



InSight 2

engaging
the health humanities

an international exhibition at the nexus of design,
the health humanities and community

this is
for real

for Real



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engaging
health hub

the humanities

*Edited by Lianne McTavish
& Pamela Brett-MacLean*

*InSight 2: Engaging the Health Humanities
international exhibition*

*Curated by Bonnie Sadler Takach,
Pamela Brett-MacLean & Aidan Rowe*

*May 14 to June 8, 2013
Fine Arts Building Gallery
University of Alberta*

InSight 2: Engaging the Health Humanities

Edited by Lianne McTavish & Pamela Brett-MacLean

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international exhibition curated by
Bonnie Sadler Takach, Pamela Brett-MacLean & Aidan Rowe*

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contents

8 *Preface*

**At the Nexus of Design, Health
Humanities and Community**

*Bonnie Sadler Takach, Pamela Brett-MacLean
& Aidan Rowe, curators*

10 *Introduction*

**Transitions in Health Humanities –
Towards a ‘Critical’ Health Humanities
that Embraces Beauty**

Alan Bleakley

15 *The Work*

Exhibited and Other Selected Work

102 *Acknowledgements*

preface

At the Nexus of Design, Health Humanities and Community

Bonnie Sadler Takach, Pamela Brett-MacLean & Aidan Rowe, curators

In 2012, straddling interdisciplinary worlds encompassing art and design, health and medicine, with a common interest in illuminating and exploring the scope and possibilities of the medical/health humanities within our local academic setting, we invited design students and our wider university community to help us visualize extant and emerging interdisciplinary connections characterizing the health humanities. The outcome was *InSight: Visualizing Health Humanities*, which featured 32 exhibits from over 20 of our faculties and educational and research units, displayed or performed in or near the Fine Arts Building Gallery at the University of Alberta from May 15 to June 9, 2012. With the gallery located adjacent to the two major educational sites for health professional students, this exhibition illuminated a rich diversity of voices, conversations, media and forms, which were also profiled via a dedicated website (insight.healthhumanities.ca), book publication, and media coverage—all of which suggested new opportunities for discussion, along with the potentials of dialogical meaning-making regarding the possibilities of this emerging field.

Over four weeks, 840 people viewed the exhibition and shared positive feedback. Media coverage promoted awareness and active discussion regarding the health humanities. In his foreword to the *InSight* publication, Alan Bleakley recognized the value of “first exposing local contributions to the emerging dialogue,” but encouraged us to expand our efforts “to include international input and output of the highest quality, showcasing a vital cultural force—the subtle and unstoppable impulse to democratize medicine for the public good.”

Fast-forward to 12 months later. Building on the success of our first exhibition project, we have expanded our exploration to include a broader range of perspectives.

In May 2013, *InSight2: Engaging the Health Humanities* opened as an international exhibition featuring work from 36 exhibitors as well as this publication (both profiled on a dedicated website: insight2.healthhumanities.ca), a two-day symposium, and a collaborative course project that brought together learners in design and the health sciences. All of this offers frameworks for examining linkages,

experiences, visualizations and productive imaginings at the nexus of design, health humanities, and the community. Through this interconnected set of projects, we offer an opportunity to open up an expansive, exploratory conversation regarding how we can intentionally engage design and the health humanities, and work collaboratively across disciplines and communities, to create innovative and transformative processes, products, services and experiences that can help to promote health and well-being across specific local and also global contexts.

In embarking on this phase of what we imagine will be an ongoing, interdisciplinary collaboration, we appreciate the value of taking a generative, active and interactive design approach to exploring interconnections between design, the health humanities, and the community. In particular, we value both design and health humanities as continuously evolving area of practice and inquiry, particularly when we begin to respond to social accountability mandates characterizing our fields.

With *InSight 2*, we offer a few of our reflections on our journey. We invite you to offer your reflections as you experience the text and images profiled in this publication and in our *InSight 2* exhibition. We also invite you to share your ideas with us and the growing community of scholars, practitioners, community organizations and activists at the “Design, the Health Humanities, and the Community” symposium (May 24 to 25, 2013), and in response to the “Designing for Health” collaborative course project that we are piloting in connection with the “Radical Imaginings and Imaginings: Social Design and the Health Humanities” course offered through the Department of Art and Design. You can write to us at info@healthhumanities.ca.

InSight 2 focuses on what roles design brings to different processes, not just the production of things, but as a means of working and thinking together. Design looks at the idea of what the whole project does, allowing for the communication of design beyond just capitalist activity. It's much broader than that, flowing into community engagement and social responsibility. This project is an interesting exemplar of this, moving outside of the classroom to enrich learning environments that achieve visible results. It's a nice balance of chaos and structure. AR

It was interesting to follow a question without needing to figure everything out beforehand, but rather just opening oneself up to the inquiry, through dialogue and a community-based process, taking time to become slowly aware of various aspects or dimensions of the question. I appreciated the intuitive, design-based process we followed, with its emerging sense of fit and rightness that helped keep us on a productive track, where new openings for inquiry and collaboration would emerge. Already, I believe, new collaborations have developed through this process, both close to home and internationally as well. PBM

InSight 2 helps us explore how we can learn to work in teams across disciplines, areas and communities on critical issues connected to health and well-being. Students respond well to these collaborative, community-based and meaningful projects. These experiences prepare students to develop questions and work towards solutions with others; to share resources and learning among professions; to pool their collective wisdom and fresh ideas; to frame chaos; and to imagine the future together. BST

introduction

Transitions in Health Humanities – Towards a ‘Critical’ Health Humanities that Embraces Beauty

Alan Bleakley

A Peek Through The Window

A small group of fresh-faced medical students—only 22 or 23 years old—is intently focused on a practical in the laboratory, hunched over what look like racks of test tubes. One woman suddenly recoils, her face screwed up in disgust. A tutor smiles knowingly and asks her to pass the test tube to another member of the group to smell. These are fourth year students undertaking a five years’ long undergraduate medical program. Next year they will be shadowing doctors, already sniffing the full identity of ‘physician’ and relishing more legitimate acceptance into hospital ward-based clinical teams and community practices. The year after they will legitimately enter their first jobs as practicing doctors, shedding the now defunct skin of ‘medical student’.

In the United Kingdom, residents no longer don white coats, but they will display a certain demeanour, an air of confidence, although many of them will be quite out of their depth, carried along by senior colleagues before finding their feet some years down the road in family practice or a specialty hospital career. Let us hope that this generation will develop—to use William James’ terms—a ‘tender-minded’ rather than a ‘tough-minded’ medicine in which patient care is at the centre. Here, self-care and mutual support for colleagues is high on the agenda, and the care and treatment of patients is genuinely considered to be an art as well as a science—humane, sensitive and generous, and, to use a term that is not often used to describe healthcare practice, also an act of beauty. Let us hope also that these young doctors will be graceful and accomplished—not merely competent, but exquisite. To draw on the famous Canadian physician William Osler (1849–1919): ‘The practice of medicine is an art, not a trade; a calling, not a business; a calling in which your heart will be exercised equally with your head’. This argument can readily be extended from medicine to healthcare as a whole.

Before immigrating to Canada, several generations of Osler’s family lived in Falmouth in West Cornwall, United Kingdom, just a stone’s throw from where one of the centres of the innovative medical school (Peninsula) in which I work is located. Let us return to that present-day medical school and to those young students smelling the contents of that ‘test tube’. The ‘laboratory’ they are working in is actually

a classroom for a ‘smell and taste’ workshop—part of a summatively assessed medical humanities special study unit—and the tube they have just passed around is emitting a noxious odor whose composite ingredients they are trying to discriminate with the help of their tutors. One tutor is an expert perfumier and wine taster, the other a senior consultant pathologist with a long-standing interest in the medical humanities.

A little later in the workshop, the pathologist projects a PowerPoint slide with a quote from the celebrated Hungarian chemist and philosopher of science Michael Polanyi, and asks ‘what is missing from Polanyi’s important insight?’ Polanyi’s words are: ‘no science can predict observed facts except by relying with confidence upon an art: the art of establishing by the trained delicacy of eye, ear, and touch a correspondence between the explicit predictions of science and the actual experience of our senses to which these predictions shall apply’.

While Polanyi draws our attention to the importance of educating the senses for scientific observation, and calls such observation ‘an art’, he ignores the senses of smell and taste. The next slide projected by the doctor contains a quotation from an article called ‘Soundings’ by Abraham Verghese: ‘There are many distinct smells in medicine: the mousy, ammoniacal odor of liver failure ... the urine-like odor of renal failure; the fecal odor of a lung abscess; the fruity odor of a diabetic coma’. Here is the link providing both meaning and relevance to what these medical students are learning through the workshop experience. The perfumier/wine taster and the doctor are collaboratively teaching the students how to develop the neglected senses of smell and taste (wine tasting is also part of the experience). Later, the students will leave the smell and taste ‘laboratory’ to test their knowledge on a structured ward round and then they will debrief their experiences in small group discussions.

Abraham Verghese is a distinguished physician and Professor for the Theory and Practice of Medicine at Stanford University Medical School and a best-selling and award-winning fiction writer. He was a keynote speaker at the

Association for Medical Humanities (AMH) conference in 2005 at Peninsula Medical School (Truro campus). He is a renowned champion for retaining the fast-disappearing arts of ‘hands on’ diagnostic medicine through the physical examination—the ‘soundings’ of palpation, auscultation and percussion. Verghese’s fear is that students (and clinical skills tutors) are losing interest in the high art of physical examination in an era of sophisticated imaging techniques, and that such artistry will gradually be eroded unless we emphasize its value in medical education.

In his novel *The Tennis Partner*, Verghese warns against trying to accelerate the learning of such arts, which must develop with experience or mature like a good wine. But he persuasively points to the benefit of developing the ‘animal snout’, and other senses, of the doctor-in-training: ‘Smells registered in a primitive part of the brain, the ancient limbic system. I liked to think that from there they echoed and led me to think ‘typhoid’ or ‘rheumatic fever’ without ever being able to explain why. I taught students to avoid the ‘blink-of-an-eye’ diagnosis, the snap judgment. But secretly, I trusted my primitive brain, trusted the animal snout’.

The Health Humanities in Transition

Trusting their own animal snouts and building on the great success of the 2012 exhibition, symposium and subsequent publication *InSight: Visualizing Health Humanities*, Bonnie Sadler Takach, Pamela Brett-MacLean and Aidan Rowe have combined their formidable talents to plan and curate the 2013 exhibition and symposium, *InSight 2: Engaging the Health Humanities*. The trace of that marvelous exhibition and symposium is what you now hold in your hands—a valuable addition to the growing archive on the medical and health humanities.

InSight uses the term ‘health humanities’ rather than ‘medical humanities’. This is for two reasons—firstly, the ‘health humanities’ describe bringing practices and insights from the arts, design and humanities to bear on the topic of ‘health’—however we might interpret this word. (I am personally a critic of naïve, idealistic and utilitarian readings of ‘health’ and ‘well-being’ as ideal goals, preferring, like Voltaire’s

Candide, to accept that life is necessarily full of suffering. For example, many people have to live with chronic illnesses that will never translate into ‘health’. They may, however, gain ‘meaning’ for their illnesses, even if debilitating, while they will never achieve ideals of ‘health’ and ‘well-being’. In this sense, we can talk of ‘being well’ as a relative term.)

Secondly, the ‘health humanities’ indicates a move away from the apparent exclusivity of the signifier ‘medical’ humanities, to include professionals who are not doctors such as dentists, nurses, pharmacists, operating department practitioners, paramedics, social workers, occupational therapists, optometrists, physiotherapists, dieticians, radiographers, and so forth. Such inclusivity, importantly, brings service users, or the general population, into the equation. Arts and humanities interventions ultimately serve the public in improving clinical care. Such interventions, especially television medi-soaps, or soap operas about healthcare, also raise popular debate about cultural issues such as what constitutes public and individual ‘health’, and what is ‘good treatment’ by professionals. So the public must not be left out of the equation. It is then gratifying to see that the theme of *InSight 2* is health humanities, design and ‘community engagement’.

Those of us who work in the humanities in medicine and healthcare seem to be forever apologizing for being unruly teenagers who refuse to grow up, engineered specifically to irritate grown-up and hardened anatomists, biomedical scientists and clinicians. We should shed this image and allow ourselves an adult voice, praising the coming of age of the humanities in medicine and healthcare. Technically, George Sarton coined the term ‘medical humanities’ in 1947 in the journal that he founded—*Isis*, the official publication of the History of Science Society. But historically, medicine has always been considered an art as well as a science, and we saw above from Michael Polanyi that science does not proceed without its art of close observation, and this art is central to science-using clinical medicine.

It seems strange that proponents of the art of medicine and healthcare should have to fight for recognition of such artistry in the contemporary era. For those who are

sceptical of using precious curriculum time to educate, for example, the development of the artist's eye in medicine and healthcare, there are historical antecedents such as Leviticus 13 in the Old Testament from 400BC. In the section 'how leprosy is to be recognized', the priest (the original physician) is given this advice: 'If the priest, looking at the place on the skin, finds that the hairs have turned white and the skin of the part affected seems shrunken compared with the rest of the skin around it, this is the scourge of leprosy.' Moreover, recognizing the exact shade of the color white was central to diagnostic acumen, where the symptom was compared with a range of natural referents—over 30 shades of white, including 'wool', 'quicksilver' and 'the skin of an egg'.

If medicine and healthcare are arts, then let us draw on experts in the field—artists and designers—to work collaboratively with doctors and other clinicians to realise the artistry of care through clinical education. While doctors use the senses in the art of diagnosis, let us also involve experts with developed sensory awareness—visual artists for the eye, musicians for the ear, perfumiers and oenophiles for the nose and taste buds, tabla players for the fingertips, and designers for the synesthetic experience of multiple senses acting in harmony, just as we draw on the inspiration of writers to help to educate narrative intelligence for close listening, appreciation and interpretation of patients' stories. As those medical students advance through their careers, surely they will become connoisseurs in their chosen fields of expertise. Let us then introduce connoisseurship to them as students.

Engaging the Imagination of the Community

In such collaborations between healthcare students, clinicians and artists, I think there are two big themes that the humanities in healthcare must grapple with as it continues to develop. Firstly, healthcare humanities education should be accountable to the public if its ultimate aim is to improve patient care. This means that education providers have to work closely with those in public engagement to work out how the benefits of the healthcare humanities can be best communicated to the public—hence exhibitions such as *InSight 1* and *InSight 2*. This is, however, a double-edged sword.

Engaging community interests must be active and reciprocal, and not passive or show-and-tell. The community's imagination must not only be ignited, but the community must be allowed to speak back. Further, this dialogue must be critical and not merely self-congratulatory. In turn, artists and designers should address social responsibility in their work. In my foreword to last year's *InSight* exhibit publication, I reminded readers that Nietzsche had pointed out that writers and artists act as 'diagnosticians of culture'—part of their role is to point to the symptoms of a culture that may be addressed through literary and artistic interventions. Such interventions may be unsettling because they question habits and traditions that may act to stifle progress, innovation and the life of the imagination.

Secondly, how will using the arts and humanities in health education and healthcare practice benefit the communities of artists and humanities scholars who collaborate with clinicians and the public? The older 'medical humanities' for too long have lived off the good will of artists and designers who would provide their labour, intelligence and creative flair for the benefit of medicine or medical education without the medical community giving something back to the arts and design communities. This has led many artists to flirt with medical themes but to then abandon such potential collaborations as they saw their artistic licence and freedoms gradually strangulated and eroded by the need to adapt to the conservative aspects of medical culture, hospital design and 'safety' consciousness. The risk of art and the risky shift in culture that can be induced by arts-based interventions has too often been constrained in collaborations with medicine.

Importantly, artists have a responsibility to critically re-interpret social provision such as healthcare and medicine, asking fundamental questions about the meaning of illness and its treatments. Increasingly, such arts interventions have become institutionalized within the provision that we have traditionally called the 'medical humanities'. The role of the artist within the healthcare humanities is dual—firstly, as I have said above, to translate health issues into media for public engagement and debate through exhibitions such as the *InSight* series, preferably interactive; and through theatre and performance including television, visual art and film, literature, and so forth. Secondly, there is a further,

reflexive, step. These artists must also turn their collective critical imagination to transform the culture of the healthcare humanities itself.

I am pleased to see that *InSight 2* addresses the points above, and the remainder of this introduction will summarise these points in terms of transitions in the healthcare humanities. Readers of this extended catalogue, and those who were lucky enough to see the exhibition *InSight 2*, will have noted that there were many penetrating observations by artists and designers, involving a range of media of expression, where risks were taken and the work was not blunted by associations with conservative and risk-averse medical and healthcare culture and themes. Such archived work has lasting value in transforming the healthcare humanities culture in a processional sense.

In summary, artists, in collaboration with clinicians, academics and service users, must work hard to:

Maintain their integrity, as argued above. This means having their work accepted not on the terms of the host institution—medicine, healthcare, the hospital, and so forth—but on the terms of the artist. The artist's economic livelihood must be respected, so that their work is financially rewarded. And their artistic vision and integrity must be respected, so that they are able to take risks, produce challenging avant-garde work, without their imaginations being reined in. It is only through such license that good diagnoses of cultural ills will be made. This is not to argue for abuse of such license. Collaboration between artists and host institutions in healthcare is vital, but to maintain the impact of risk (art generating unique insights through risk) artists must be afforded license to push the boundaries, especially of so-called 'taste'.

Be political as well as aesthetic and ethical. By this, I mean that artists working within the healthcare humanities culture should work hard to be good citizens, educating for democracy and tolerance of difference. Part of this is inclusivity – hence the 'dental humanities' (rapidly growing in my own institution), and, more widely, an inclusive healthcare humanities.

Recognize that there can be 'well-being' without being well. As noted earlier, 'health' must be a relative term to include those with chronic illnesses whose lives will never be one

of 'well-being' but may include elements of well-being, and where meaning is made of illness without seeking 'wellness'.

Critically engage with the medical and health education provisions of institutions to promote the medical and healthcare humanities as core, integrated provision and not just add-on or supplement to core learning by professionals. All health professionals engage in communications with patients and colleagues requiring sophistication and sensitivity, and constituting a health intervention in its own right. The medical and healthcare humanities provide a primary medium for learning and applying empathy, tolerance of ambiguity and improvisation in professional encounters. The medical and healthcare humanities should be twinned with learning professionalism, ethics and communication as a fundamental part of the curriculum, providing a core critical counterweight to potentially reductive science.

Shift the healthcare humanities culture from passive to active community engagement through interactive exhibitions and events. Public engagement through the arts must not be show and tell, but include dialogue and debate so that there is collective responsibility for diagnosing and treating the cultural symptoms that in turn become a burden on the healthcare system. I am talking about issues such as lifestyle choices and diet, but particularly psychological and emotional symptoms. It is no wonder that we have high rates of depression in such a manic culture, where the bar for depression is lowered. Inequalities lead to health problems—this is a political as well as an economic issue. Environments are built as if to anaesthetize or dull. The healthcare humanities culture has a duty to engage the public, reciprocally, in public health debate and this includes politics, economics, and ecology.

This brings me to my conclusion and this will focus on the value of aesthetics and the lyrical genre. We do not give enough air space to aesthetics in healthcare and medicine. We are more embarrassed to discuss aesthetics than pornography. It seems to me that medicine and healthcare go out of their way to suppress beauty. Nobody wants to talk about it, let alone celebrate it when it appears. Medical students learn clinical 'skills' in an instrumental fashion, but they are rarely taught how to execute skills in an elegant or beautiful manner,

beyond the mundane. But what if we deliberately set out to create a curriculum for doctors, dentists, nurses, social workers, pharmacists and so forth that was ugly, dulling, insensitive, blunt, deadening, unpleasant, even repulsive? This would be curriculum design madness—yet it is a reality for some elements of curriculum implementations. Without evangelizing, surely we can be more proactive in translating the medical/ healthcare humanities into a medical/ healthcare aesthetics? We might then see ‘beauty’ as a significant learning outcome or (surely an oxymoron!) as a ‘competence’! —for example, in shifting from a merely competent practitioner to an exquisite practitioner, as mentioned at the beginning of this essay.

To put the last point into a bigger frame, I am concerned that we have not yet adequately addressed repression of the lyrical genre in medicine and healthcare, where epic, tragic and dark comic genres are dominant. We are still in the grip, to some extent, of the heroic individualism of epic medicine, with its hierarchies and idealized portraits of dead white males in medical school boardrooms. Where are the portraits of great clinical teams (led by women)? We are also in the grip, to a greater extent, of healthcare as an occupation tied up with the tragic, while catharsis is achieved for staff by letting off steam through black humor (often at the expense of patients and behind their backs). I say this because the great tragedy in healthcare remains largely unaddressed—that we are still needlessly causing harm to and killing patients through medical errors grounded not in technical incompetence but in the non-technical realm of poor teamwork and communication. This must be addressed through improving teamwork for patient safety.

We should, through the healthcare humanities, challenge these genre dominations, to allow a shift to the pastoral and the lyrical. Here, collaborative endeavour (gathering the harvest) is emphasized. Metaphors switch from heroic endeavour such as ‘medicine as war’ to collaborative endeavour such as medicine as community care. Importantly, here too the quality of care is emphasized, where the form, or aesthetic of work matters. Work in future healthcare environments can be elegant, graceful and beautiful, as well as technically proficient.



the work



Yanks

The Trees Have Grown

I retrace the route I followed my first six grades.
The trees along the way have grown with me,
- they still look large, make me feel small.
The autumn earth-dark protects the tattered plaster school walls
as they sop recollections, reflections.

Returning, the chill, dry air swirls now-fallen leaves,
lifts them from the gutter,
- skittering scattering across the sidewalk, the pavement
hands stuffed in pockets, almost to my knees,
I realize that I can't recall
the last time I entered The Test.

So, once more
- I keep my eyes lowered,
striding with purpose, tracing the sidewalk's texture,
- until I make the turn...
and must take three more steps:
- one, two, three...
before I'm allowed to raise my gaze,
- to the horizon, the glowing sentinel
out-block, splashing light on the sidewalk,
- illuminating the chalk lines.

Past two houses, then another,
I approach, eyes shaded as the streetlight looms,
seen the concrete for chalk - the Magic Chalk
that demarcates the Path:
- shining numbered squares
that must be followed in proper sequence
- to reach Safety.

My gate takes me to where our house light beckons.
Smells: boots, coats (and hopefully, hot chocolate),
work-memories bubble up into my throat:
"He-ho-o! I'm ho-o-one!"

But. First. I. Must. Pass.
- The Test.

