toward fixing what doesn't yet work in medicine" (Bate, P., And Robert G (2008). The environment of a cancer centre, therefore, should be designed to embrace and enhance these *touch points* derived from their stories, with the goal of making the journey as supportive, nurturing and human as possible for patients and caregivers alike.

## Research study: *Testing the emotive responses to design*

Understanding how to best design a space means that we must **unpack all the emotions** that define a person's experience in that space. A cancer patient or family member is struggling to make sense of something. As designers, we need to help map their emotions visually in order to help make sense of them. We need to determine which design typologies are most likely to evoke the emotional responses necessary to counteract the more salient

negative emotions that a cancer diagnosis tends to evoke. As noted earlier, research tells us that cancer patients and families are overwhelmed by a spectrum of emotions often characterized by:

**Pain**
**Loneliness**
**Worry**
**Anxiety**
**Helplessness**
**Anger**
**Dread**
**Despair**
**Darkness**
**Unfairness**
**Confusion**
**Danger**
**Guilt**

Figure 3: Negative Emotions

I wondered, therefore, what are the design responses that best serve as a counterpoint/antonym to these powerful emotions? What, therefore, can be considered effective design reflections for:

| | |
|---|---|
| Pain | **Wellbeing** |
| Loneliness | **Loved** |
| Worry | **Calmness** |
| Anxiety | **Tranquility** |
| Helplessness | **Control** |
| Anger | **Happiness** |
| Dread | **Bravery** |
| Despair | **Hope** |
| Darkness | **Illumination** |
| Unfairness | **Fairness** |
| Confusion | **Clarity** |
| Danger | **Safety** |
| Guilt | **Blamelessness** |

Figure 4: Negative | Positive Emotions

In an effort to better understand how cancer patients respond to various design typologies emotionally, I designed a simple qualitative research study to try to begin to understand if trends or relationships appear to exist between a set of design typologies and the emotions they tend to evoke.

**Methodology**:
Patients and family members (respondents) who had recently experienced a cancer diagnosis and subsequent treatment in a Cancer Facility (Patient and Family Advisory Committee of the Carlo Fidani Regional Cancer Centre at the Credit Valley Hospital in Mississauga Ontario, Canada) as either an inpatient or an outpatient (or both) met with the researcher. The researcher gave each cancer survivor a booklet that included 5 categories of images. As large scale versions of the images were projected on a screen, the respondents were asked to reflect for no more than 20 seconds per image and to place a check mark(s) in the boxes corresponding to 13 negative emotions found to be typical among all cancer patients and/or the 13 antonyms for each negative emotion based on their own personal emotional response that the image evokes at that moment.

The 5 categories of 15-20 images per category included: *Environment*, *Nature*, *Arts*, *Distractions* and *Companions*. At the end of each category of images shown, the respondents were invited to elaborate if a particular image elicited a particular emotional response and why. This offered more insights into the qualitative data and helped to eliminate researcher bias when interpreting the data. At the end of the session, each respondent's scoring booklets was collected and results tabulated.

Figure 5: Sample of Image Score Card

**Summary of findings:**

1. Worry and Anxiety are omni-present throughout the cancer journey: for the patient and the family.

2. Parking garages evoked universally negative emotions, regardless of the design. They are sources of great frustration and anger.

3. Waiting rooms, whether stark or luxurious, tended to evoke negative emotions including anger and frustration.

4. Inpatient bed images tended to evoke emotions of pain, loneliness, worry, anxiety, helplessness and dread, regardless of the design ambiance.

5. Chemotherapy infusion chairs were viewed as stressful in general, particularly if there was insufficient space for a caregiver/support person. Images of more starkly designed rooms evoked more negative emotions than did those with views to nature, and natural light.

6. Radiation therapy suites tended to evoke strong negative emotions including worry, anxiety, helplessness and dread regardless of the ambiance.

7. Although most respondents scored "home-like" images positively, they qualified their response in discussion to say that "home-like" designs may be more appealing to inpatients who spend more time in the facility, however, as an outpatient, all you want to do is "get home" after a day or clinic time, chemotherapy or radiation therapy. They said, "that is not my home", which only caused them to feel sad and expressed guilt…they missed home.