The thrill returns:
- poised on the brink of an abyss,
squeals suppressed at the prospect of a "horrid fate",
- not "horrible...", not "terrible...", but "horrid".
A fate greed upon with certainty by Sylvie and Rita and me,
which we risked every Tuesday night
- beneath the streetlight, in our train dress-uniforms.

I find myself reaching inside my coat,
for my Bravie pin,
the dancing gold figure
- protection for my journey.

Heartland Project

Stuart Adams & Jim Davies

A series of 14 'poem-paintings'—paintings and poetry presented within the same frame—were commissioned for the Diagnostic Imagery area of the Mazankowski Alberta Heart Institute. The artists created the works with patients, visitors and healthcare workers in mind; their intent was to provide a 'restful place' for those being tested (or testing) for heart disease. To that end, they selected scenes and subjects that represent the diverse nature and history of Alberta—ones for the viewer to recognize as familiar and comforting. The process was community-based on two levels. Initially, the subjects for the poem-paintings were solicited, and approved, through an interactive process with the selection Jury as community representatives. Second, the artists presented each poem-painting to evoke familiar experiences for the viewers—the words and images working in concert to transport the viewer to their own *Heartland*. All viewers were taken into consideration in the process—as patients, staff, or visitors.

Using Transmedia to Promote Dialogue about the Moral Distress of PICU Teams

Wendy Austin, Pamela Brett-MacLean, Daniel Garros, Timothy Anderson & Erika Goble

In Canada, and elsewhere, the arts are increasingly being used to explore and portray the experience of health and illness, and issues relevant to the provision of quality healthcare.^{1,2} An integrated research programme undertaken over the past several years by Wendy Austin, Canada Research Chair in Relational Ethics in Healthcare, has involved exploring the moral distress experienced by healthcare professionals. In this work, the term “moral distress” (MorD) is used to refer to the experience of health practitioners when they have been restrained from acting ethically based on their personal values and understanding, as well as training and experience³ (the term “ethical distress” is also sometimes used in this literature). Given that MorD is a significant workplace issue that affects practitioner well-being and staff retention, early stages of this research programme have been directed toward gaining an understanding of MorD as experienced among pediatric health care teams.

The pediatric intensive care unit (PICU) is one of the most ethically challenging and emotionally charged practice areas.⁴ The PICU offers high-tech, life-sustaining treatments that invariably involve intense critical care situations which frequently ‘push the envelope’⁵ leading to emotional and conflicted discussions and decision-making related to diverse treatment options, consent for treatment, and end-of-life decisions. PICU practitioner MorD has been linked to an array of issues: unrealistic expectations, aggressive treatment, suffering, medical error, patient quality of life, poor prognosis and outcome, resource shortages, and lack of institutional support.⁶ Recognizing that MorD is exacerbated by formal decision-making structures, power imbalances and authority issues, attempts to address MorD in PICUs have included such administrative approaches as continuing education, encouragement to report, debriefing sessions, and shift worksheets. However these approaches have not been particularly effective. What has not been fully explored to date is the need to share practice stories

to enhance communication and understanding among members of the healthcare team, policy makers, and also the general public.

Over the course of the project, from 2007 to 2012, more than 60 stories were collected from members of PICU healthcare teams that provide high level intensive treatment, such as extra-corporeal life support, organ transplantation, and complex heart surgeries. Health practitioners who shared their stories of moral distress in pediatric intensive care included dieticians, nurses, intensivists, medical residents and clinical fellows, respiratory therapists, and social workers. An analysis of their stories supported earlier research that has shown that MorD occurs when practitioners believe that they are not fulfilling their moral obligations, and thus feel their integrity is in jeopardy. This research also supported earlier findings regarding the impact of MorD: when moral distress is unresolved, health practitioners’ perceptions of their care and workplace are affected⁷ and many contemplate or do leave their job or their profession entirely.⁸ In this research phase, the stories that were collected were characterized into five types: Stories of Bearing Witness, Stories of Collusion, Stories of Resistance, “Phantom” Stories (stories that haunt), and Untold Stories (unspeakable and unknown stories).

Very often MorD is not recognized, or is minimized by those in management roles, who we can imagine are frustrated by a parallel sense of obligation to provide the highest quality of care to patients and their families, while feeling powerless to introduce a responsive or effective solution to the ethical dilemmas healthcare staff experience in PICU, and other clinical care units. Even after developing a typology of the stories our research participants shared, it was difficult to imagine how to adequately represent the diversity and intensity of their stories through usual qualitative data approaches. It became apparent that we needed to develop a dissemination approach that: 1) respected the diverse stories and manifold tensions related

to the experience of MorD among members of healthcare teams in PICU, and 2) could potentially reduce the gap between “evidence” and “practice.” Ultimately, the research study culminated in the creation of the play *Just Keep Breathing* by playwright and director Timothy Anderson. In this play, the moral distress stories gathered in the research come to life portrayed within the practice lives of a range of characters, representing different health professions, who work in a fictionalized PICU setting. The play gives voice to the anguish, anger, and sadness of moral distress experienced by members of the PICU team, and also portrays how they work to find both support and solace, along with some form of resolution, together and individually.

The play has been through two cycles of performance, critique, and revision based on advisory group, PICU staff, and audience feedback. In 2012, *Just Keep Breathing* was included as part of the *Ir/*sight: Visualizing Health Humanities exhibit,⁹ with three performances that took place within the Edmonton Clinic Health Academy, located two blocks away from the FAB (Fine Arts Building) Gallery, the site of the visual arts exhibition. Audience feedback has suggested that further dissemination of this work would be effective in promoting rich, focused dialogue about moral distress, ethics, and interdisciplinary teams. Currently, we are implementing a dissemination project that is intended to widen the audience for this play, and enhance its impact in facilitating change in health care management and policy.

We have received funding from the Canadian Institutes for Health Research to implement a progressive, participatory action research (PAR) dissemination plan. Using a “transmedia” platform, we hope to engage a wide number of practitioners and educators, policy makers, and the public in ongoing discussion regarding experience of moral distress and related issues. Our dissemination project will consist of film, videoconferencing, a website, a blog, and an educational DVD. Originating in narratology and first adopted in the field of education,¹⁰ transmedia is the process by which multiple media are used to explore an issue. The goal is to create an ‘open-ended knowledge environment’¹¹ that engages a wide audience,¹² with the potential for reaching audiences for whom traditional dissemination and engagement approaches have often proven ineffective. The effectiveness of a transmedia approach lies in the way various senses, modalities, values, and emotions are engaged,¹³ numerous subjectivities and perspectives are reflected,¹⁴ and spectator involvement encouraged. The ontology of transmedia approaches

is grounded in “play, experimentation, co-creation, and collective action,”¹⁵ as well as interdisciplinarity and co-ownership.¹⁶ Moreover, this approach is seen as crucial to the discussion of contentious ethical issues,¹⁷ though few studies exist to date.

While evidence-based clinical practice guidelines derived from systematic research establishes knowledge for best practice,¹⁸ these guidelines do not necessarily change practice.¹⁹ To date, our theatre-based dissemination approach has proven valuable in focusing attention on experience of MorD but only for a limited number of audiences. This is a common outcome in theatre-based dissemination. Depending on available budgets, literary and research-based theatre productions developed for purposes of sharing insights and knowledge about the meaning and experience of illness and healthcare have a limited-time run, which often restricts the educational and policy impact of the work. Few such plays have been adapted for film (a notable exception is the play *Wit*),²⁰ or been introduced across a number of media. The overall purpose of our dissemination project is to explore how arts-informed dissemination using a participatory, transmedia approach can progress dialogue to enhance awareness and responsiveness to MorD in pediatric intensive care. We believe that the effective promotion of dialogue about MorD demands their accessibility for all stakeholders. In addition, congruent with the original research, we are using a PAR approach to ensure research activities are relevant, useful, and enable stakeholders to make positive change.²¹ Based on the principles of stakeholder collaboration, valuing local knowledge, and meaningful knowledge translation,²² we believe PAR is appropriate to addressing issues arising in shared habitus especially when changes in work environment are sought.²³

In moving from a theatre-based representation of research findings to a transmedia dissemination approach, we hope to enhance the potential for engaging multiple stakeholders in considering the findings of earlier phases of our research programme in an encompassing and engaging way. By considering various design features and outreach strategies as part of our dissemination approach our hope is that we will not only enhance awareness and dialogue, but also promote critical and reflective thinking that helps to identify practical means and approaches to mitigating MorD and ensuring the highest quality, patient-centred care. In a subsequent phase of this research,

we plan on testing the pedagogical value of the video resources we are developing, specifically in relation to health professions education.

Acknowledgements: We would like to acknowledge Canadian Institute of Health Research (CIHR) funding support for this research.

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Let's Talk About Aging



Let's Talk!



"I love to watch children grow and become the people they were meant to be. It's an amazing time of life. Babies are so totally dependent, and yet they change so much week by week, you can actually see the changes happening. By the time they are about 16 months the changes don't seem so rapid but you know they're maturing physically and emotionally, and growing intellectually. My favorite age is when they're around four or five years old. That's when they really start to show you who they are... and they're so smart then! It's amazing to see how they figure things out. I think the most important thing for children in the early years is to feel secure, so they can explore their world. I wish there was something I could do to make sure all children feel safe and loved ..."

Loretta, mother of five, grandmother of seven and great-grandmother of three

Let's Talk About Early C

Let's Talk...

Alberta Health, Office of the Chief Medical Officer of Health

Let's Talk About the Early Years and Let's Talk About Aging are two reports recently released by the Office of the Chief Medical Officer of Health to raise awareness about the importance of early childhood development and healthy aging. Each report is a vehicle to spark dialogue within the community and challenge dominant perspectives. Community engagement is inherent throughout the process of developing the reports and is essential to their success. The reports are developed collaboratively and rely on the knowledge of researchers, experts in the field, passionate stakeholders and individual Albertans who, guided by a common vision, help to shape the focus, content, and language of the reports. The outcome is a network of enduring relationships that support the intention of the reports after their release. The reports are distributed to stakeholders across the province, reaching beyond traditional stakeholder groups, inspiring 'communities of practice', community groups, families, and individuals, who use the reports to initiate conversations that drive change within their networks.

Narratives of Medical Miniatures

Rachael Allen

Medical miniature models have been exhibited widely since 2008 within both art and academic contexts. They enter the health humanities domain by virtue of exploring the predicament of modern medicine in its approach to illness experience, and the requisite for more human-centred methods that honour the patients' stories, creating a space for dialogue and debate surrounding current tensions within medicine and healthcare. Engaging with these art objects prompt narrative recollections and conversations amongst their viewers, creating momentary communities who are inspired to share personal insights, perspectives and experiences as students, educators, practitioners, and health professionals, as well patients and carers. In the same way literary work communicates topics studied by the health humanities and the continuous re-assessing of humane practices, the miniature artworks probe these issues by entertaining both our visual and intellectual perceptions, and stimulate dynamic debates surrounding humane medicine from both the (absent) patient and practitioner terrains.

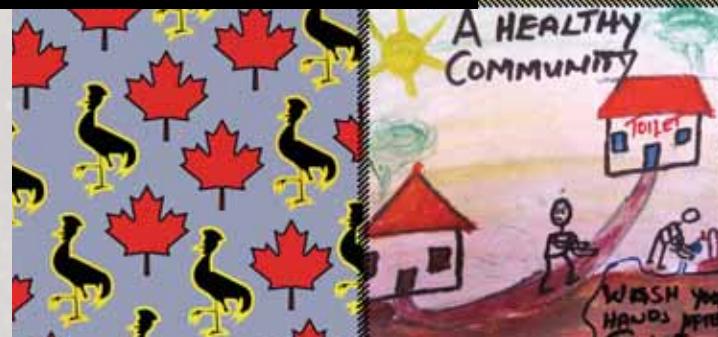




Artivists Quilting Across Cultures: Building Community and Exploring Health

Artivists & collaborators

This co-exhibit showcases messages created throughout an inter-cultural exchange between the Ugandan youth collective *artivists 4 life* and students from the Department of Art and Design. Informed by *artivists 4 life* participatory processes for identifying and responding to social/health issues the quilt weaves together personal reflections and visual communications created and shared across the two groups as they engaged in dialogue around topics such as community sensitization and notions of what it means to be healthy. At the interstices of art/design and health this co-exhibit responds to *Insight 2: Engaging the Health Humanities* by creating an interactive learning space for re-thinking and re-imagining how we communicate and relate across cultures and around notions of health and well-being. Through an inter-cultural and inter-epistemic creative space this activist intervention aims to engage exhibit-goers toward new understandings of other peoples' realities of health and community, participating in collaborative knowledge-making while redistributing agency across cultures and spaces.



Systems of Panic: Negotiating Boundaries of Social Anxiety Disorder

Louise E. Boyle

Mental forms of space are impressionable and delicate, acquiescent to our social and spatial experiences. At the intersections between place, body, and identity lie the crucial fabrics of everyday lived and embodied experience which remain pertinent to understanding the ways in which our spatialities are reflective of the reciprocal relationship between the self and the spaces we encounter. They encompass the connections to the environments we are immersed in and the relationships we encounter while in those spaces weaving through the materiality of daily life and grounding our experiences in routines and familiarities that harbour physical, metaphorical, and symbolic dimensions of space, so often unacknowledged until something happens to break the ‘normal’ connectivity with it. When gazed at through the lens of mental health, specifically Social Anxiety Disorder (SAnD), there is scope to explore how various relational and responsive ‘systems’ of spatial experience enable individuals to re-negotiate the spaces around them, particularly in moments of intense panic. With these ‘systems’ in mind, I draw attention to how individuals actively rescript their own social recoveries through virtual spaces engaging in processes of agency, resistance, and empowerment, particularly in relation to the medicalisation of their disorder. Such aspects call in to question, and potentially disrupt, the discursive and material construction of those with mental health ‘problems’ challenging the habitual frames of mind and socio-cultural constructs of mental ill health demonstrating the necessity of “a human-centred design approach to health and well-being involving community members in identifying, and co-creating solutions to, issues and problems that affect them.”¹

Systems of Panic

“It’s [Social Anxiety Disorder] a destructive force on your daily life. The panic is debilitating. Suffocating. Claustrophobic. Relentless.” (Anna)²

The scenes and spaces of anxiety are dissonant and convulsive, continuously altered and reproduced by heightened moments of panic. They encapsulate a multiplicity of intersecting planes of experience demonstrating with incredible clarity the innate ways our mental and emotional experiences sensitise the connections between the self and the surrounding environs. Although not a constant factor, the physiology of panic and spatial experience are intrinsically tied to the emotional experiences harboured by heightened moments of panic in social space and reflective of the powerful ways space can be re-negotiated. The systems of panic negotiated throughout reflect experiential perspectives and a complex whole of interconnecting techniques and entanglements that shape and are shaped by everyday social and spatial circumstances. Expressed through feelings of dislocation from their own bodies and detachment from their spatial surroundings, the embodied processes of systems of panic are made manifest, problematising subjects understanding of themselves as a clearly separate and distinct entity from the world around them:

“A panic attack is overwhelming. Something as mundane as going outside holds the threat of a panic inducing situation. I don’t just panic. I am the panic. Everything around you becomes unknown; it feels like it falls away and your mind and body are separated.” (Olivia)

The polarization of the mind from the body during intense moments of panic highlights the catastrophic impact of the threat of perceived danger has on how individuals view different spaces but also how that space can place situational demands on a person and consequently lead to a panic attack. She continues:

“My first attack was at home. Not being able to anchor yourself to home just dissolves everything.” (Olivia)

Her inability to ‘anchor’ herself to a known, safe place ultimately challenges the concreteness of her world. As her sense of place become unbound and abstract she loses her sense of self becoming disembodied from her spatialities. The normalcy of space begins to disintegrate by having no solid, mappable location in which to ‘locate’ her sense of self. Olivia becomes divorced from her-self, questioning her place in the world and her connectivity with her surroundings.

Olivia’s experience highlights the idea that complex psychosocial processes impact socio-spatial experiences, offering insights that enrich our understandings of such forms of engagement. With respect to panic, discussion void of clinical frameworks that tend to trivialise the particularities of individual or community experience through reductive processes may evolve. Instead, rich, textured accounts of experience that embody the emotions, thoughts, feelings, affects and instances of particular places and spatial experiences may be helpfully considered. An understanding of how physiological aspects are woven into the fabric of everyday life through systems of panic embraces more of the embodied and material dimensions of subjectivity, including space and place. In addition, in the context of health-related research, narratives written by informed authors should seek to take seriously the story of illness, “valuing the individual as the empowered author-narrator of her own story.”³ Developing geographical narratives of mental health experiences does more than just uncover the places and spaces that shape, and are shaped by, experience; they aim to develop participatory geographies for the production of context-bound knowledge(s).

Embodied Knowledge(s) and Online Spaces

“The body is not just seen as an object worked on by medical professionals in medical institutional geographies, but rather it is acknowledged that individuals work on their own bodies, enacting and embodying their newly acquired healthy knowledges.”⁴

The diversity among various planes of experience is complex, constantly evolving and unfolding within and across socio-spatial and technological boundaries. Emerging from these spaces are individuals engaging in processes that seek to re-negotiate their socio-spatial worlds and re-fashion identities as active agents rather than the static model of self that is perpetuated by reductive tendencies of clinical frameworks concerning mental health. The uptake of new and complex technologies demonstrates

in creative ways how individuals are able to re-claim their identities through active engagement with their own diagnosis through the sharing and acquisition of medical and health related knowledges and shared experiences. The processes through which individuals acquire such knowledges are a complex, exploratory journey. Medicalisation in particular is a turbulent subject for most who, while mostly content to accept that their experiences are intrinsically related to the ‘state’ of their mental health, feel restricted and caged in by the categorisation of their mental health as a ‘disorder’ or ‘problem’. For some there is a sense of normalcy engendered by having their socially anxious experiences defined, for others there is an incessant need to externalise Socially Anxiety Disorder as something the individual ‘has’ rather than something the individual ‘is’, reflecting the ways in which those diagnosed begin to fashion identities and construct new boundaries of the self. Medicalisation engenders further issues of social exclusion ultimately caging the person and defining their experience through a checklist of associated symptoms:

“I joined an online community [after seeing her doctor]. I didn’t believe in those clinical terms. I believe they reduced something real into nothing. Slapping a label on somebody doesn’t mean anything. It just means you ignore the rich texture of that person’s unique human experience.” (Anna)

The availability of medical knowledges on the Internet has the ability to empower “individual patients to understand more about particular health conditions in ways potentially disruptive of traditional hierarchies in medical relationships.”⁵ Engagement with others enables profound feelings of belonging to occur and provides validation through subjective experiences free of clinical frameworks and medicalisation:

“I was welcomed into their community and they shared their knowledge and experiences with me. For the first time I felt like I belong somewhere, I didn’t feel alone.” (Lisa)

Online spaces provide a platform whereby individuals can increase their own stores of knowledge. Interaction with medical information and discourses online and the subsequent attention required for facilitating an understanding of experience through community engagement poses questions regarding the diagnosis, treatment and shaping of social attitudes in relation to mental health and the shaping of policies of self-management. Such engagement promotes the individual as an active agent void of the

phenomena of ‘dependency’ that is highly valued in society concerning mental ill health. Social Anxiety communities online portray intimately networked individuals resisting medicalisation and challenging stigmatising conceptualisations of the isolated and static subject.

Community engagement in online spaces facilitates a respect, particularly in relation to the specific nature of Social Anxiety Disorder, of the socio-spatial difficulties faced by individuals living with SAnD. Creating planes of discussion through community engagement opens up avenues for reconciling medical knowledges and the experience of illness. Situating these aspects within socio-spatial and technological contexts providing insights to inform how people with Social Anxiety Disorder make sense of and manage mental health whilst engaging with the idea that, through alternative medical spaces, individuals are able to contest their status as someone with mental health difficulties.

At the intersections between geography and mental health studies, there is a unique interdisciplinary opportunity to broaden understanding of mental ill health through various spatialities offering diverse frameworks for engagement with experiential accounts through community engagement. Active collaboration with mental health communities encompasses aspects which address critical societal issues, particularly in relation to the stigma that surrounds mental health, contributes significantly to knowledge and understanding recognising creativity and agency in everyday spatialities. By embracing geographical narratives there is scope to re-draw the boundaries across disciplinary fields to co-construct knowledge(s) of the nuances and subtexts of individual’s experience of mental health and “locate the integrative and agentic aspects of their subjectivity.”⁶ The aspects explored here are twofold, reflecting both academic and experiential linkages between narrative geographies for the production of context-bound knowledges and the subjective experience of psychosocial processes, and the use of online spaces for community engagement to creatively “imagine and design innovative and transformative processes, communications [and] ... environments... that can help to promote health and well-being.”⁷

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Truth Serum

Sarah Aziz

Medical laboratory technologists provide crucial health information that can change the course of a patient's life, from revealing a pregnancy to confirming the presence of a malignant tumour. However, despite their crucial role in these intensely personal events, technologists rarely learn anything about the living, breathing people they are meant to be helping except for their names and dates of birth, while few members of the public understand or give much thought to the role of the human being who performs their tests. In *Truth Serum*, I attempt to bridge this gap by inviting the viewer to consider the laboratorian's unique challenge of remembering the human impact of the test results when confronted with an essentially anonymous tube of serum. Like the laboratory technologist, the viewer must rely on their imagination to piece together the life story of the patient in the test tube.





Nobody's Home

Susan Bleakley

Key to the nexus of the health humanities, design and community engagement is the issue of public access to spaces that are normally off-limits to all but medical and healthcare professionals. The morgue is a location known to most of us only through television simulation, and where public scrutiny is normally denied, which is not true for, say, a crematorium or cemetery. This film not only provides direct representation of the space of the morgue, but also an interrogation of the strange mixture of beauty (aesthetic) and dulling qualities (an-aesthetic) of that space, now available for public engagement through galleries or conferences. We trust in pathologists, their assistants, and the hospital administration to provide appropriate care for the dead at post mortem in what is surely in some sense a hallowed space. However, this film reveals that the space of the morgue is not 'patient-centered' but pathologist-centered, where dilapidation goes unnoticed.





Weaving Relationships

Laura Boffi

Weaving Relationships is a set of tools for symbolic communication and sensemaking that supports the patients, the caregivers, and the palliative care equipé in sharing individual representations of the illness and in building meaningful end-of-life relationships. The project started with three weeks of fieldwork in a hospice. By interviewing and actively engaging with the palliative equipé, families, and patients through cultural probes and brainstorms, the researcher reached deep insights on the way the different actors cope with the illness and the end of life, which led to the design challenge of the project. Early prototypes of the developed concept, *Weaving Relationships*, were built and given to the palliative equipé and caregivers to react to them and to rehearse with them how they would use them in their hospice practice. This experience prototype was video recorded and the video stands as the final outcome of the project.

Malaria Education of School-aged Children in the Kwahu-Eastern Region, Ghana

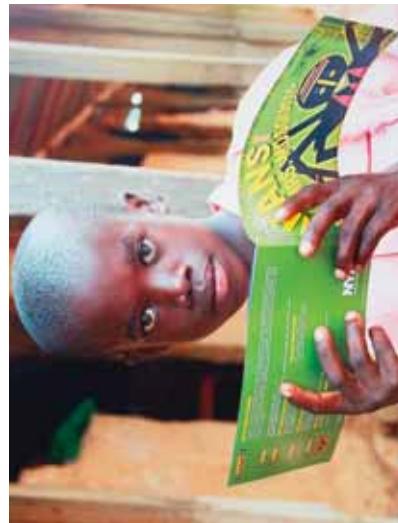
Edward A. Gottfried & Deborah Lardner

The World Health Organization (WHO 2012) reports that “malaria—an entirely preventable and treatable disease—takes the life of an African child every minute.” Malaria accounts for one in five of all childhood deaths in Africa, and of the one million annual malaria deaths worldwide over 75% occur in African children less than 5 years old. Malaria also causes severe morbidity in children, such as anemia, low birth-weight, epilepsy, and neurological problems, which compromise the health and development of millions of children living in malaria endemic areas.² The most vulnerable communities in the world continue to lack sufficient access to long-lasting insecticidal nets (ITNs). In several sub-Saharan African countries, the rapid, widespread implementation of insecticide treated nets—which can prevent malaria by protecting those sleeping under them from the bites of night-flying malaria parasite-carrying mosquitoes—has been accompanied by significant reductions in child deaths. These are real life findings that reflect the results of clinical trials and support continued efforts to scale-up and maintain ITN coverage in sub-Saharan Africa.³

In 2011, the NYIT Center for Global Health began developing an educational tool to teach children in Oworobong, Ghana, the benefit of using malaria bed-nets. We decided to use a West African folktale with characters to which the children could relate. Our goal was to increase awareness of malaria and its prevention in Oworobong during a three-week-long outreach project during the summer of 2011, designed to provide health care. In the end, we developed a multidisciplinary project with the NYIT School of Education and the NYIT College of Osteopathic Medicine, with students and faculty of the NYIT Center for Global Health performing a play with rod puppets. Created in the style of Southeast Asia shadow puppets, our puppets were about two feet tall and manipulated by sticks or rods. They were created to be lightweight and durable in the extreme heat and humidity of West Africa. The play was presented at schools during the day, and since there was no electricity, it was performed using flashlights and headlamps at night.

Translation was delivered in Twi, the native language of Ghana, and English because school children are taught in English. Approximately 500 Ghanaian students—100 at each of 5 village primary school sites located about a 1 to 1.5 hour hike from Oworobong—saw these performances. A question and answer session was conducted following each performance of the play. Children demonstrated immediate recall of the signs and symptoms of malaria, the mosquito as the disease vector, and the benefit of prevention by using a bed-net. Fifty malaria bed-nets, donated by the manufacturer Best Net, were given to teachers at the schools for further distribution.

In 2012, the educational content was reinforced by the development of an illustrated book, created and published by the Publications and Advertising Office at NYIT. As English is the official language of Ghana, the story was written in English with the character names in Twi. Several hundred copies of the book were brought to Oworobong and given to children at the end of each performance of the play. The book *Anansi** Tricks Mrs. Mosquito*, quickly became a “treasure.” Books had never before been given to children in Oworobong. Older students read it to their younger siblings and friends.



Sibling teaching is encouraged by elders in African societies, and is seen as an important form for the transmission of knowledge. It is characterized by the inclusion of traditional games, singing, dancing, use of riddles and story-telling. Some of the songs and stories observed during sibling teaching have moral lessons or values embedded in them, enabling children to listen to stories in a pleasurable atmosphere while learning the values upheld by their society.⁴ Many African societies readily practice sibling teaching and care-giving, all part of children's training for the responsibilities they will be expected to perform in the future as adults and parents. Older children then have the skills necessary to teach their younger siblings various concepts or values, and young children are likely to pay attention to their older brother or sisters. The innovative project collaboratively produced at NYIT, which utilizes rod-puppets, graphic comic books, and videos, reconstructs this ancient art of "story telling", or in the Ashanti culture—established in Ghana during the 11th or 12th century—Anansesem⁵ "Spider tales", to advance health, well-being, the popular trickster character of Ashanti folklore, who serves alternately as hero, villain, moral inspiration, and comic relief. His presence in Ashanti folklore appears to be ancient, for he figures not only in humorous tales but also in some that have the character of creation myths. Anansi is responsible for the moon (or sun) being in the sky. Anansi is also the owner of all stories that are told, and therefore when people wish to tell a tale they first acknowledge that it belongs to Anansi.⁷⁸ Using traditional or indigenous characters in stories makes learning enjoyable for children, guiding them towards a more comprehensive understanding of the material. The knowledge achieved by children in this fashion may serve as a foundation for health education.

Perhaps the best way to evaluate the effectiveness of our malaria education play will be when we return to Oworobong to see whether or not the children have been using their bed-nets, how many books remain in use, and how many children have developed malaria. We will continue to perform the play, distributing more bed-nets and Anansi books.

One medical student described his participation in and experience with the Anansi performance during the summer outreach project of 2012: "At many of the schools we acted out the Anansi play only to be amazed at the interest and interaction shown by the kids simply from cardboard puppets and strings. The play's best night was the first night. After a full day of practicing the puppets (i.e. figuring out how to hold them best without being crooked, ensuring they were up against the white cloth the entire time, making sure the puppets shook as the translators served as their voices and ironing out all other details) we finally debuted the play to a giant audience of locals from around Oworobong. Spotlights consisted of 6-7 headlamps shining brightly from all angles. Each person's puppet slowly became 'their' character over time as we mastered how to put the puppets in and out and how to appropriately 'act' each one. By our 5th or 6th showing, the play had been done so many times there were very little mistakes. All we needed to find each time was two sticks to hold up the backdrop and a group of engaging children—both of which seemed plentiful. Personally, what made me most proud was that we were actually helping the communities when everyone was opened to questions after the play was over. To see the kids ask about malaria and how it can spread showed me that they were in fact learning from the play and took it to heart. This was one of my primary goals of the entire trip—to promote health and wellbeing in any way that I can."⁹



It is clear from this passage that the medical student was participating in his own learning even as he brought lessons to the community in Ghana. The skills acquired by our medical student(s) through the theatrical performance of the Anansi story included “the altruistic joys of teaching and of compassion” and the realization that a simple puppet show and story book could change a child’s life. This project provides a wonderful example of the role of the arts in a form of medical humanities that promotes what Arthur Kleinman has called the “interpersonal skills of kindness, respect, compassion and communicative competence, are the building blocks of what it means to be a physician.”¹⁰



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Collecting the Wounded (for Nelson Algren)

Blair Brennan

I present an artefact from a difficult time in my life, involving my addiction to morphine initially prescribed for pain relief. I place this artefact in front of receptive viewers with the expectation that something of that difficult time is transmitted to them. I can't say precisely how this works. Nor can I say why I believe that it works. I have only my passionate belief that all art is communication and that, at the best of times, this communication is complete and thorough, and that images and objects will inevitably convey things that words alone cannot.



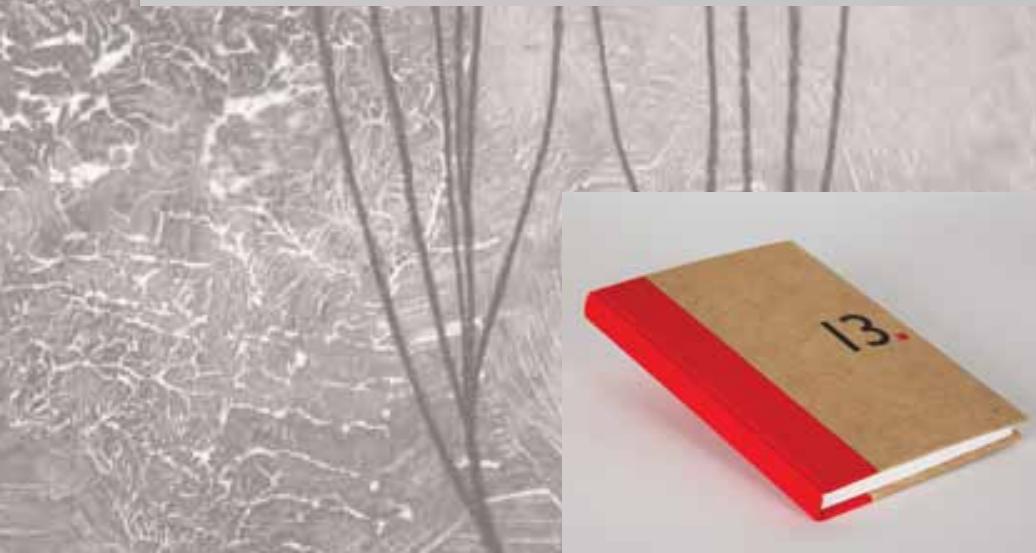


engagingdesign: 'Stigmas'

Paul Chamberlain

This collection of furniture metaphorically highlights both society's biggest challenge and opportunity in response to the ageing population. 'Stigmas' is a collection of furniture that embodies issues relating to the physical, cognitive and attitudinal challenges older people face in everyday life. These 'critical artefacts' do not present solutions but a series of considered questions that illuminate a landscape of old age. 'Stigmas' form part of an ongoing research enquiry 'engagingdesign' that explores artefacts as metaphors for stimulating community engagement and co-creation and challenge existing methods and paradigms. These critical artefacts help overcome specialist jargon, encouraging broad disciplinary and community participation. The work provides a scaffold for collective creativity that positions older individuals as active participants rather than passive respondents of research focusing on their preferences and aspiration. Chamberlain constructs through his work a context that provides a 'theatre for conversation' that prompts and provokes to develop further insight and meaning.





gratitude / I feel lucky

Sue Colberg

Following a life-altering illness, reflections I recorded in a blank book helped me to learn from and release aspects of my experience. This gave me a renewed sense of well-being and gratitude for the people in and the elements of my life. I gained unexpected spiritual and emotional insights, in the process of writing, which found symbolic expression in the making of a series of hand-bound books meant as offerings of thanks for the kindness and love that played a role in my healing process. There is no need to be a professional writer or artist to transform difficult situations into artistic works in order to give them meaning. Humans are creative. As long as we recognize this and give ourselves permission to respond to health difficulties creatively and intuitively, not just medically or rationally, we can use this way of healing... making something meaningful concrete so that it can be shared and may benefit us all.

End of the Never Day

Carol Hodgson

Before the Story

The vision for the creation of the *End of the Never Day* came from two driving needs. The first stemmed from a desire to help practicing physicians and physicians in training improve their ability to discuss difficult diagnoses with patients and their families. The second driving force was a personal one—a journey of self-reflection and growth as I coped with my own daughter's difficult diagnosis.

Digital storytelling is a visual medium for telling a first-person, authentic story. Typically, the storyteller provides his/her story verbally and uses pictures, video, and music to highlight elements of the story, all of which are recorded digitally. Digital storytelling as an organized practice was first developed in Berkeley, California by Dana Atchley and Joe Lambert. From this practice came the Center for Digital Storytelling. I created *End of the Never Day* when I completed a Center for Digital Storytelling course in Denver, Colorado in 2012. The *End of the Never Day* is presented here in a format conducive to a print publication.

The language used in the *End of the Never Day* is aimed at the level of the health professional. It's not that non-health care professionals cannot understand the story, however some of the terminology, such as the term "chromosomal allele" was used specifically for the intended audience—physicians and physicians-in-training. I nevertheless hope that the story is universal—one of a parent who learns devastating news about her child and then struggles to receive the appropriate diagnosis, in a thoughtful, caring, and humanistic manner.

Our Children Are Different, But Not Less

We arrived at our hotel in Chicago. I had just been offered a job at the Feinberg School of Medicine at Northwestern, my family was with me to see if the job and place were a good fit. I was putting our suitcases down when our 6 1/2 year-old daughter Jane walked from one end of the room to the other.



We pulled out our phones and immediately started taking pictures.



Only 30 minutes before we had pushed Jane into the hotel in her wheelchair; she had never walked independently before.



Five years ago it was a different story. It wasn't clear what Jane would accomplish after we heard from her pediatrician all the things Jane would never do.

Before that day I was a typical parent with dreams and expectations for our child just like any other parent.



We began to worry, though, when Jane started to miss one developmental milestone after another, but our pediatrician continued to tell us. “Every child develops at her own speed.” I wish we had heard more of that sentiment later—on our “never” day.



A few days later we arrived in Denver with no family, no friends, no one to support us, but with some pull as a new Associate Dean, I made an appointment with the best developmental pediatrician. We provided Jane’s history, she was examined, and genetic tests were ordered. When we came back for the test results we sat nervously. We had been in Denver just over two months. We were alone in the office with Jane who was 19 months old. That was our Never Day.



NEVER
NEVER

Bright White.

That day I heard that Jane had Prader Willi, a genetic disease with hypotonia, developmental delays, and the inability to feel satisfied when one eats; these kids usually become very obese. One of the PBL cases in my course was a Prader Willi case; I knew the diagnosis too well. My heart stopped. Then the never started.

Jane will never drive a car. Never go to college. Never get married. Never do this, never do that. Never. Never. Never! The world seemed to end that day, it was like everything turned white in front of me, no future, no hope. There was Never going to be a decent future.

That night as I thought about the never of the day my world went black. Up until this day, the worst day in my life occurred 11 years ago when my mother, Jane’s namesake and my best friend, died of cancer. This day was like that other horrible day, because this day the little Jane I knew in my mind’s eye died. All I saw ahead of me was blackness.



By now we were referred to a developmental pediatrician, who told us that Jane would catch-up by age 3.



Her diagnosis—idiopathic benign hypotonia of infancy. Jane began PT.



Eventually Jane was referred for an MRI and we were told that our little 17-month-old had a paucity of white matter and that no one really knew what that means yet, except that signals in her brain will not be conducted at the normal speed. It did not seem good. Searches in PubMed did not help.

I survived the next few days when we met with a family with a little girl, Jennifer, who had Prader Willi. Then there was hope again. She was not obese, the whole family practiced a very careful food regimen. Jennifer was mainstreamed into school. She played soccer.

We were so grateful for this hope.



I began to wonder if the diagnosis was correct.

It was not a Never day, it was a Yes day.



There are other things that didn't match,

then she had her first seizure.

We saw our pediatrician again and she decided to run more tests, the ones she didn't run the first time, the methylation study.



Yes there is a future,



yes Jane can accomplish things,
A disease of low tone, seizures, and as the website describes it severe mental retardation.

We now say intellectual disability, but it means the same.

Angelman kids don't talk, she may never walk on her own, she may never get out of diapers, she certainly will never go to college.

yes our lives, especially Jane's were not doomed.
But that came from a family, not from the physician.



There were many *nevers* again. But what we never heard were the positives. We never heard that all kids are different—some will do better than others, some will do worse. I would have liked to hear from our pediatrician, “I don’t have a crystal ball to tell you all the things Jane will accomplish, but I know she will have accomplishments.”



Video: Jane using walker

Like getting up when she falls down.



Jane 3 months after starting to walk independently.



Jane walks the Angelman walk for the first time (age 7).



Let there NEVER be a Never Day again.

After the Story

Each patient or caregiver has different needs and desires for how they want to learn about a difficult diagnosis. Given that all individuals are unique, there is no one magic, formulaic way to have that discussion. In our story, the first time we met with our pediatrician after receiving the diagnosis of Angelman Syndrome, the first words out of her mouth, really before we could even speak, were “I’m sorry. I should have ordered the methylation study. I thought it was Prader-Willi Syndrome.” That was all it took for us to trust her again and have her continue as our pediatrician. And she is a great pediatrician. Even really good doctors can be poorly skilled at discussing a difficult diagnosis.

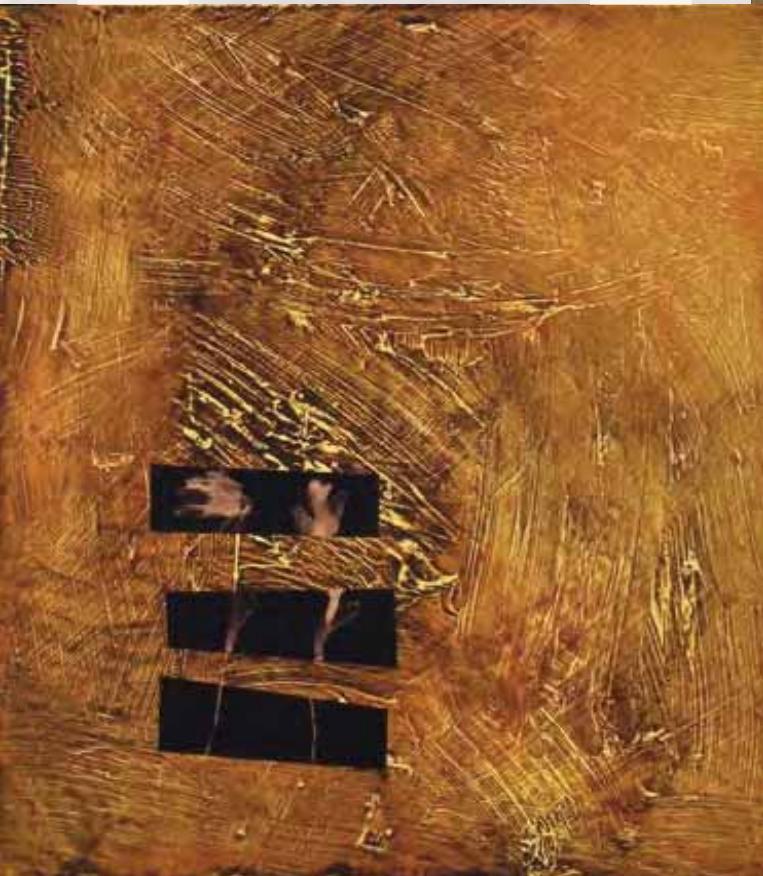
These conversations are difficult for everyone, including the physician. In patient-centered care, the patient comes first. The physician also needs to take care of his/her own emotional needs, but in that moment, during that discussion, the patient comes first. The physician should take a few moments before the discussion to mentally prepare for the conversation, imagine the possible scenarios, and come up with a plan. The discussion should be done in private and there should be enough time with the patient. When a patient or family member hears those hateful words—cancer, Angelman Syndrome, diabetes, asthma – whatever the diagnosis, the physician’s mental plan may have to change. The physician needs to be flexible and respond with compassion and empathy, always keeping the needs of the patient forefront. This prescription for the physician, assumes that he/she takes care of him/herself by preparing beforehand and reflecting after the fact on how the discussion went and by learning from the experience. Some physicians may say that there is not enough time in a busy physician’s daily schedule to do this. But without it, the patient may be left in darkness, suffering in despair, without hope. And the physician loses too, because he/she has missed out on an essential essence of the profession—connecting to and caring for another human being while remaining human. With more training and conversations about this topic within the profession, hopefully there will be an end to the never day.

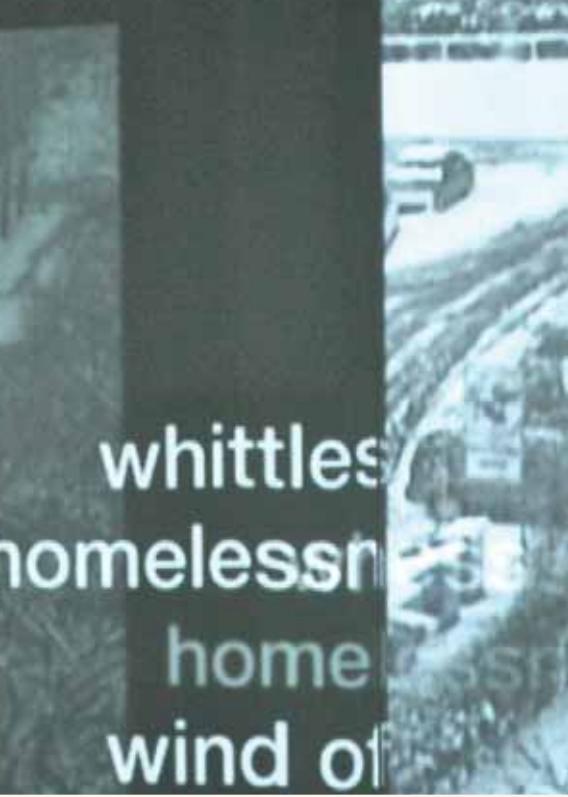
Will You Be My Hands?

Kate Collie & Mia Weinberg

Will You Be My Hands? is a foray into the uncharted territory of mixed-ability visual art. It is a collaboration between Mia Weinberg, a professional visual artist and art consultant, and Kate Collie, a psychologist working in cancer care. The original premise was that Mia would ‘be Kate’s hands’ so she could realize creative visions beyond her current physical ability. The structure of this interdisciplinary collaboration challenges habitual frames of mind about authorship in contemporary art. The content challenges assumptions about aging and disability.

As is often the case in disability arts, the lines between advocacy, education, creative expression and rehabilitation have been blurred, even erased. The purpose of the project as it goes forward is to use assisted art making to foster community building and community engagement through shared creative expression. *Will You Be My Hands?* opens up exciting possibilities for innovative applications of the arts in cancer care.





BIPOLAR DISORDER

whittles
homeless
home
wind of



adrift

Jannie Edwards, Bob Lysay & Agnieszka Matejko

adrift addresses the growing social problem of homelessness through an interdisciplinary artwork. The metaphor of wind and the weather it creates symbolically links to the powerful but often invisible socioeconomic systems that result in “shadow people”—the homeless, who are disproportionately afflicted with mental health issues, and who drift through the edges and alleys of the city—marginalized, largely unsupported and virtually invisible. For mainstream society, interactions with homeless people are often at an uncomfortable distance—they are “other.” This poetry-based video installation attempts to dramatize and visualize that sense of disconnect and marginalization. Designed for display in a wide range of non-traditional spaces, this work takes art into the broader community where it has the potential to generate discussion and gently challenge negative preconceptions about homelessness.