8. Formally designed gardens evoked more negative emotions such as loneliness, anxiety and confusion as they implied too much "control", something they now have very little of.
9. Distraction was seen as "huge"! (very important) as it eases the complexity of the cancer journey.
10. Gardens were particularly appealing after chemo treatment. They tended evoke a sense of "welcome".
11. Images of different seasons were very appealing to all, (used the word "love" to describe images of the seasons) particularly after treatment. It evoked a sense of hope to be able to "survive to see all the seasons."
12. In general, images of internal gardens were well received, however images of "big nature", like a mountain, evoked emotions of Hope and illumination as it reminded them that "the world goes on".
13. Images of sculptures were viewed neutrally overall. If too complex or busy, respondents felt threatened and more anxious.
14. Hallways with colour offered a positive transition.
15. Technology (PC, cell phones) at the bedside tended to evoke positive emotions as they allowed for control and connections to loved ones.
16. In general, respondents scored much of the art images with positive emotions including: solitude, joy, calmness, tranquil, happy, hope, bravery and well-being. However, some abstract art evokes anxiety and negative emotions. It was noted, that the inclusion of images of the "artist" did not evoke positive emotions as anticipated.
17. Images of family and friends tended to evoke positive emotions.
18. Images of animals, particularly those with a prosthesis, evoked emotions of hope, inspiration, "life worth living", and fearlessness.
19. Images that were viewed as having clarity and order evoked positive emotions for all categories

20. Images that evoked memories of music while in treatment were viewed, in general, as soothing.

## Conclusion

My limited qualitative research effort, illustrates how, with relatively little effort, applying a process that is intended to discover or uncover the emotions that patients feel along their treatment journey, may help us to uncover salient, yet less obvious drivers of design. Beginning our design processes from a position of empathy, where we try to put **ourselves in the shoes of the patient**, enhancing our ability to understand the feelings and emotions of another, **may lead to breakthrough results**. Once we determine which design typologies are most appropriate in this regard, we then must design studies that attempt to measure the effectiveness of the intended emotional responses. For example, drawing on my limited study:

- Did the design of the environment affect the patients as intended?
- Did the design affect their overall sense of control, or well- being or sense of hope or reduce their sense of helplessness, or decrease their sense of blame?
- Is our assumption about the value of a "home-like" environment in a health care setting valid for both inpatients and outpatients?
- Can parking garages, regardless of how bright, and accessible they are designed, be eliminated as a common source of anger and frustration for patients with cancer? Can the advent of autonomous vehicles make parking garages obsolete, thus resolving this conundrum?

Empathy Based design can be viewed, therefore, as a more meaningful approach to Patient-Centered Care within the context of Design Thinking, enabling us to more accurately direct our design efforts to forge new relationships with people who ultimately use it. Starting with empathy, I believe, will lead to great

design breakthroughs.  The key is to understand the *touch points* to humanization that make such relationships possible.

To conclude, the limited research study described above revealed a very telling example of the potential to transform healthcare design by employing **empathy** as possibly, **our most important design driver**.  As noted in my summary of results, I learned that for cancer patients, spaces that imply the need to wait including **waiting rooms and registration spaces** evoke strong emotions of anger and frustration, *regardless of the quality of the design*.  "To be a cancer patient is to be the one who waits"(Salvatore Iaconesi).  By uncovering this emotional response via an empathy based approach, I learned that for Cancer patients, the **notion of time takes on a whole new meaning**.  When we put ourselves into the shoes of a cancer patient who has been told that they may only have 6 months to live, **the design response we need to consider is completely different**.  To continue to design registration areas that take 30 minutes or more to process a patient is inhumane and unacceptable.  Therefore, if we truly designed from a position of empathy, perhaps waiting rooms and registration desks in cancer centres would no longer exist.

*Ian Sinclair is a Principal and Vice President Healthcare at Kasian Architecture in Toronto, Canada. Prior to today, he was the CEO of the Red River Valley Health District in Manitoba, Vice President Redevelopment at The Credit Valley Hospital in Mississauga, Ontario, Vice President Redevelopment at Bridgepoint Health in Toronto, Vice President Operations at Sinai Health System in Toronto and a Principal at Farrow Partnership Architects in Toronto. Kasian Architecture Interior Design and Planning has nearly 300 employees with offices in Vancouver, Calgary, Edmonton, Toronto and Doha.*