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|  |  |  |  |  |  |
| 1 VOTING Find the collaborative game on LinkedIn! Introduction of Bipolar disorder to the participating Design Fundamentals class. | 2 BRAINSTORMING Then, students were encouraged to come up with a number of headlines for the campaign. | 3 VOTING Because there were many rich and diverse ideas, students voted on which strongest phrases to be developed during the production stage. | 4 PRODUCING Students produced a number of posters using traditional media such as acrylic paint, pencils, markers, collage, etc. | 5 DISPLAYING All final posters were publicly displayed on the LinkedIn platform during a Design Fundamentals exhibition at the end of 2012. | 6 PRESENTING Only five of the most effective posters were selected by MAHI to be further digitized for use in the final campaign. |



UNDERSTANDING BIPOLAR DISORDER

Lyubava Fartushenko

The fundamental goals of the Mental Health and Awareness Initiative (MAHI) at the University of Alberta are to raise awareness of and to improve the quality of life for those afflicted with mental diseases, conditions, and disorders. "Understanding Bipolar Disorders" was a collaborative project between MAHI and a Design Fundamentals class that presented a visualization of bipolar disorder through a series of public posters. This collaboration provided an interesting learning experience for students by offering them an opportunity to work on a real project. Under the guidance of the instructor, students were encouraged to conduct independent research, to explore a variety of visual techniques, and to participate in progress meetings with MAHI representatives. The resulting awareness campaign was exhibited during the Bipolar Symposium at the University of Alberta in January 2013.

Bipolar Disorder: Mental Health and Awareness Initiative (MAHI), Faculty of Nursing, University of Alberta, 2013. © Faculty of Nursing and MAHI. Bipolar Awareness, 2013. © Faculty of Nursing and MAHI. Bipolar Awareness, 2013. © Faculty of Nursing and MAHI.

RESULTS:



CAUSE

Bipolar disorder is a frequently occurring illness, which affects on 1% of the population, more than a million people worldwide. The World Health Organization estimates that bipolar disorder is the sixth leading cause of years lived with disability, and set the disease as the 14th leading cause of years lost due to disability in 2004. In 2005, i.e. Bipolar disorder is characterized by more than 50 percent of extreme high mood lasting at least a week. Manic periods often release reduced stress, increased self-esteem, and a sense of well-being. However, manic episodes may bring panic or anxiety. (Bipolar Symposium 2013).

PROCESS

| | | |
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| 1 BRAINSTORMING Find the collaborative game on LinkedIn! Introduction of Bipolar disorder to the participating Design Fundamentals class. | 2 BRAINSTORMING Then, students were encouraged to come up with a number of headlines for the campaign. | 3 VOTING Students voted on which strongest headlines to produce. |
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Understanding Bipolar Disorder

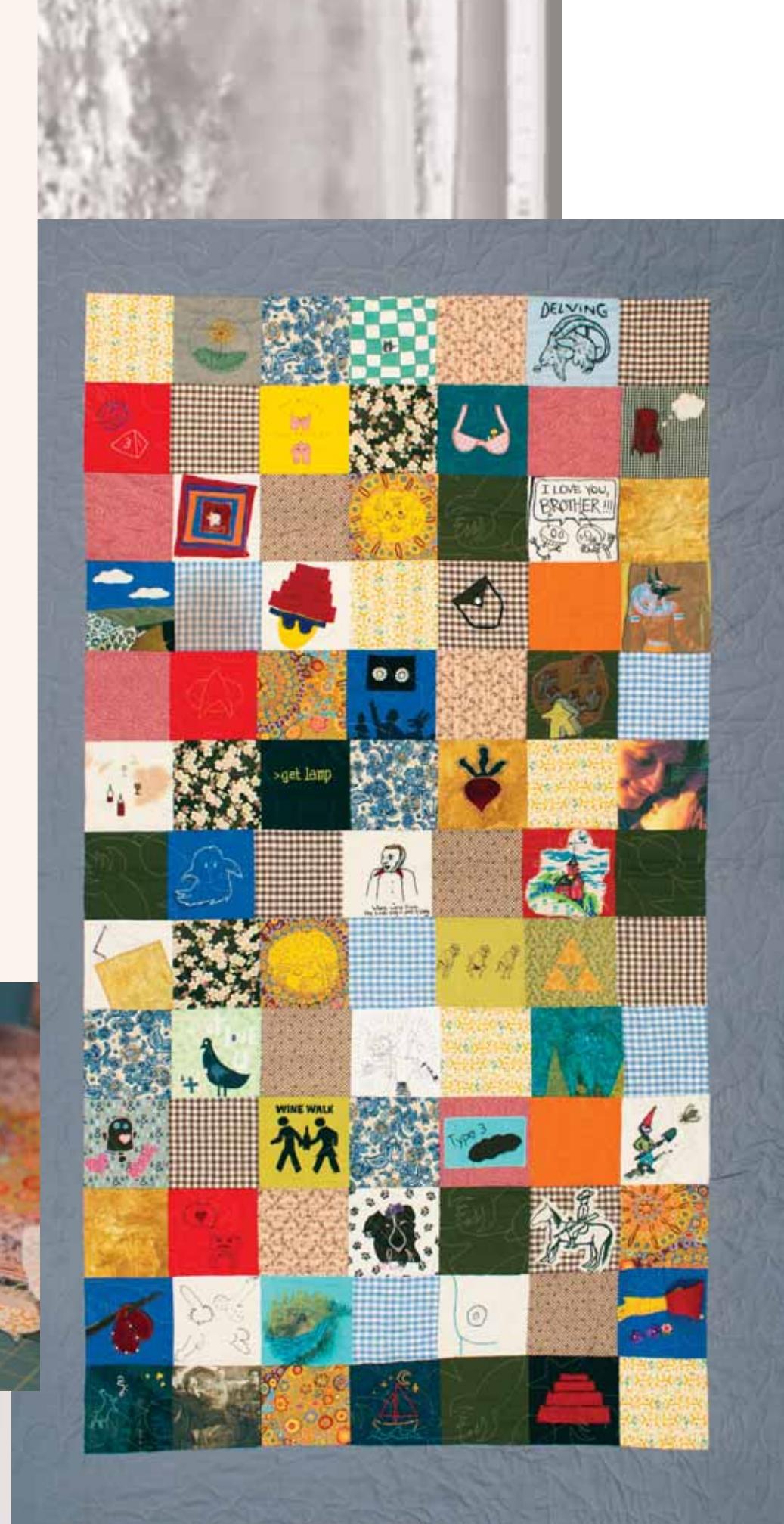
Lyubava Fartushenko

The Mental Health and Awareness Initiative (MAHI) was established to raise awareness and improve the quality of life for those afflicted with mental diseases, conditions, and disorders at the University of Alberta and beyond. MAHI was organizing the Bipolar Symposium at the University of Alberta so a group of Design Fundamentals students became involved in creating an awareness campaign for Bipolar disorder. After an in-depth introduction of Bipolar disorder, the Design Fundamentals class devised a number of headlines for the campaign. Students voted on strongest phrases to develop during the design stage, producing a number of posters using traditional media, such as acrylic paint, pencils, markers, and collage. Five of the most effective posters were picked by MAHI for use in the campaign. The final awareness campaign was the result of valuable collaboration between MAHI and students of Design Fundamentals. The anticipated number of attendees increased from 50 to 200 people, signifying the design success of the promotion.

Quilting with Love

Friends of Darren Zenko

Quilting with Love celebrates the life of Darren Zenko, a dear friend whose impact on our lives is expressed through the stories and memories represented by imagery on individual quilt squares. The quilt began as a response to his admittance to palliative care, where his battle with cancer was drawing to a close. Through the quilt, we sought a way to comfort Darren, express our love, and honour the experiences we shared with him. As a community of over 30 participants in different cities, we became a closer-knit group by commemorating our time with him and addressing our loss through storytelling and image making. In the act of making our squares and constructing the quilt, we were able to share and remember experiences about our friend, and share those memories with Darren in a tangible form.



Ways of Knowing, Ways of Seeing: Creative Arts in Medical Education

Arno K. Kumagai

The work of art is not an object that stands over against a subject for itself. Instead the work of art has its true being in the fact that it becomes an experience that changes the person who experiences it.

Hans Georg Gadamer¹



Alex Donaghy & Sara Neil. Family Centered Experience Interpretive Project: Two Worlds Apart (2011). Oil combine. Featured in Academic Medicine 87(12) December 2012.

How does one teach empathy? Actually, the question is embarrassingly arrogant and presumptuous. After all, medicine is a profession that is particularly adept at taking idealistic, compassionate students and turning them into overworked, jaded, cynical physicians. So, to rephrase, how does one enhance empathy?

One way to do this is through stories. Throughout the history of humankind, stories have been the most powerful way in which one human being passes on the meaning of experiences to another. The stories that we tell ourselves and each other frame our world and our lives so that we can try to make sense of it all—especially of those moments and times where we struggled, suffered or grieved. Stories of illness, if quietly absorbed with attentiveness and humility, have the power to transform—to prompt reflection, to broaden perspectives, to engender action in the world.

In the University of Michigan Medical School's Family Centered Experience (FCE) Program, we have attempted to harness the power of stories for

incoming medical students to help to foster perspective-taking, imagination, empathy, and a humanistic view of medicine as a core component of an emerging professional identity.² During the first month of medical school, pairs of students are matched up with volunteer families in the community who have a serious or chronic medical condition. Over two years, the pairs make scheduled visits to the homes of their volunteers for the sole purpose of listening to the stories that they tell of their illness and its care. The visits are organized around different themes: the impact of illness on self and family, doctors and patients, stigmatization of illness, and breaking bad news. Each visit is supplemented by small group discussions, reflective essays, and readings—activities designed to stimulate in medical students a type of reflection that engages consideration of their own life experiences, thoughts, feelings, values, and biases in approaching health, illness, suffering and care.

The learning from these interactions goes deep. It is not a list of facts that can be recalled on a multiple-choice exam, nor is it limited to a set of skills that can be used in with simulated patients. It is an awareness and an understanding of oneself, others and the world. It resides, I believe, in tacit knowledge, and becomes, in Polanyi's words, a type of wisdom where "we know more than we can tell."³ If approached with sincerity and openness, the lessons acquired through these stories of illness and this process of exploration come to reside deep and "dwell within" learners⁴ and although largely unconscious, may nonetheless guide future actions. They also add to the complexity and subtlety, the mystery and richness of the understanding that individuals may develop of themselves, their patients and of this most humane of professions.

So, from an educational perspective, how does one assess this type of learning? If one attempts to free oneself of the constraints imposed by outcomes-driven, demonstrable competencies, how does one get an authentic sense of students' understanding? Revealing comments during

conversations and discussions might allow glimpses at it, reflective essays may provide a sort of educational “artifact” that one can save for later analysis. However, another approach is the creation of art.

According to Dilthey, art can reveal the overall connectedness that a single work or idea has for the entire life of an individual: this expression may “draw from depths not illuminated by consciousness.”⁴ The mystery of the person lures us for its own sake into ever new and deeper attempts at understanding. In such understanding the realm of individuals, encompassing human beings and their creations, opens up (p. 233).⁴ By exploring the meanings of students’ creative art we may understand the ways in which they come to understand the stories and struggles of individuals with illness, as well as the ways in which these acts of interpretation impact their own worldviews.⁵

Midway through their first year, students in the Family Centered Experience Program are asked to form teams of 2-4 students, each student representing a different patient-volunteer and a different story, to identify common themes among a very diverse group of life experiences. The students are then given the task of using any arts-based medium of their choice to express their understanding. Projects arising from this activity are as varied in type and scope as the stories they portray: original music, paintings, sculpture, multi-media presentations, poetry, dance, and photography.⁵ Projects are presented to each FCE small group, comprised of medical students and their faculty preceptor, and a select number of art works are displayed at an annual FCE Interpretive Project reception for medical students, faculty, and patient volunteers in the spring. Numerous projects have been published⁷⁻¹¹ or presented in national and international conferences.

So, how does creative art enhance a humanistic view of medicine? In this context, art may serve as a tangible manifestation of the students’ bearing witness to their patient-volunteers’ stories—to the reconstruction of their volunteers’ selves, their struggles, sense of loss and pain. Art may serve as an affective anchor between the subject of the artwork, the artist, and ultimately, the viewer. Art may also serve as a method of critique: through art, students have explored how the self is fragmented into a list of diagnoses or of lab results, how the individual is stigmatized in illness by acquaintances, classmates, coworkers or health care professionals, how finances and insurance concerns and prescription renewals may bury the individual beneath

paperwork and distract her or him from attending to the things that really matter: their health, their family, their work, to life itself. This critique also often includes a call to action: it may inspire a sense of moral outrage, a challenging of the status quo, and a desire that to change things for the better.

Student artwork also engages a critical function of art: that of “making strange.”² By portraying everyday things, events, and occurrences in a strange and new light, this type of art forces us back on our heels by challenging our assumptions about normalcy and by problematizing our worldviews. Through disruption, discomfort and alienation, it forces us to look at ourselves, our patients, and the world with fresh eyes.

Above all, art created by medical students based on themes arising from stories of illness reaffirms a sense of community, of shared human feelings, fears, values, and aspirations between individuals with chronic illness and their future health care providers. In other words, art has the potential to “re-humanize” interpersonal relationships in the practice of medicine. Finally, art empowers. While portraying individuals’ difficulties and challenges with illness, it also provides testimony to their courage, perseverance and achievements in their Sisyphean struggles in daily living. Furthermore, through the acts of interpretation in which the student-artists engage, they too are empowered. In creating art, they place a highly personal stamp on their emerging professional identities and become active agents of their future by committing their whole selves to the humanistic enterprise. Finally, the sharing of stories and artwork in the context longitudinal interactions between medical students, faculty, and patient volunteers and their families stimulate the engagement of physicians-in-training with communities (and visa versa) in acts of collaborative learning and appreciation. These interactions strengthen connections between an academic health system and its surrounding communities in mutually beneficial—even transformative—ways.

The Family Centered Experience Interpretive Projects, a collection of which may be viewed in the Media Gallery of the FCE website (<http://www.med.umich.edu/lrc/fce/index.html>) represent a tangible manifestation of this commitment to education for community health and humanistic care.

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Giving Voice to Health: “Sanitation” in Liberia

Michael Frishkopf

“Sanitation” is a critical, collaborative documentary music video focused on dire health issues afflicting post war Liberia—as well as much of the developing world: water pollution, inadequate waste facilities, and resulting disease. Fusing expertise from ethnomusicology, media arts, and health sciences, the video deploys popular music, combined with interview and documentary footage, as a catalyst to draw attention and stimulate debate about global health issues by raising awareness, facilitating cooperative engagement, and changing behavior. In North America, “Sanitation” confronts viewers with an acute ethical challenge: How can we live in relative comfort while maintaining an ethical self image, without addressing basic health needs of our fellow human beings? Simultaneously, “Sanitation” asks Liberians to recognize environmental risks, and to consider practical strategies for their mitigation. Produced by Liberians, with guidance from Canadian partners and global health organizations, the video empowers musical voices towards greater community engagement and improved global health.





What We Learn When We See People

Marie Gojmerac, Akua Gyambibi, Crystal Zhou, Michele DuVal, Eric Chan Tai Kong, Amanda Vanderhoek, Danielle Gabert, Mahsa Kamali, Kirsten Marshall, Jennifer Ortynski & Jesse Stach

This project was created through an Art In Medicine club initiative. The participating medical students found inspiration from patient experience, and encouraged each other to reflect on experiences in the health care community. We allowed these impressions to guide our design, though we frequently collaborated on the final appearance of the piece. This piece examines how, from a physician's perspective, the complex physical aspect of a patient can overshadow their internal and vocal aspects. The interactive quality of this piece allows the community viewing the project to explore the internal and vocal world of the patient, just as a patient-centered physician does. The interaction with the viewer is engaged through the invitation written on the piece itself to touch and move it. It is hoped that this representation demonstrates the latent communication deficit that exists between physicians and patients, and that viewers may form solutions and ideas based on this insight.



DisEase: Living on the Brink of Disability

Darian Goldin Stahl

My work portrays mobile disability with thoughtful consideration to the inward emotions one feels with the prospect of inhabiting an unresponsive body. I am working across disciplines with my collaborator and sister, Devan Stahl, who is a PhD candidate in Bioethics and has multiple sclerosis. This project was created in response to the callousness that was shown to my sister from her doctor when she was first diagnosed with MS. Instead of ending the conversation with a diagnosis, we are working through how her prognosis will impact her encountered life today and in the future. Perhaps through the empathetic exchange of dialogue on disability and disease, we can create connected knowing of others' lived experience. Dialogue is nurtured through the confrontation with a frozen figure. Viewers cannot know what it is to inhabit an unresponsive body, but we can imagine. This approximation and empathic reaction can radically alter one's perceptions of embodied agency and how we relate with difference.



Selected Encounters with Health and Its Definition Within Diverse Communities, 2010–2013

Lianne McTavish

They appear slowly, taking up different roles. Some immediately start to help set up the room, unfolding tables and unstacking chairs. Others fuss over a squeaky newborn, tucked into a mechanically swinging cradle. A few of the incoming women regard me with silent suspicion, a stance that is no doubt reasonably based on past personal experience. We are strangers.

Adopting my relaxed professor stance, I begin. “Today I would like us to think about the politics of looking and being looked at. The visual domain is rife with power dynamics, within which we necessarily find our place and exist. We need to be looked at. Yet the look of the other can also be limiting or disempowering, especially when it transforms us from subjects into objects. Here is a picture of me on stage during a bodybuilding/figure competition last year. What do you think? Am I a subject or an object? What is going on?

I am at the gym, lying flat on my back on a narrow bench, doing cross-chest extensions to work my brachialis. Breathing in with my right arm raised above me, I bend it at the elbow to lower a 15-pound dumbbell to my left shoulder, then exhale as I raise it. My left hand lightly encircles my immobile upper right arm, ensuring that the targeted part of the triceps is engaged. While performing this self-reflexive gesture again and again, I listen to myself breathing in

time with the music that enters my earbuds: Paul Oakenfold’s Everything in Its Right Place. The repetitive Radiohead remix pounds to a climax as I look up at my isolated gloved hand, which is backlit by fluorescents as it grips the weight. I feel an intense yet measured sense of pleasure. Yes, everything is in exactly the right place.

The class is no longer under my control. I try to breathe slowly and listen, two things that I am not usually good at. A young Aboriginal woman leans in and stares at me steadily. I return her gaze, ready for a challenge. “I don’t mean to be disrespectful,” she says, “but you are rich and white, able to reject that which you could easily have. Whereas people like me, like us, would love to have that husband and family, the big house and car. All of the things that confine you are not even within my grasp.” I am struck by a thunderbolt of understanding. My ideals are informed by privilege, by my ability to say yes and no at the same time.

According to *The Walking Dead*,¹ the wildly popular post-apocalyptic television series, to be fit is to be independent. A real survivor will be a no-nonsense country boy or at least former member of the boy scouts, able to catch fish and survive the odd stabbing. For the most part, cities are associated with disease and hidden dangers in this program, reviving anti-modernist tropes of the nineteenth century when urban life was thought to soften the human race, potentially turning men into ladies. Cities were furthermore considered dens of iniquity deserving of god’s plague-happy wrath, but that’s where *The Walking Dead* might part ways with the standard narrative.

For me, one of the most compelling aspects of *The Walking Dead* is its fascination with the fleshliness of the human body. Not being a big fan of horror films, I have never seen so many skulls explode, with brain matter flying this way and that, and lower intestines evacuating. This show wallows in abjection, going even farther than the plethora of recent television programs like *CSI: Crime Scene Investigation*,² which are based around the corpse. During the



early modern period, people would have witnessed public executions, seen dead bodies rotting in the streets, and viewed anatomical dissections. They may well have used mummified remains in leg poultices, or ground up bones to drink as a cure. In other words, they had an immediate, physical relationship with the dead, one that most of us currently lack. And oh how we miss our corpse encounters. We want that metallic taste of blood in our mouths, that straining of viscera in our bellies, that festering wound allowing us a glimpse of our own insides. Without leaving our comfy sofas, of course. This *The Walking Dead* delivers, in spades.

Yesterday I remembered why I am a gym rat. While training quads with my delightful young trainer, I was focused and determined; sweat dripped from my curly long hair, muscle spasms engulfed my legs, dizziness filled my head and chest. It was like old days and god how I missed them. My current regime of 3-hours-each-day pre-competition training is often easier than before because I now need to get smaller, targeting my shoulder caps with volume instead of weight, and replacing muscle growth with fat loss. Rather than grunt my way to failure, I regularly do half-way chin ups that engage lats while mostly avoiding my hulking traps. Even my cardio is low-key; I maintain a stable heart rate between 123 and 128 beats per minute for an hour or more every day.

I avoid thinking about the past, for good reason. Today, however, my guard is down as I sit in a dark sweat lodge, covered in bear grease, deeply breathing in sage scented smoke. I feel other hot bodies, including the feet of an elder woman, pressing against me. After accepting the invitation of a friend to join her sweat family, I am determined to experience it as fully and openly as I can.

When more water is thrown onto the heated lava rocks, I repeat my chosen mantra: submit, endure, submit, endure. It's the same one I use when receiving a painfully deep tissue massage or visiting the athletic therapist who digs his fingers behind my shoulder blades to, in his own words, "rip my arms off."

I will admit to having what Oprah would call "trust issues." I fight this limitation by saying yes as often as possible. Today I have decided to rely on those people, mostly strangers, who have kindly welcomed me into their sweat lodge, a sacred space of healing. I doubt that I am worthy. Deciding that I want to learn without either idealizing or appropriating Aboriginal culture, I do something that is rather novel for a white person: I shut up and attentively listen. The sweat leader generously explains the rituals, urging me to leave the smoky hut if I become uncomfortable or afraid. "No, no, never," I think

to myself. He explains that for him the sweat is about self-confidence, self-discipline, and self-worth. It is cleansing, in a spiritual way that I cannot really understand, even as the toxins pour out of my skin and down my back, even as poisonous memories rise and let me taste them again. When I emerge from the lodge three hours later, I touch the butterfly hair band that my friend's sister has given me, just in case I feel "reborn" after the experience. I am not sure what rebirth would feel like. Does it involve wide open pores and a sore lower back? Does it include a much-needed dose of humility? I thank my hosts and then join them for a feast of rabbit stew, savouring the dark chewy meat while seated inside a family home that is both safe and secure.



1.Darabont, F, Hurd, G.A. (Executive Producers), *The Walking Dead*. New York: AMC Networks.

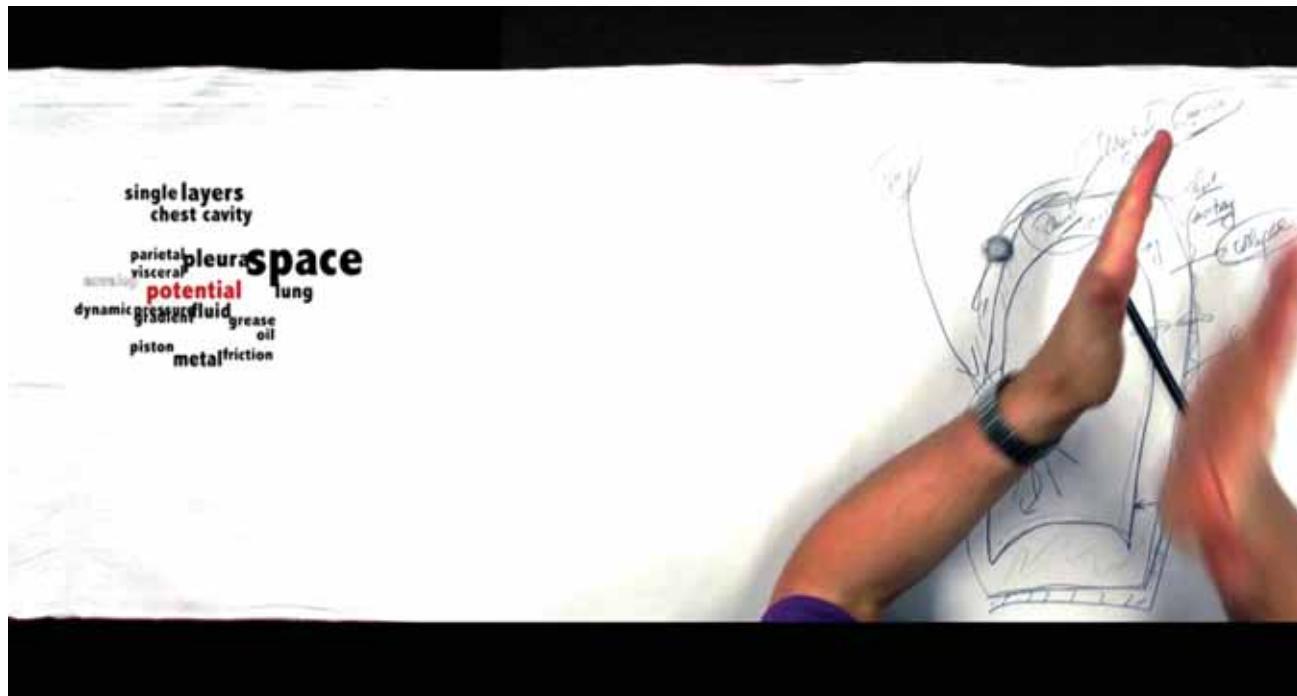
2. Bruckheimer, J. (Producers), *CSI: Crime Scene Investigation*. New York: CBS Television

Mongolian Shamanic Ritual: Ensuring Community Balance Through Intercession with Ancestral Spirits and Masters of the Mountains

Catherine Kmita

I explore, in photographs, shamanic rituals and sacred sites in Mongolian shamanism. Unlike the west where religion and medicine often collide, shamanic and medical practices coexist in Mongolian shamanism: shamans fulfill medical functions in their communities, practicing as midwives, herbalists, and bonesetters. Practice is also often a daily ritual for shamans and community members. The most recognizable shamanic practitioners, those with a shaman's headdress, coat, and drum, perform rituals to honour the masters of the local landscape and ensure their protection for the community, endeavouring to keep good relations between humans, the landscape, and the keepers of those spaces. Shaman and community members come together to make offerings, offer their prayers to the powerful spirits of sacred sites, and ask for the blessings and help of ancestral spirits. Community health involves the landscape, those who people it, and the spirits that populate it.



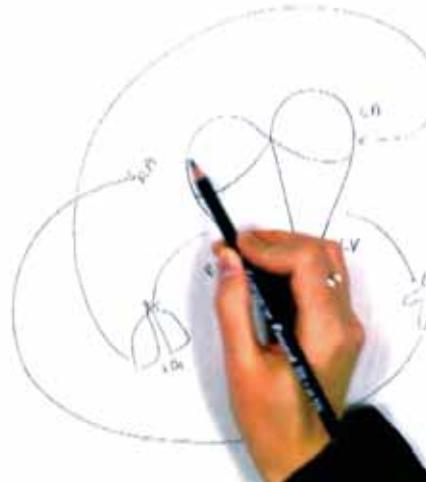
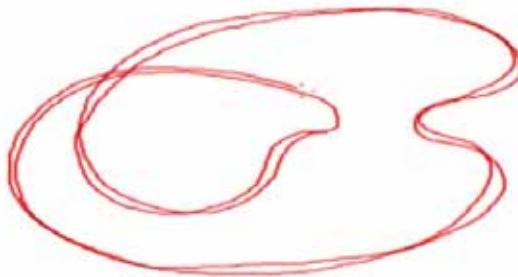


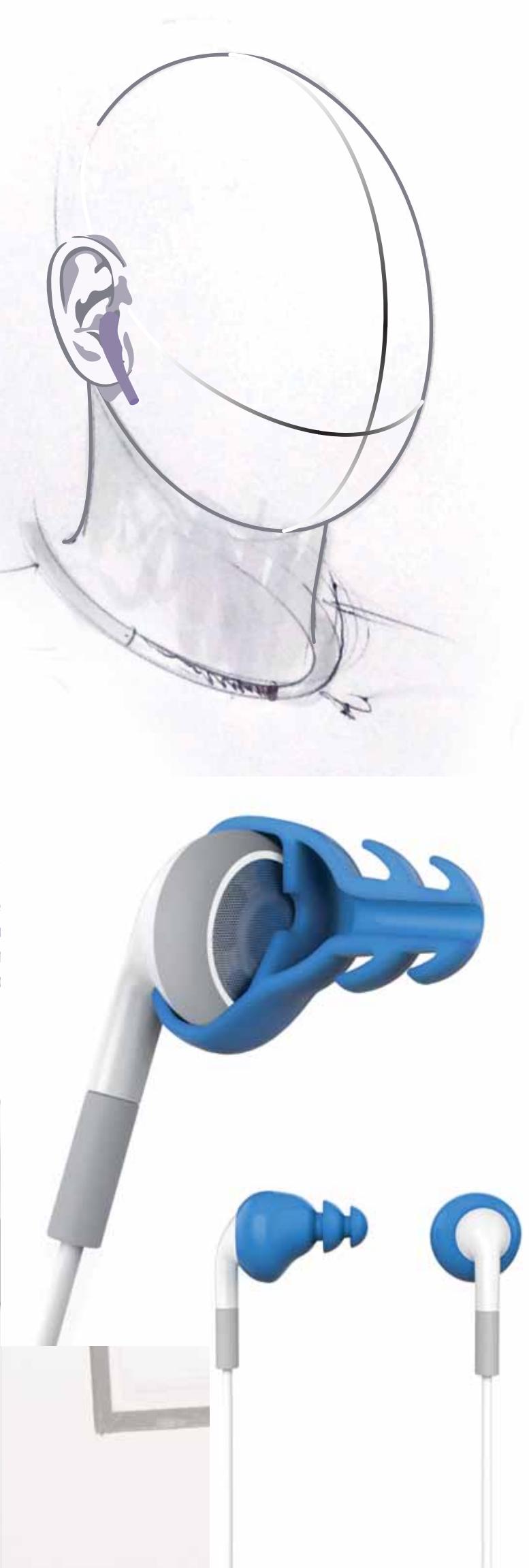
given away by charities), replaceable universal attachment. This would be the only way to create a mass effect in people's music listening habits. It would be unrealistic to expect a new headphone to address a social phonomenon of this size.

Four lessons in anatomy

Kaisu Koski

The video piece, *Four lessons in anatomy*, explores the visual culture of medical education, and the potential of hand-made drawings in anatomy teaching. It gives voice to medical students and educators as not only medical specialists but as storytellers and artists in their own right as well. It creates an alternative to sterile and impersonal diagrams of anatomy atlases by showing hand-made and sometimes hesitant trajectories in communicating about the body and health. The work process has engaged the medical educational community; medical students and teachers at the University of Alberta generously donated the four embedded anatomy lessons. The video illustrates how an artist can generate a dialogue with medicine by using her expertise in composition, rhythm or dramaturgy. Next to engaging both with medical and artist (-researcher) communities, the work invites the 'regular' art gallery visitor to ask where her or his 'body image' derives, and whether the medical diagrams seem to match with their own body experience.





Preventative Design: Understanding and Designing for Music Induced Hearing Loss

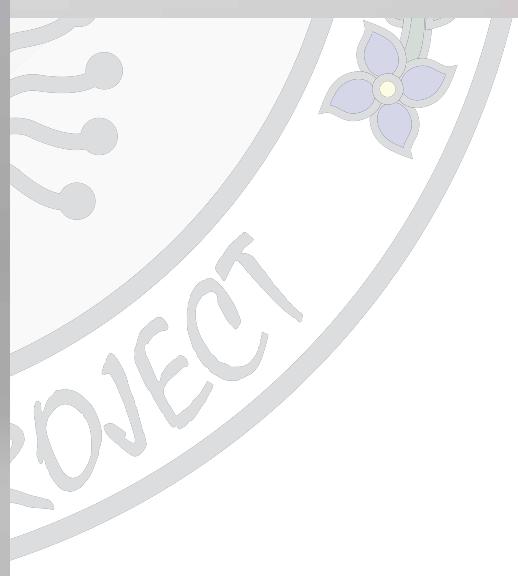
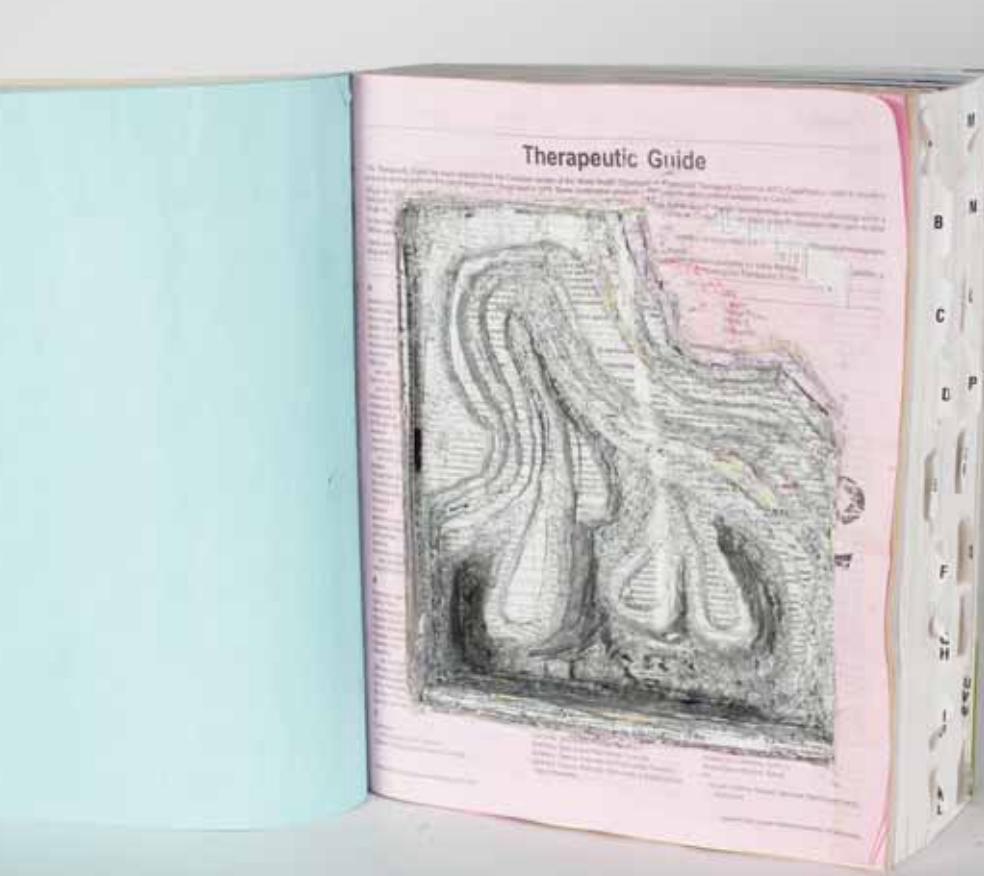
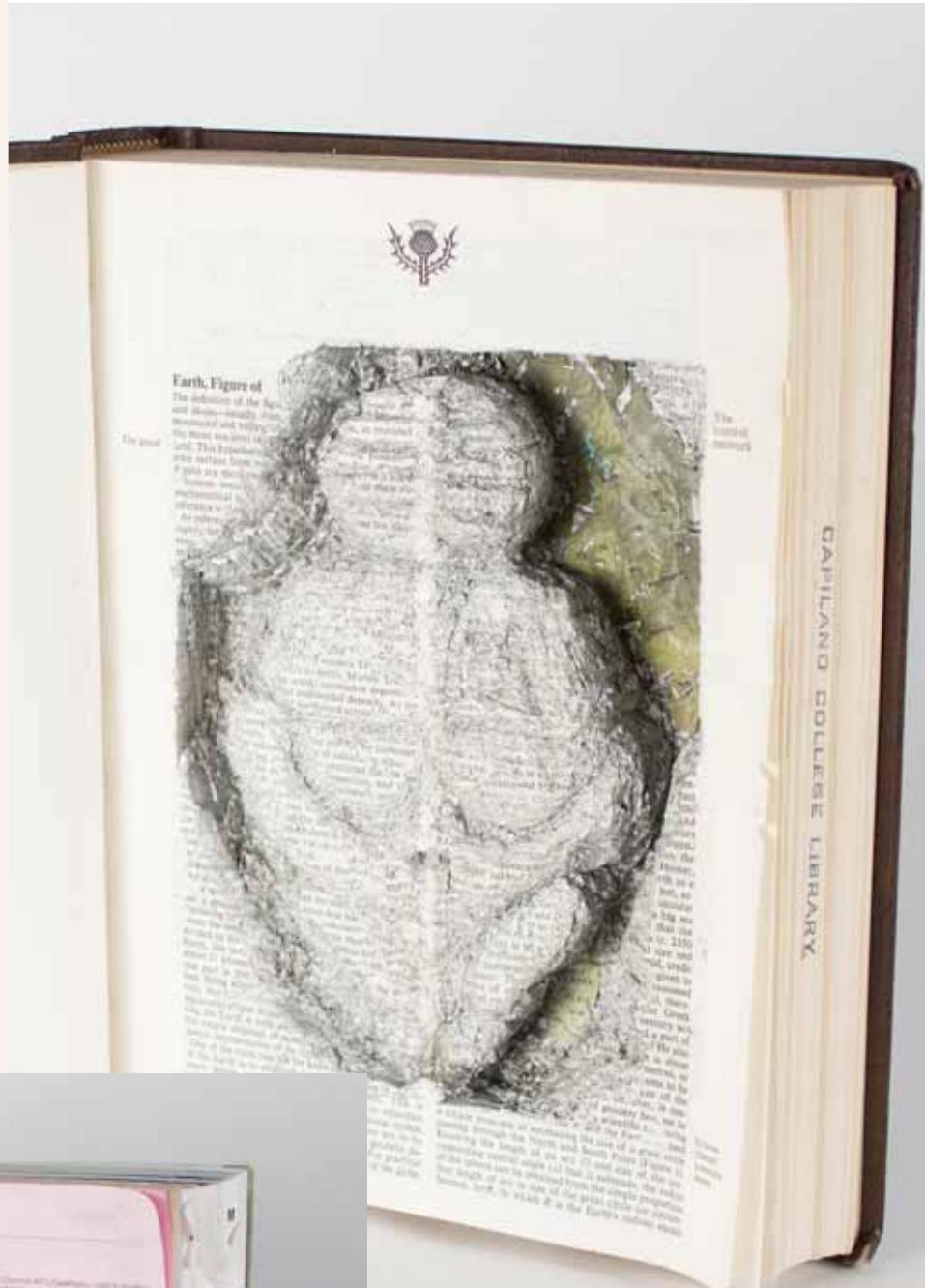
Hamit Kuralkan

In 2012, the number of smartphones in use has reached 1 billion and is expected to double by 2015. Most smartphones are capable of delivering volumes over the safe level of 85 decibels. While results of previous short-term studies over their relation to music-induced hearing loss may have shortcomings, one could argue that a cautionary approach to develop a strategy for the worst-case scenario is warranted. The music experience is very personal, from our headphones to our style of music as a representation of who we are. Therefore from a design perspective, user engagement is vital. Both technical and aesthetic attributes need to talk to the personality of the user. One user might prefer a heavier bass output, while another user might prefer clarity of sound. Their perception of aesthetic may differ; one may prefer a colorful item, while another may prefer a matte black look. Through engagement of different users, designs can be created that will be embraced by all.

Nothing is Created, Nothing is Lost, All is Transformation

Pierre Leichner

I believe that art needs to reoccupy its place as a means of exploration and knowing in the health humanities. My artistic practice has evolved to become increasingly socially engaged and community participation has become primary to many of my projects. In the *Windows to Discover* project, consumers in an outpatient mental health clinic, its staff, and I constructed an art installation piece to explore the meaning of social isolation. In the *Grassroots* project the community nominated grassroots workers to be sculpted. The grassroots sculptures were exhibited in the community's senior center, library, and swimming pool entrance. In the *1000 DSM origami cranes* project that is part of my altered texts art show, I teach the public to fold cranes out of *Diagnostic and Statistical Manual of Mental Disorders* pages. Finally, the theater play *Maladjusted* emerged from public consultation regarding the mechanization of mental health services and engages the audience in finding solutions.



LIMP (a poem)

Allan Peterkin

Every limp
is a story
of risk or accident
ENTROPY
(perceived as fate)

Every limp
is a failure of
CAUTION
(the driver, the jumper, the prankster, the surgeon)

Every limp
is a
COMPROMISE
(could be worse, won't get better)

Every limp
is a triumph of
FORGETTING
(but a shuffle of nostalgia)

Every limp
is an
ABSENCE
of running, of jumping
(and dancing)

Every limp is a
STORY
wordless,
no longer asked for
(no longer told)

Community-Driven Research in Northern Canada: Visual Representations of a Health Research Project

Multiple artists

Community-driven research involving several Aboriginal communities in northern Canada is being conducted to address concerns about *H. pylori*, a bacterium that is a known risk factor for stomach cancer. In each of three communities, competitions were held to create a local ‘project logo’. This initiative was accomplished through close researcher-community collaborations. It opened discussions about the project, the bacterium, and its health effects, and resulted in dozens of logo submissions from diverse community members of all ages. It also fostered interest and awareness of the collaborative research endeavour and created opportunities for engagement and education. These drawings capture the imagination and innovation of community members. They illustrate community perspectives on a health issue and on research aimed at promoting health and well-being. In addition to illustrating community perspectives, these figures also promote and showcase a strong community-researcher partnership where questions are posed and solutions to health problems are discovered together.



Aklavik H. pylori Project

*arts and do what it is
according to their
beliefs*

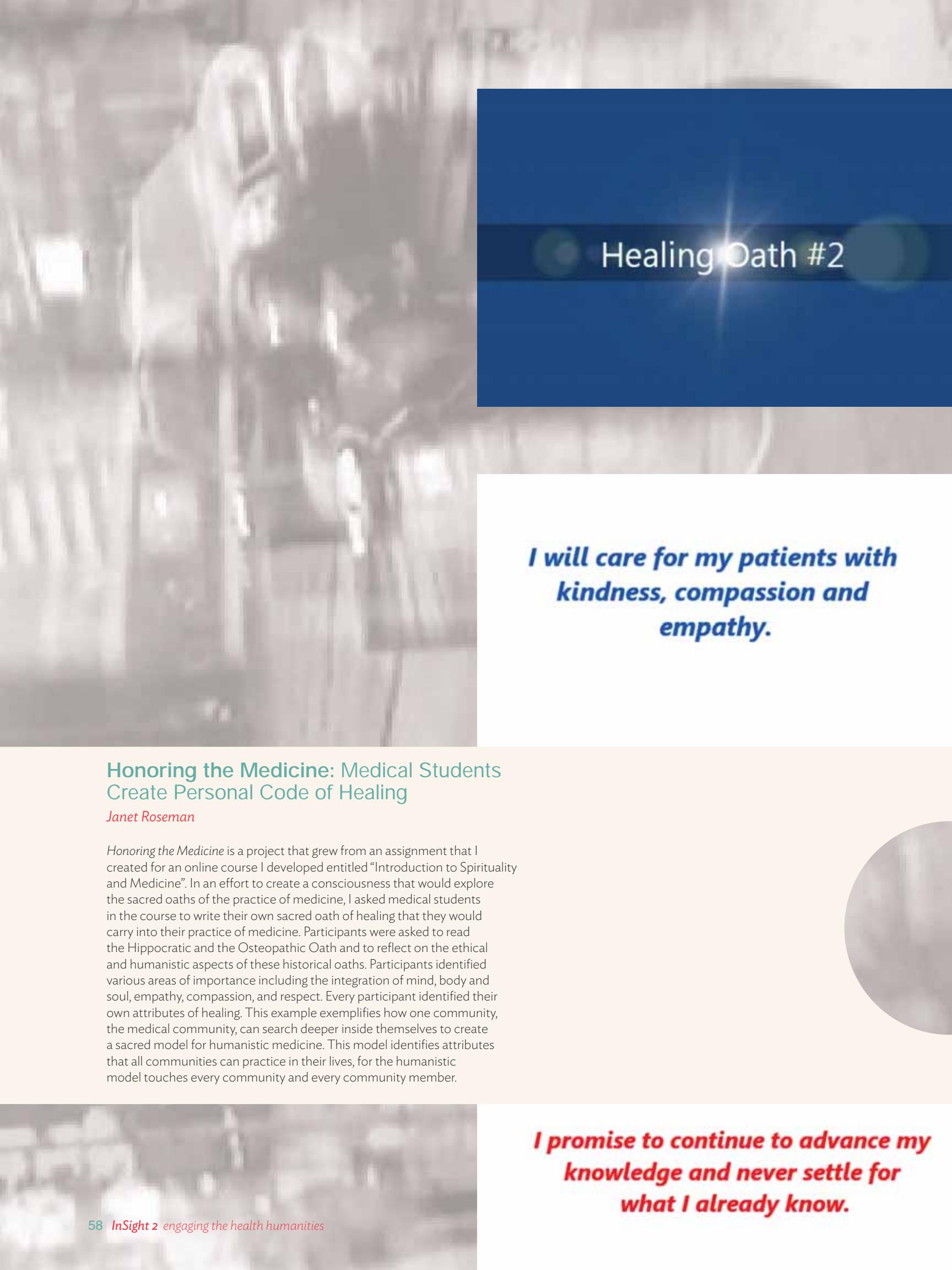


Malaria Education of School-Aged Children in the Kwahu-Eastern Region, Ghana

NYIT Center for Global Health

We developed an educational tool to teach Ghanaian children the benefit of using malaria bed-nets to increase awareness/prevention of Malaria. Puppets, comic books, and videos demonstrated a visual approach constructed upon the ancient Ashanti art of “story telling”, using Anansi the Spider. Traditional or indigenous characters in stories make learning more enjoyable to children, guiding them towards comprehensive understanding. The knowledge achieved serves as a foundation for health education. Through myths and legends, we pass on our visions, values, feelings and memories in a way that is both enjoyable and entertaining. The best stories are those that motivate, inspire and connect—stories that make students feel some emotion and allow them to see themselves in similar situations. Students treasured the book, *Anansi Tricks Mrs. Mosquito*. Older students read it to their younger siblings; elders in African societies encourage such teaching as transmission of knowledge.





Healing Oath #2

***I will care for my patients with
kindness, compassion and
empathy.***

Honoring the Medicine: Medical Students Create Personal Code of Healing

Janet Roseman

Honoring the Medicine is a project that grew from an assignment that I created for an online course I developed entitled “Introduction to Spirituality and Medicine”. In an effort to create a consciousness that would explore the sacred oaths of the practice of medicine, I asked medical students in the course to write their own sacred oath of healing that they would carry into their practice of medicine. Participants were asked to read the Hippocratic and the Osteopathic Oath and to reflect on the ethical and humanistic aspects of these historical oaths. Participants identified various areas of importance including the integration of mind, body and soul, empathy, compassion, and respect. Every participant identified their own attributes of healing. This example exemplifies how one community, the medical community, can search deeper inside themselves to create a sacred model for humanistic medicine. This model identifies attributes that all communities can practice in their lives, for the humanistic model touches every community and every community member.

I promise to continue to advance my knowledge and never settle for what I already know.

Designing for a Better World – Across Boundaries and in Partnership with Communities

Leslie Robinson & collaborators

About a decade ago, as a design student, my mind began to open up to the idea of design as a trans-disciplinary problem-solving practice capable of improving life. Prior to this revelation, I had chosen a career path in design because I enjoyed art and was convinced that design, like art, was a creative discipline, yet one with better prospects of getting a job. Half way into my degree my outlook broadened as I became aware of participatory design. My understanding of this approach, which features the active involvement of community members in the design process, was greatly informed by the teachings of author and professor Jorge Frascara. My instructors encouraged practical explorations of participatory design through collaborative concept generation exercises and feedback sessions with the public. I learned that designing with people can change not only what we see but how we see it. I no longer consider design as simply a profession, but rather as a lens for seeing, being, knowing and doing in the world. My ever-evolving practice of designing for a better world has taken me to many unexpected places, close to home and far away, where many ordinary people's ways of living life have impressed on me in profound ways. In what follows, I share insights that can inform and elucidate participatory design processes with an eye to some broader notions of human experience. Because I believe in theory that is directly connected to action, I relate each teaching principle to specific design projects. My hope is to provoke a renewed dialogue around the potential role of design as an ethical practice committed to the creation of synergistic partnerships for improving lives both locally and globally.

Participatory Design for the Betterment of the Common Good

“Regardless of how the final piece comes out, whether through art, design, theatre, creative writing or any other way, everyone is equally important in this project”
—artist

Participation, in the sense that I outline in this contribution, aims at voluntary and genuine involvement, driven by the goal of advancing egalitarian human relations. Genuine participation is not the enlistment of targeted consumers

in order to appropriate their ideas to increase market or other one-sided incentives. It is the reconfiguration of the communication process with an emphasis on people-to-people interactions around a shared objective, such as communicating with youth about the risks of unprotected sex. Participation in this way is an ethical response to dominant market-driven communication systems structured by hierarchical relations among stakeholders, epitomized by the conveyor-receiver model.

Participatory design encourages participants to act as co-designers in a shared project committed to the common good: the well-being and betterment of a given group or society defined according to democratic processes and egalitarian aims. Employing horizontal communication, this approach opens up possibilities for co-intentional awareness and behavioural change. Participatory designers act as facilitators, working with members of an identified community (and possibly other partners such as researchers and/or community leaders) to design communications or experiences employing consensus-making processes. More of a philosophical approach than a rigid methodology, participatory design demands a sensitive and flexible outlook to honour the specific needs, desires and perspectives of participants. With the ability to transgress knowledge boundaries, such as those of education, art and health, it is a useful framework for critically and collectively intervening in dominant communication systems toward design outcomes that come from within the community.

Example: *activists 4 life* Participatory Design Process

Activists 4 life is a youth collective based in Uganda of which I am a co-founding member. In partnership with the community we use educative activities including design processes in an ongoing effort of “creating for a better world”. We co-identify and respond to local youth issues by creating, assessing and disseminating messages and interventions with and for the community. The seven processes in table 1 comprise the activities that make up the development of community messages facilitated by *activists 4 life*.

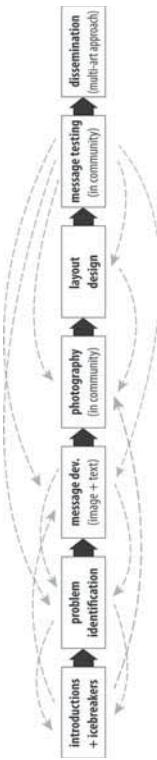


Table 1: *artivists 4 life* problem identification and response process (*artivists 4 life*, 2012)

The artwork in figure 1 depicts how we work together to arrive at messages about community-identified issues.



Fig. 1: *artivists 4 life* message development (*artivists 4 life*, 2012)

Collaborative problem identification techniques lead to carefully situated work while serving to ground action. Messages (text and images) are shared with community members to elicit responses as figure 2 shows. Improvements on the designs continue until community members and project partners approve the message.



Fig. 2: *artivists 4 life* message testing process (*artivists 4 life*, 2012)

When photographs are required members of *artivists 4 life* and other community members are invited to be models (with written consent). The message testing process is revisited as needed. Then final messages are reproduced on a variety of media such as murals, as figure 3 illustrates. Through a multi-modal approach, messages are further disseminated through dance, drama and visual presentations alongside other interventions such as condom distribution.



Fig. 3: *artivists 4 life* message dissemination (*artivists 4 life*, 2012)

Degrees of participation

“By developing messages I have learned to talk to people, brainstorm and come up with something good for the community” —artist

It is important to note that degrees of participation vary considerably. In my design practice I have worked toward an ever-increasing degree of community participation. I have engaged with *artists 4 life* in a process of knowledge exchange over years of community building. Many members of the collective are now able to facilitate the process for participatory message development without my involvement. A high level of knowledge transfer is an indication of a very high level of community participation and demands a sustained commitment to the process by all parties. Working toward full and sustained participation, however, is not practical in most contexts. It is still possible, and desirable, to engage in effective design processes whereby participation is limited to a finite period. In such cases, the goal of the design project should be modest, as participation always prolongs the design process. For example, I have facilitated effective participatory design projects that have consisted of as few as three to six workshops. Such projects have culminated in modest outcomes such as a logo, a community calendar or the design for a mural. These projects of mid-level participation are appropriate for responding to an identified problem, and can successfully achieve a design outcome premised on consensus. Projects of low-level participation abound. They often involve the collection of data from audience members through a survey or focus group. Such approaches can inform the design process, as any level of participation is better than none. Broadly speaking, in the case of any design project the limitations and benefits of levels of participation need to be considered and weighed.

Building Relationships for a Trans-Disciplinary Design Practice

“Working together we are able to make so much more change to go so much further with our ideas ... and that’s relevant in the classroom and outside”—design student

The task of the participatory designer is to build connections with other disciplines and community partners, sharing specialized knowledge and a willingness to engage boundaries. This practice demands an ongoing process of broadening one’s understanding of human interactions and experiences. My own practice has brought me into partnerships within the realms of public health and community development, both in relation to youth experience and cultural diversity. In doing so I have attained transferable skills and understandings, such as project facilitation techniques and the importance of intentional listening. I have also adopted the principle of professional humility, through the understanding that although I, as a designer, bring specialized knowledge, all other project participants bring their own form of expertise. Whether as highly trained technicians, intellectuals or experts in living life, all partners in the design process have something to offer. With activists *4 life*, we follow the proverb “each one teach one”.

When the design process is well facilitated we can surpass the mere identification of different viewpoints and develop new strategies for designing solutions based on mutual understandings. By working across boundaries and in dialogue we can go beyond our own certitude and participate in collaborative knowledge-making that is far greater than the sum of our previous experiences.

The greatest barrier to engaging in such trans-disciplinary work is the widely held understanding of the designer as translator of content into form. We need to re-educate the public (and ourselves) about how designers can also act as catalysts for informing content and shifting contexts. Dominant design practices operate around the assumption of a triad of distinct stakeholders: the client, the designer and the public. The communication typically flows from the client through the designer to the public. Participatory design aims to blur the boundaries between stakeholders by encouraging communication to flow in all directions.

Participation and Visual Language

“This (participatory) process for me has challenged me think that maybe I can engage in (design) and be creative and communicate with people in a different way”
—project participant (Edmonton)

With regards to visual language, participatory design projects can be broadly grouped into concept projects and full design projects. In the former, participants work with a designer to develop the content for a message, usually expressed in a combination of words and images. Emergent sketches or mock-ups can be executed using simple and available tools such as paper and coloured pencils. Once the concept is agreed upon, the designer follows a more conventional design practice, drawing from his/her specialized skills to compose a ‘professional’ design. The designer should present the design back to project participants for feedback and adapt it as necessary until all parties are satisfied. These design outcomes may not result in a visual language drastically different from more standard design projects, yet it is the highly contextualized nature of such projects that set them apart.

In full design projects, the designer will work with participants to co-design the content, concept and final design. Here the designer must be careful to select appropriate tools and processes that are accessible to participants. In many ways the designer’s responsibility is to foster an experience for engaging participants. The visual language emerges through the collective expression of the project participants and the chosen approach, such as painting a mural or collaging a poster. In either of the two approaches described the role of the designer should not be to imposing a certain ‘style’, but rather to be resourceful and innovative in guiding the process.

Co-Designing Learning Spaces for Crossing Boundaries

To be realistic about participatory design, as teachers, students and collaborators, we need to create learning environments to help us gain the necessary skills for trans-disciplinary and inter-cultural work. Recently, I partnered with fellow activists *4 life* members and University of Alberta design students through what came to be known as the artist ‘design exchange’. We engaged around youth identified health/social issues while sharing identities, perspectives and creative and collaborative processes. This open-ended collaboration moved toward the creation of a community quilt, whereby participants from both cultures contributed design ‘squares’ that responded to the collective

learning experience. Components of the quilt can be seen in this catalogue. Throughout the process and its evaluation three principles emerged which can inform future design projects that seek to engage across cultures and knowledge systems.

Toward a Practice of Problem-Identification

“This exchange as a whole has provided a great opportunity for those who were involved to really think about the issues that need addressing in their own communities and to learn about the communities of others” —design student

In standard practice, designers respond to problems that are presented by clients. If we are interested in advancing socially responsible design we need to work toward a complete paradigm shift. This necessarily involves the designer taking on an increased role in all stages of the communication process, beginning with problem-identification. Involvement of the participatory designer from a project’s onset leads to greater community involvement and hence more contextualized outcomes.

In the activist ‘design exchange’, participants engaged around problem identification as a basis for guiding our interactions. Drawing from participants’ own lived experiences leads to the meaningful exploration of real issues, such as ‘drug abuse’ or ‘social inequality’, while exercising critical thinking skills, personal initiative and the conscious consideration of values.

Toward Inter-Cultural Understanding

“Not only have I become more aware of other cultures ... more patient with understanding the perspectives that people are coming from, but also a lot more aware of my own culture and how we interact” —design student

Engaging across boundaries we have the opportunity to dehabituate from our known lifeworlds and gain access into the realities and circumstances of others. Glimpsing into the perspective of another we shift our own view of ourselves, gaining at once a renewed sense of other and self. As Ugandan activists and their Canadian counterparts exchanged stories and creative works, differences, similarities and contradictions were revealed. Those present had the opportunity to learn toward consensual understandings of other peoples’ realities, thus redistributing agency in the construction of social meaning. For example, one activist observed that so-called first world countries have some

of the same problems of so-called third world countries. He explains, “I came to know that Canadians also can face a problem of unemployment, yet before I was thinking that you can’t find anyone in such a country who is unemployed”. By creating learning spaces for such discoveries we gain understanding of human factors involved in relations between people and their environments.

Creating Synergies Around Community Engagement

“By stretching or going outside of your boundaries you can create new things and you can be with new people and it just opens a lot of opportunities when you learn to be a little bit uncomfortable and that is a good thing”
—project participant (Edmonton)

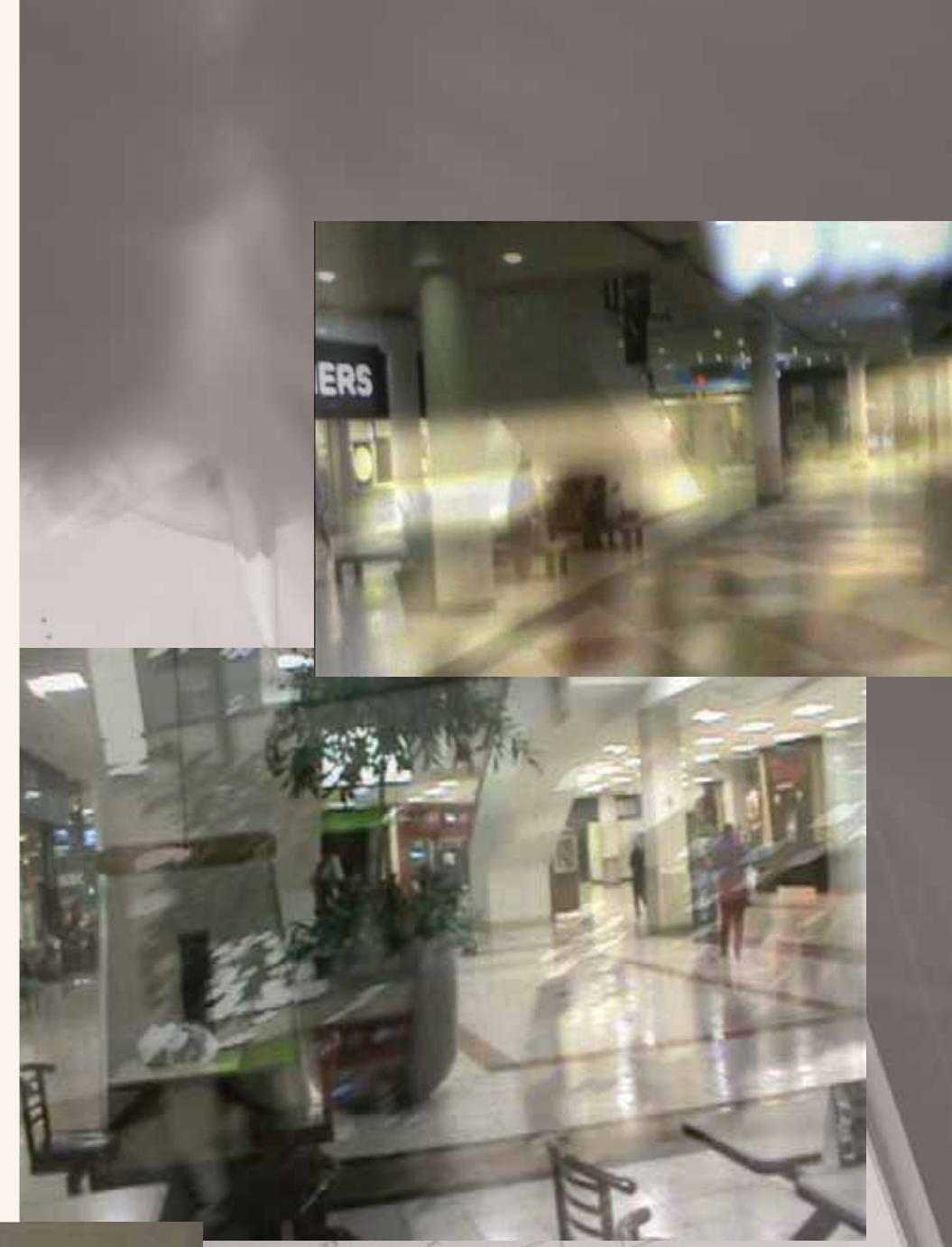
An emergent theme identified by young Canadians in this exchange was the issue of ‘youth apathy’. As one student explains, “it is a little bit harder to get people to become active here because there is so much going on, there are so many distractions ... I think it is really exciting what activists are doing and I hope that we can bring that excitement here”. Through the creation of inter-cultural, inter-epistemic and inter-human spaces we can allow ourselves to go beyond our comfort zones, provoking new curiosities through entry into the symbolic worlds of others. Through the creation of such synergistic learning spaces we open ourselves toward a greater understanding of individuals, communities, contents and contexts.

I have explored participatory design as a lens for engaging in a tense dialogue around the potential role of the designer as change agent and culture shaper. Within this same potential, however, exists a danger. If we continue to exercise our skills while closing an eye to the larger context of how our work affects real lives, we risk acting as creative perpetuators of the status quo. My hope is thus visionary and it lies in our potential to transform our creative and conceptual skills into tactics that can reconfigure human relations in ways that support a humanity premised on multiple common goods.

Light in the Borderlands

Adolfo Ruiz & Megan Strickfaden

Light in the Borderlands is a research project and short film in which legally blind participants have shared and recorded their experiences of Edmonton's built environment. Through a series of co-designed investigations, members of the CNIB community along with researchers from the University of Alberta, collaborated in a creative process involving urban journeys, storytelling, and filmmaking. This narrative-based approach provided a collaborative framework through which the university and the CNIB community worked together in exploring and documenting how urban spaces are perceived and navigated. Throughout this research, the "blindness/sightedness binary" was challenged by exploring how "legally blind people move back and forth across the unique border between the sighted and blind worlds" (Omansky, 2011, p.184). In an attempt to follow Rod Michalko's (1998, p.4) idea of treating "blindness as a story", participants from the CNIB and researchers from Design and Human Ecology have investigated the ambiguous and often misunderstood experiences of legal blindness through urban and narrative explorations.



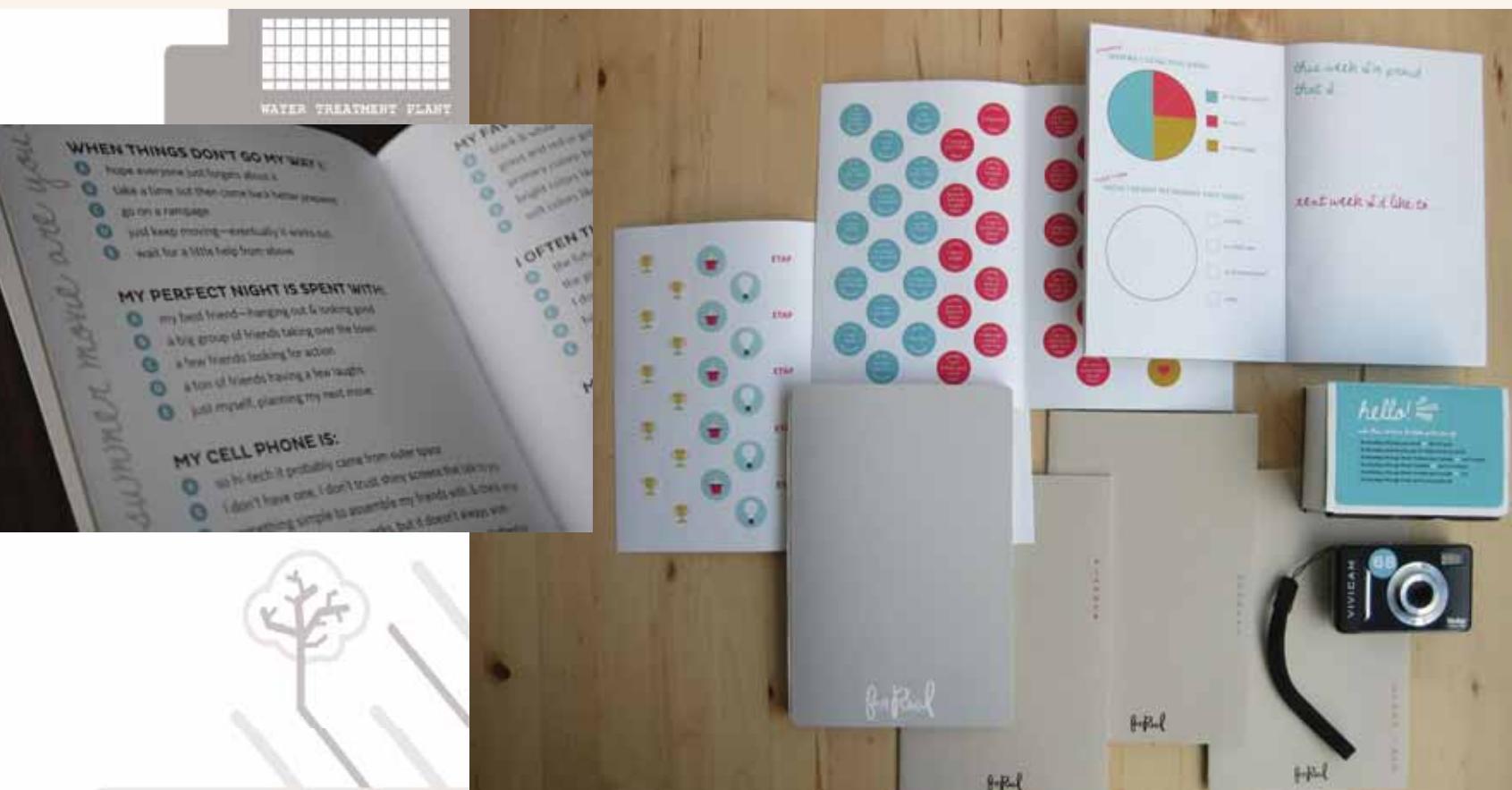
As the mixed amalgam is packed into the tooth, the dentist carves away excess amalgam material, which is suctioned out of the mouth and flows through a filtration system.

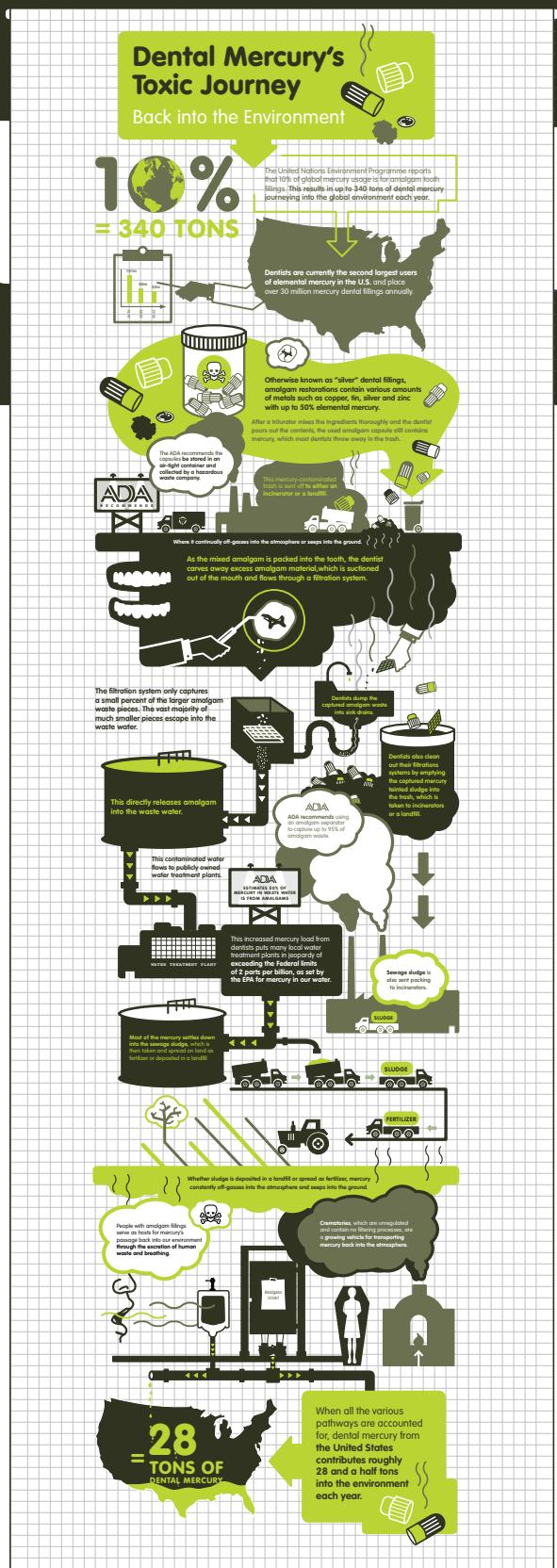


For Real Journals for Pregnant and Parenting Teens

Helen Sanematsu & collaborators

The For Real journals for pregnant and parenting teens are an example of the capacity of design to be a nexus for interdisciplinary work in the health humanities. The journals brought together designers and academics (a sociologist, a health communication scholar, and a health literacy specialist) to develop an engaging venue for reflection and expression that was scientifically rigorous. Working side-by-side to write, design, and evaluate the journals, we formed a partnership that gave the young mothers-to-be a place to write, draw, plan, reflect, and dream. The journals were the second iteration of a three-year, three-part, people-centered design process. In the first year, we designed and tested prototypes. In the second, we developed the journal, implemented it, and conducted our evaluation. As of March 2013, we are poised to design the last of the journal iterations, which will involve co-design sessions, and the development of support material for family members and friends.

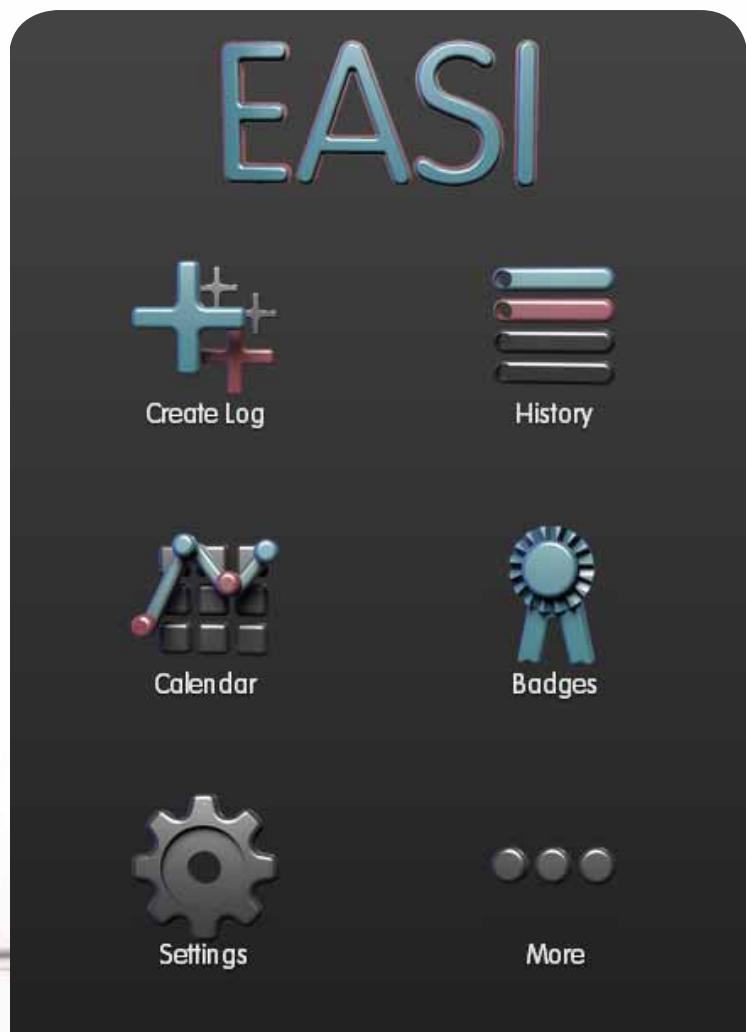




You Put What In My Mouth?

Jeremy Shellhorn

The argument surrounding the safety of "silver" dental fillings, which contain roughly 50% elemental mercury, has centered on the potential adverse health effects from long-term use. The one aspect that both the FDA and ADA refuse to acknowledge is the centerpiece of this large-scale infographic... that huge toxic exposures during routine dental procedures violate safety regulations, and don't just affect those with mercury fillings but all of us, including the environment. This work engages the community and health humanities through its message, but also in its installation. The design employs a long flowchart or timeline and tells an often unheard story with facts and figures. The work's installation is inventive in the use of space/scale to create a reflective moment for an otherwise didactic narrative. This piece is a collaboration between a filmmaker, designer, and several dental scientists that supports the documentary film, *You Put What In My Mouth?*



Socially Engaging Apps

Eleni Stroulia, Shayna Fairbairn, Blerina Bazelli, Dylan Gibbs, Robert Lederer, Greig Rasmussen, Robert Faulkner, Janet Ferguson-Roberts & Brad Mullen

We are witnessing a burgeoning trend of devices and applications that enable users to quantify their daily behaviour. A variety of wearable/embedded devices and mobile applications are incorporated into a person's daily life in order to acquire data about the person's inputs such as food consumed, exercise, sleep quality, states (e.g., mood), and performance (e.g., mental and physical). A major challenge in proper evaluation and enabling lasting positive behavioral change is that, although easily adopted because of their novelty and general appeal, most of these quantified-self technologies are abandoned after an initial period of experimentation. By incorporating features that allow social interaction and engagement we feel the problem of abandonment will be minimized. We advance two mobile applications—*Connect* and *Phisitivity*—as instances of a larger family of applications under development. These two mobile applications are attempting to embed reminders, data-collection features, community-building, and information-sharing within a person's daily-life context in a way to more consistently formulate intentions and carry out the corresponding desired actions.



How Do You Do? Design Research Methods and the ‘Hows’ of Community Based Participatory Research

Helen Sanematsu & Sarah Wiehe

Community based health research aims to re-define health in ways specific to those it serves. Community Based Participatory Research (CBPR) is recognized as a best practices approach that aims to “level the playing field” between the academy and the community. In an ideal CBPR scenario, academics and community members participate as equals in all phases of a research project, from conception to methods and the dissemination of final outcomes. Additionally, such projects directly benefit the community via their research products, establishing health interventions (health improvement programs, for example) and optimally, policy changes that have long lasting and sustainable effects on community health.

While the principles of CBPR (the ‘whats’) are well articulated (Fig 1), the ways to ‘do’ CBPR (the ‘hows’) are not. Case studies report on the institutional, environmental, and higher level systems contexts of research projects, but rarely report in concrete terms about how those projects were conducted at the sidewalk level. While the CBPR approach prioritizes respect for the communities it studies, its literature generally does not cover how that respect is made manifest except in the broadest terms.

In our work with local communities, we have found that design research can address this methodological gap, supplying the ‘hows’ to achieve the aims of CBPR. Design research encompasses a range of activities in many fields (product design and HCI? are perhaps the most visible) that combine techniques from the social sciences (in our projects, the visual sociology methods of photo voice and photo elicitation) with design practices to create study specific tools. Design researchers can apply 2-D, experiential, service, and interactive design to tailor methods for specific CBPR projects and in doing so can achieve many of CBPR’s aims. These methods are transferable to other areas that prioritize the experience of the individual in context, as for instance in the emergent area of Patient Centered Outcomes Research.

In this illustrated article, we demonstrate the relevance of design approaches to CBPR, using examples from three studies. We present a ‘roadmap’ that indicates specifically how study artifacts and design research methods support CBPR (Fig 2). In the course of our analysis we also introduce CBPR and relevant design research principles.

How Do You Do?

Design Research Methods and the 'Hows' of Community Based Participatory Research

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Community based health research aims to re-define health in ways specific to those it serves. Community Based Participatory Research (CBPR) is recognized as a best practice approach that aims to "lead the playing field between the academic and the community, in an ideal CBPR scenario, the community and community members participate as equals in all phases of a research project, from conception to methods and the dissemination of final outcomes."

Participatory/participation
Participatory methods in design research draw out the 'native expertise' of design users. In o-design, all stakeholders participate as experts in their own area.

Iterative process
Design processes are iterative. A complete cycle takes the end design, evaluates it, and feeds it back into another round of design development. Rapid prototyping is practiced to speed innovation.

Principles of Design Research²
People (or user, customers)
People—design's end users—are the standard measure of people centered design. People centeredness also addresses specific contexts of use, human factors (ergonomics) and other variables that affect experience and the expertise of the individual user in her or his own experience.

Integrating/participation
Participatory methods in design research draw out the 'native expertise' of design users. In o-design, all stakeholders participate as experts in their own area.

Iterative process
Design processes are iterative. A complete cycle takes the end design, evaluates it, and feeds it back into another round of design development. Rapid prototyping is practiced to speed innovation.

Fig 1 Working definition of CBPR and Principles of Design Research

1. From Muller, M., Gane, A., Raliv, V., Wallenius, N., School of Public Health, University of California, Berkeley 2012. Community-Based Participatory Research: A Strategy for Conducting Healthy Communities and Promoting Health Through Change. Berkeley.
2. For general discussions of mixed methods design research, see William J. McAllister, *Journal of Design Research*, Vol. 2, No. 1, pp. 1-12.

Community Based Participatory Research (CBPR) Principles¹

1. Recognizes community as a unit of identity
2. Builds on strengths and resources within the community
3. Facilitates a collaborative, equitable research partnership
4. Fosters co-learning and capacity building
5. Achieves a balance between knowledge generation and intervention
6. Focuses on the local relevance of public health problems and on ecological or systems perspectives
7. Involves systems development using a cyclical and iterative process
8. Disseminates results to all partners
9. Involves a long-term process & commitment to sustainability
10. Openly addresses issues of race, ethnicity, racism & social class
11. Works to ensure research rigor and validity while seeking to "broaden the bandwidth of validity" within research

1. From Muller, M., Gane, A., Raliv, V., Wallenius, N., School of Public Health, University of California, Berkeley 2012. Community-Based Participatory Research: A Strategy for Conducting Healthy Communities and Promoting Health Through Change. Berkeley.
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Fig 1 Working definition of CBPR and Principles of Design Research

Indiana University
IU School of Medicine
Child & Health Services Research
401 W. State, Indianapolis, IN 46202

Seeks Research Volunteers to Participate in a Research Study of Adolescent Girls using Cell Phones

Benefits:

- * Up to \$1000 for participation
- * Quality free meals
- * Up to \$1000 for transportation
- * Be able to speak and understand English
- * Be willing to travel for (four) weekly periods
- * Work Resides within the WISCO Areas
- Risks and Benefits Will Be Disclosed Prior to Enrollment

If Interested, Please Call
+1-317-278-9665
For More Information

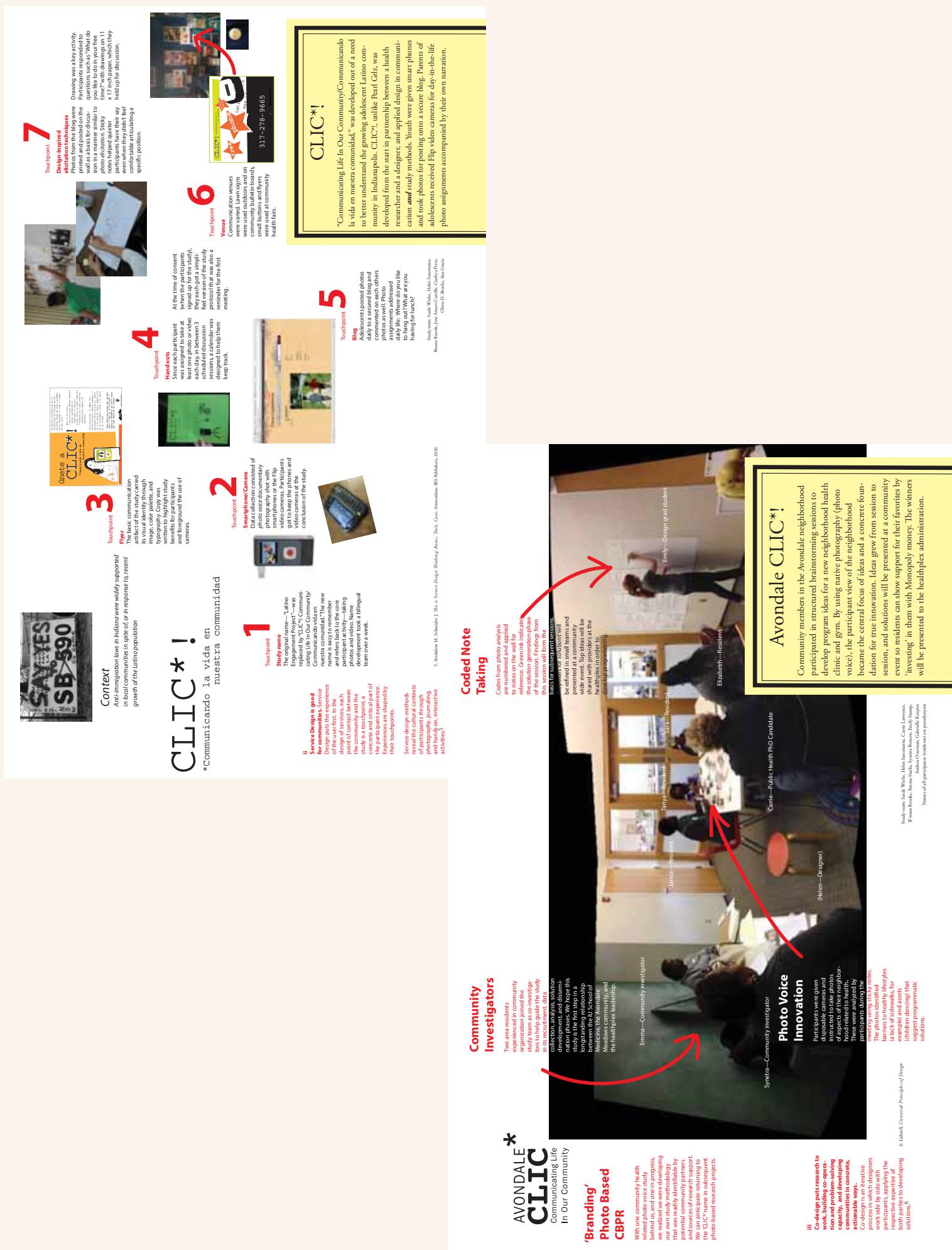
Before
Design can help establish the relevance of the study in the community starting with recruitment. Study recruitment is the hand-stake of community health research. The study team that includes designers can maintain a keen eye on the values and interests of the community it addresses, starting with this crucial first step.

After
Study flyer designed using the principles of user-centeredness and basic application of 2-dimensional design elements and principles. The new flyer looks at this study from the perspective of its intended audience—adolescent girls—and foregrounds its most salient benefit: the use of a cell phone with unlimited texting.

4. For more on Patient-Centred Outcome Research see the Patient-Centred Outcomes Institute website: www.pcot.org

Pearl Grizz, or—"Mapped and Perceived Contexts of Adolescent Health Risk Among Adolescent Females Residing Within the WISCO Areas, Phase 1, 2, and 3," was presented to the design team as a recruitment problem; the study gave cell phones to adolescent girls as a data collection method, yet in spite of its inherent appeal, was not finding participants. Other aspects of the study, however, were not as in tune with its audience, starting with its original name and its key communication artifact, a flyer. We incorporated the perspective of the girls and redesigned all messaging materials.

Study flyer: Sarah Wiebe, B. Wren Brooks, Amy Goss



| Pearl Griz <i>Mapped and Perceived Contexts of Adolescent Health Risk Among Adolescent Females Residing Within the WESCO Areas, Phase 1, 2, and 3</i> | CLIC*! <i>Latino Engagement Project recruitment study</i> | Avondale CLIC*! <i>The Avondale Health Study: Community Engagement for Place-Based Patient-Centered Outcomes Research</i> |
|--|---|--|
| 1. Recognizes community as a unit of identity | Study communications tailored specifically to adolescent girls [People-centeredness] | Study communications & methods tailored specifically to Latino adolescents & their parents [People-centeredness] |
| 2. Builds on strengths and resources within the community | Pearl Griz uses community familiarity with mobile technology as a asset [People-centeredness] | Strength building initiated through asset identification in photo voice [Participatory] |
| 3. Facilitates a collaborative, equitable research partnership | Participants collaborated on flyer design [Participatory] | Collaborated with investigator from the community to assist with recruitment [Participatory] |
| 4. Fosters co-learning and capacity building among all partners | Not applicable | New social relations were formed. Participants received and learned to use cameras and blog [Participatory] |
| 5. Integrates and achieves a balance between knowledge generation and intervention | Not applicable | Not applicable |
| 6. Focuses on the local relevance of public health problems and ecological perspectives | Study design looks at adolescent health within localized contexts [People-centeredness] | CLIC*! sought to uncover local ecologies using photo voice and photo elicitation [People-centeredness] |
| 7. Involves systems development using a cyclical and iterative process | Not applicable | Discussion sessions were developed in cycles based on photos taken between meetings [Iterative Process] |
| 8. Disseminates results to all partners | Not applicable | Not applicable |
| 9. Involves a long-term process and commitment to sustainability | Not applicable | CLIC*! is the first step in learning how to establish a shared, long term relationship with the Latino community [Participatory] |
| 10. Openly addresses issues of race, ethnicity, racism, & social class | Not applicable | Study team integration addresses race, but it has not yet emerged as a singular issue [People-centeredness] |
| 11. Works to ensure research rigor and validity but also seeks to 'broaden the bandwidth of validity' within research | Not applicable | Participants analyze findings as part of a creative problem solving process in design [Participatory] |

Fig 2 Design Methods Are CBPR Methods

Conclusions

Through People-centeredness (all three studies), investment in Participatory methods (photo voice in CLIC*!) and Iterative process (Avondale CLIC*!), design research methods are shown to be relevant to Community Based Participatory Research to engage community members, initiate meaningful partnerships, and work toward health solutions. [Fig. 2] In subsequent studies we hope to explore design research as a means to combine goals shared by CBPR and Patient Centered Outcomes Research to develop new ways of defining, determining, and improving community health.

VOICES FROM THE VISUAL VOLLEY

THERE IS AN **intimate** RELATIONSHIP BETWEEN ALBERTANS *and the* ENERGY INDUSTRY.

Canadian Association of Petroleum Producers

CANADA IS HITCHING ITS STAR
to the oil sands and everything it stands for.

OIL-SANDS DEVELOPMENT GENERATES
20 TO 30 BILLION DOLLARS
IN CAPITAL SPENDING EACH YEAR.

Canadian Association of Petroleum Producers

Voices from the Visual Valley: Filmmakers, Tar Sands and Public Health

Geo Takach

In recent years, several documentary films have attacked Alberta's stewardship of the tar sands as threatening the health of people, their communities, and the environment. This short video draws on conversations with the creators of these films, a community of filmmakers from Alberta and beyond. Their voices blend with images and with texts from interviews with people from government and industry involved in producing videos defending Alberta's stewardship, and from related public documents. In voicing disparate views on the tar sands as a public-health issue—performed by student actors—this work connects the health humanities (surveying attitudes on a bellwether health concern); design (presenting those attitudes in a textual/audio juxtaposition); and community engagement. Community members are engaged through interviewing concerned filmmakers, and also by inviting *InSight 2* audiences to reflect on and add their voices to a public dialogue to improve our stewardship of the tar sands as a vital issue of public health.

WE'RE USING UP OUR
WHITE WATER
TO FEED
BLACK GOLD



A Customized Board Game: Visualization as a Tool for Teaching Social Skills to a Child with Autism Spectrum Disorder

Andrea Van Der Ree

My project exemplifies how designers can work across disciplines to create meaningful design pieces to encourage learning of basic concepts and skills. It explores the role of visual communication designers to create visual tools, environments, and experiences for promoting communication and social interaction between children with ASD and their families. During the development of the customized board game, a selected community constituted by a family (mother, father, and sister) of an autistic child, an Applied Behaviour Analysis specialist, and a visual communication designer, collaborated in this research project for the benefit and integration of the autistic child to his environment. Each participant contributed their knowledge about the main participant and their field of scholarship to provide the resources for producing a considered board game. Additionally, this project serves as an invitation to professionals in different areas, and especially designers, to discover new disciplines in the health field, to investigate and apply design knowledge when producing tools, systems, methods, products, etc. for the well-being of communities.



Socially Engaging Apps

Eleni Strouilia, Shayna Fairbairn, Blerina Bazelli, Dylan Gibbs, Robert Lederer, Greig Rasmussen,
Robert Faulkner, Janet Ferguson-Roberts & Brad Mullen

Currently we are witnessing a burgeoning number of devices and applications that enable individuals to quantify their daily behaviour. Mobile interventions are becoming increasingly popular for a number of reasons, including lower development costs and the far reaching potential of the devices.¹ In the area of health promotion, the use of mobile applications for chronic conditions is a relatively new but growing field.² A variety of wearable and embedded devices and mobile applications (apps) are being used to collect and process personal data across a range of health indicators such as food consumed, exercise, sleep quality, mood states, and performance (for example, mental and physical). Due to their novelty and general appeal, these “quantified-self” technologies tend to be widely adopted, but are often abandoned after an initial period of experimentation.³

We have begun to explore incorporating features that support social interaction and engagement to minimize abandonment and instead promote ongoing use of health-related apps. We have focused on mobile applications which have several advantages over traditional web-based applications. For example, interaction can be more tightly coupled with the application as the user does not require Internet access to enter their data. Mobile devices are also perceived as more fun and engaging, as opposed to work-oriented, which may enhance the likelihood of the application being adopted and consistently used. Finally, the application can prompt the user at all times of the day as the mobile device is always with them, which may also help to effect lasting positive behavioural change. We are adopting a software framework for developing mobile applications, informed by three guiding principles: concern for aesthetics; grounding of application development in behavioural theory; and a multiplatform set of components to support consistent and familiar shared user interaction with the aim of influencing long-term adoption and use.

Edmonton Automated Sugar Intelligence (EASI) and Physitivity are two examples of a larger family of applications we currently have under develop-

ment. In our current prototype, we have focused on lifestyle management for young adults living with diabetes given the increasing prevalence of this chronic condition and the significant burden of diabetes on both patients and health-care systems worldwide. In relation to this, it is recognized that a sedentary lifestyle is often associated with a diabetes diagnosis and that increasing physical activity can help reduce symptoms and side effects of many chronic diseases, including diabetes.⁴

The names “EASI” and “Physitivity” were specifically chosen. The acronym “EASI” is free of a disease association, and has a rather positive, encouraging connotation. By inventing the term “Physitivity” we hoped to reduce the stigma and fear that is often associated with being physically active in sedentary individuals. In both applications we are embedding a variety of data collection features (including reminders, information sharing and community-building) within the user’s daily life context to help motivate them to adopt, or maintain positive lifestyle patterns. Through our specially designed data analytics system, based on machine-learning algorithms and interactive visual exploratory interfaces, we aim to assist individuals in consistently formulating their positive intentions for healthy living, and carrying out corresponding desired health behaviours.

The premise of good information design relies on the clear distinction between the tasks of organizing information and the visual presentation of information. Within these tasks there are commonalities, the primary consideration being how to enable users to navigate the app quickly and easily. To this end, we have ensured images and instructions are both clear and brief, with clarity always taking precedence over brevity.⁵ These guidelines, along with concerns related to text comprehensibility, have underpinned the role of the designers in this project. Integrating our commitment to aesthetics with our guiding behavioural theories, the two mobile applications have been designed to be visually appealing while also being seamlessly embedded and effectively used within the context of an individual’s daily life. In addition, the

design of our applications were informed by the Theory of Planned Behavior (TPB)⁶ and work that has recognized the gap between intention and implementation, or “intention-behavior gap”?

In collaboration with their healthcare team, people living with diabetes need to actively self-monitor to manage their health. EASI has been developed to encourage users to regularly monitor their blood glucose, food intake, insulin doses and physical activity. With EASI, the user can configure their mobile application with their personal insulin regimen, as provided by their clinician. Settings can be entered according to a formula (intensive), or the more typical sliding scale (conventional). The app provides the user with specific information. When data are inputted, the app calculates the advisable insulin dose that the user should inject themselves with.

The aesthetic of the EASI app was conceived by a college-aged designer who lives with diabetes. He chose a dark background, tailoring its stark and bold design featuring 3D icons to young adults. To motivate consistency, the application supports a variety of ways for browsing through the data, including a simple linear data history, a high-level monthly calendar overview—summarizing a month’s data in a color-coded scheme—and a weekly overview—combining color-coded days with detailed graphs and data. This last view is particularly interesting: the seven-day window on the left-hand side of the screen can scroll in time to include earlier or later seven-day periods. At any point in time, each day is associated with a color and the same color is used to draw a line linking the user’s current data with previous day-to-day data.

The Physitivity app has been developed to encourage users to increase their daily physical activity. When installed, it recognizes a number of standard activities such as walking, running, cycling and climbing stairs. In addition, it also enables users to define new types of activities based on their own everyday lifestyle, such as “shoveling snow” for example. The application is also aware of the user’s calendar (supported by the Google “Calendar” service) and the user’s location. As long as the application is active, it locates the user’s position every 15 minutes. If the user has given access to their calendar, the application suggests activities when it appears that the user has free time in their schedule.

The TPB construct of subjective norms is addressed through the social aspects of the applications. First, both applications connect with Twitter to

enable users to share their successes in improving their behaviours with their community. We are experimenting with two types of notifications: automatic



posts of user-configurable accomplishments and open-ended posts associated with unique “hash tags” that may have a specific meaning within the user’s social groups. The applications also support integration with Facebook. If the user chooses, their posts would also appear in their Facebook page timeline.

We have addressed the perceived behavioural control construct of TPB by allowing for personalization of the target behaviour in order to encourage the user to perceive it as more achievable. With EASI, users configure the qualitative labels for their measurements, so that they can always view how well they have been doing relative to their own history. With Physitivity, users may specify daily goals in the area of steps, active minutes, and stairs climbed. Through these features, users are held accountable to goals they have defined and, consequently, goals that they feel they can achieve.

Prompts to behaviour can be effective in facilitating behaviour change.^{8,9} Notifications, or prompts, incorporated into our applications are structured as “if-then” statements (implementation intentions) based on identified “intention-behaviour” gaps with notifications appearing on the user’s mobile phone to actively prompt the user to engage in the activity in real time. In the past, notifications have been passive and often did not occur in real time (for example, via informational pamphlets, or a wall poster). In EASI, events associated with “typically bad week days” can be defined to prompt users to be more

aware about their food intake on other similar challenging days. When a user is in an area where an activity has been previously recorded, the Phisitivty app will issue a notification to prompt the individual to engage in this activity again. Inferences about the user's location are based on location accessed through GPS or alternatively through the user's calendar (if calendar activities are associated with locations).

One of our main design goal was to make our applications approachable. This concept features in all areas, from the names adopted for the apps, to the fonts and icons used, including the size of the icons. In EASI, we adopted a bold, contemporary color scheme as well as 3D icons. In Phisitivty, a neutral but contrasting color scheme was used to make differentiation between different functions easy. The color blue was used to denote a regular activity (walking, jogging, biking, climbing stairs). Red was associated with personalized activities such as doing laundry or shoveling snow. The social aspect of the application was represented by the color yellow. The incorporation of other sensory interactions such as sound and tactile feedback will be adopted over time with the intent of creating a deeper level of engagement for the user. The idea of universal design was also considered. Although the application was designed with a specific population in mind it was still considered important that anyone who possessed the skills to use a smart phone could operate this application.

Our major goal in developing the EASI and Phisitivty apps has been to facilitate the integration of desired behaviour—effective diabetes management and enhanced physical activity—into the daily lives of users. Smart phone-based applications have the potential to affect meaningful behaviour change on a population-wide level. The efficacy of mobile interventions has been demonstrated, albeit on a small scale.¹⁰ More research is needed, but mobile applications do seem to offer a promising future for large-scale, population-wide level interventions. We believe that by grounding our socially engaged apps in behavioural theory, our app interventions are likely to have an enhanced impact on the lives of their users. Such applications are virtually non-existent in the health promotion field and the majority of those apps that do incorporate some degree of theoretical background fail to fully define key constructs. Our experience in developing apps informed by behavioural theory with attention given to aesthetics and enhanced social engagement suggests an approach that may increase the likelihood of their adoption and continuing use of health-related apps.

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ns with advanced stage colorectal cancer received
the visualization to see what mortality rates looked
would have looked like had patients had received

Conversation Cards for Obesity Management

Patrick von Hauff, Arya Sharma, Christian Rueda-Clausen,
Geoffrey Rockwell & David Holmes

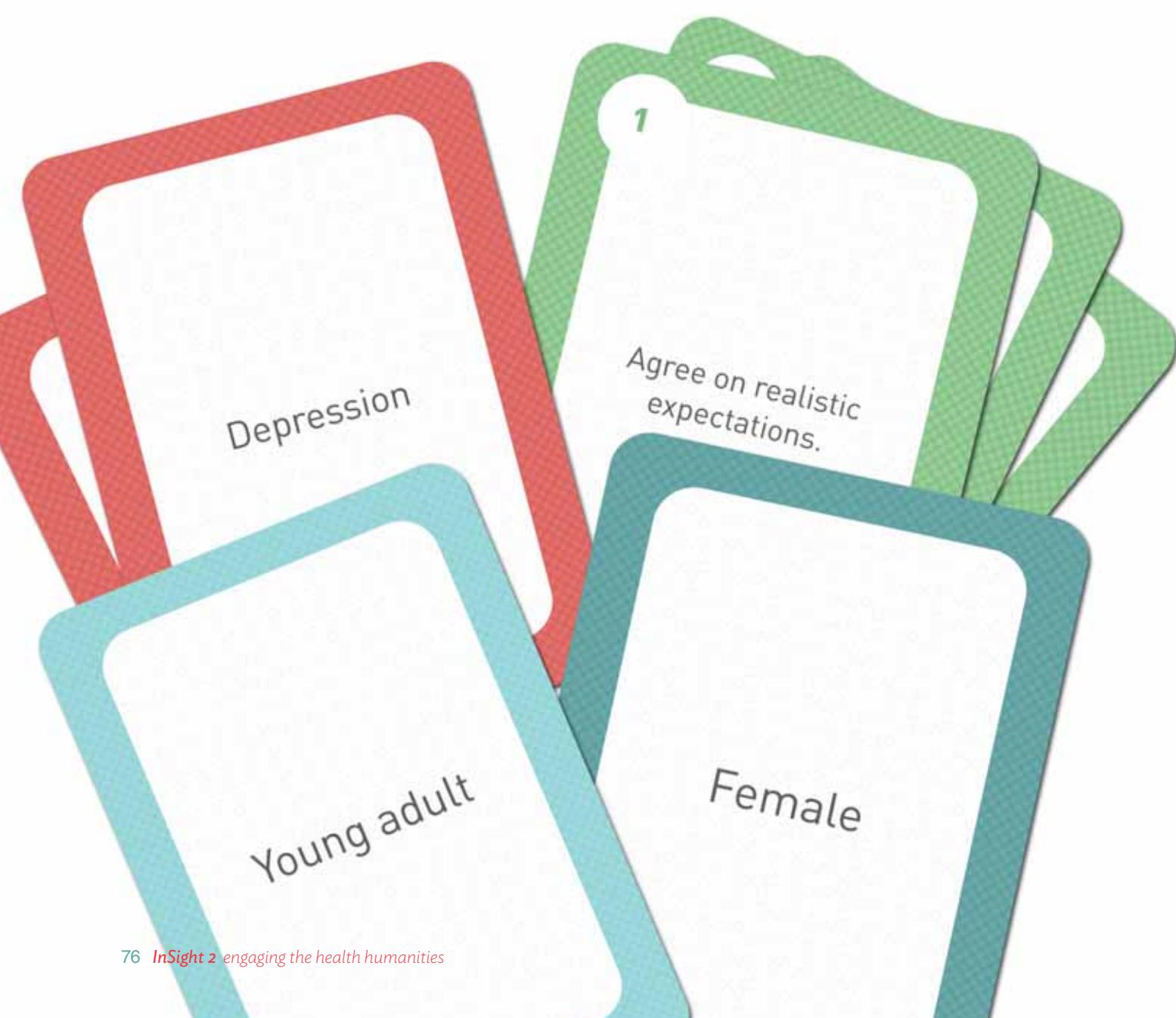
We developed a set of cards to facilitate discussion and scaffold learning around key issues and best practices in obesity management. The conversation cards are intended for use with practicing healthcare professionals who wish to improve their ability to advise patients on obesity management. The project represents a collaboration between design, medicine, and humanities computing. The project combines work by Patrick von Hauff and Geoffrey Rockwell on the use of card-based games to scaffold group exploration of game concepts with a step-by-step framework for the management of obesity in primary care developed by Dr. Sharma. The project explores approaches from each field to improvised forms of teaching and learning, creative thinking, collaboration in groups, and the representation of human-centered problems. The cards can be used to dynamically generate patient scenarios, either randomly or guided by the workshop facilitator, to explore a particular topic of interest (e.g. ethnicity), and to guide discussion of successful strategies and best practices.

CURRENTLY IN
my practice
TIMIZED
clients who
not receive

Patients who
received adjuvant



Stage



Let's Talk About Health

Alysha Visram
Blog Authors: Alysha Visram, Gillian Birmingham, Tricia Morris, Louise Forest, Annette Lemire & James Talbot

Recently, public conversation about improving the health of Albertans has focused on issues such as emergency room wait times, hospital infrastructure, physician shortages, prescription drugs, or the need for more continuing care facilities. Of course these issues are important and need to be addressed, but our efforts to improve health must go beyond seeing a doctor and begin long before we get sick or are diagnosed with a disease.

Today, advancements in public health measures and medical science have resulted in significant gains in both the duration and quality of life. Albertans value good health because healthy people and healthy communities ensure future progress and prosperity. Looking to the future, increasing challenges and pressures on the system will make it difficult to continue meeting our health goals. In order to ensure that we continue to be healthy, we need to change the way we think about health.

It's time to have a different conversation about our health—a conversation where we see our health as something we build with our families, schools, communities and workplaces, in our parks and playgrounds, the places we live, the air we breathe, the water we drink and the choices that we make. How do we accomplish that? How do we connect with and meaningfully engage Albertans in a conversation about health? How do we shift the dialogue from disease and illness and delivery of health care, to health?

In June 2012, Human Services launched *Speak. Share. Thrive* (www.socialpolicy.alberta.ca), a web-based platform that sought to engage Albertans in the planning and development of a social policy framework. Using this platform, Albertans were invited to share their opinions and ideas and interact with each other to discuss their vision for Alberta's future. Opportunities for participation included an online survey, blog, reading and editing a wiki and discussion kits to facilitate community dialogue.

The Office of the Chief Medical Officer of Health contributed six blog posts aiming to create dialogue around the broader concept of health and make the connection between social policies and health.

The contributions introduced ideas related to early childhood development, community engagement, healthy eating and physical activity, housing, workplace health and safety and healthy physical environments. Albertans were also invited share their ideas on these topics and participate in the discussion by posing a question or commenting on the post.

The public is key audience for communicating the broader concept of health because of their ability to direct the broader public discourse and in their collective ability to shape health and social policy. However, the public is generally unaware of the factors that impact health, often focusing narrowly on individual responsibility, individual behaviors and access to health care.

The Office of the Chief Medical Officer of Health's contribution to the blog aimed to challenge these dominant perspectives of health and encourage an exchange of knowledge and experiences as a first step to community engagement. Using a narrative and engaging style, the posts make highly theoretical concepts tangible and accessible by demonstrating clear cause and effect. They also offer potential solutions by providing examples of types of action that could address the problem, as well as emphasize the role of the individual and the community.

Since July 2012, the posts collectively received over 130,000 'reads' surpassing other contributions on the site. Community engagement was evident both directly on the blog site with individual Albertans responding with posts to share their ideas and thoughts, as well as informally through feedback received from internal and external stakeholders. While this was a first attempt by the Office of the Chief Medical Officer of Health to engage Albertans, this project demonstrates the potential of digital media in communicating directly with in-

dividuals and communities on social and economic factors that impact health. In the following we highlight three of our blog posts to illustrate the kind of information we have shared with the public over the past year, and the kind of responses we have received.

The Basics: Eating Right and Physical Activity

(http://www.socialpolicy.alberta.ca/Blog/Message_Chief_Medical_Officer_Health_Basics)

The first thing that comes to mind when you ask people to think about improving their health is “eat right and exercise.” Eating healthy and physical activity are two of the most important things we can do to keep our bodies strong and live long healthy lives. We have a responsibility to our health to eat right and be active; however, where we live, learn, work and play and whether we have the support of family and friends, all have a significant impact on our ability to eat well and be physically active.

Our income, busy schedules and communities influence our ability to access nutritious food. Many Albertans, especially low income or single parent families, find cost, convenience and lack of options as major barriers to eating healthy. Many low income neighborhoods have limited access to stores with healthy foods and have more fast food restaurants. In the absence of supermarkets and healthy food, fast-food becomes the food most often consumed because it is cheaper and more convenient than fruit, vegetables or other healthy options.

Many Albertans find cost, distance and time as barriers to physical activity. Sometimes the environment we live in does not allow us to be physically active. For instance, many inner city parks are not safe environments for children to play in. Creating and maintaining paths, parks or sports fields in local communities will make it easier for us to walk to work or school, play on sports teams and make more healthy choices. Having local, affordable and family friendly options for physical activity will make it easier for people to fit physical activity into their schedules.

Examples of Responses to the Blog:

“I think there needs to be increased education among youth and adults alike regarding healthy food and physical activity choices. With children especially, it’s important that they are exposed to healthy lifestyles growing up in order to

continue these patterns well into adulthood. Education within the school system is vital towards improving the health of today’s children; children need to learn about nutrition and physical activity - and the importance these factors play in longevity.” –Albertan

“With a busy schedule working two jobs, fast food is almost my only choice for a meal. With over 15 fast food restaurants around my home and little to no healthy food places my choices are limited. The time to prepare three healthy food choices a day with healthy snacks would set me back many hours. As well, the healthy food choices are costly in my neighborhood. Though I have many areas for physical activity the food choices are limited.” —Albertan

“Thank you for contributing to the discussion. I appreciate the difficulty you face in making healthy food choices. A lack of access to supermarkets is a barrier to healthy eating in some Alberta neighborhoods. These areas, known as “food deserts” are often created when restrictive covenants are placed on former supermarket sites in order to limit the future use of the site and prevent competition. Unfortunately, many of these areas are located in high-need and inner-city neighborhoods and can impact the diet and physical activity of local residents, particularly seniors and individuals lacking mobility and income. I would encourage you to continue sharing your ideas with your friends, family and local community association as well as write to your local alderman or MLA. The more people we can engage in conversation about these ideas, the more opportunities we have to create healthy communities for all Albertans.” –Dr. James Talbot

“Addressing the issue of “food deserts,” and ensuring that communities have sustainable sources of healthy food choices may take some time. In the interim, there are resources available online that Albertans can access to help mitigate the effects of “food deserts” in their neighborhoods. For example, HealthyU Alberta, at <http://www.healthyalberta.com/HealthyEating/677.htm> offers great tips, among them ideas on feasible options for “Healthy Eating for a Hectic Lifestyle” and staying active.” –Dr. James Talbot

Healthy Physical Environment

(http://www.socialpolicy.alberta.ca/Blog/Message_Chief_Medical_Officer_Health_Healthy_Physical_Environment)

The physical environment includes all living and non-living things around us such as air, water, soil, plants, animals, climate and the built environment (e.g.,

roads and buildings). The physical environment we live in affects our health and well-being and provides four key things we need to live: air, water, food, and shelter. We may often take the air we breathe, the water we drink, the food we eat, and the home we live in for granted. But if one of those things is unhealthy, so are we.

Every change to the physical environment that we live in can affect the health and wellness of a population in major ways. For example, climate change that is occurring globally may increase heat waves, drought and flooding in Alberta and around the world. These changes may affect our ability to grow food, increase the cost of food in the grocery store, and make it harder to maintain our homes. Increases in the cost of living such as food and shelter can have a large impact on families and people with low incomes.

Unhealthy air, food and water can cause serious health issues such as cancer, lung diseases, birth defects, digestive system disorders and food and water borne diseases. Wide differences in health exist among Albertans – between regions and neighbourhoods, and between people with varying levels of education and income. In Alberta, some people are more exposed to unhealthy environments than others. People with low incomes tend to live where there is more pollution that can affect their health. For example, living close to major roads and heavy traffic may make lung conditions like asthma worse. Children are most at risk to harm from unhealthy environments because their bodies are still developing.

Examples of Responses to the Blog:

“I certainly believe one’s physical environment plays an influential role in our health. Some environmental determinants that positively contribute towards my health include healthy outdoor spaces, and access to organic/local produce. It’s important to me to have easy access to healthy outdoor spaces like the river valley, trails and parks; I love being able to go for a run/walk in clean outdoor spaces, all the while reconnecting with nature within a urban setting. I also like to take advantage of the abundance of local fresh produce available here in Edmonton; community gardens, local growers, markets etc. can be found everywhere!” —Albertan

“Physical environments are really important for health, as we all know. While I do enjoy the river valley and some of the parks I do feel that I’m caged into my local area and unable to easily access the rest of the city. Edmonton isn’t very ‘walkable’

if that makes sense—I’d love to see more sidewalks, cross walks and sheltered bus stops. I’m also really interested in urban green design and how we can incorporate more nature into our urban planning. I hope the transit system will enter this conversation as well, because it would be fantastic to get them on board. It’s not just about making these available and accessible though, I think we might need to have a conversation on safety, or perceived safety. People won’t let their kids play in parks if they are worried that it is unsafe, right?” —Albertan

“Thank you for your ideas on ways the physical environment can be improved to support health. We also believe in healthy physical environments where Albertans can integrate physical activity into their everyday lives. Walkable communities also strengthen the social fabric of a community by creating opportunities for us to meet our neighbors, visit the local grocery store, and enjoy public spaces. As you mentioned, it is also important that communities are safe and accessible for everyone. I would also encourage you to share your ideas with your friends, family and local community association as well as write to your local alderman or MLA. The more people we can engage in conversation about these ideas, the more opportunities we have to create healthy communities for all Albertans.”

—Dr. James Talbot.

The Importance of Creating Engaging Communities

http://www.socialpolicy.alberta.ca/Blog/Message_Chief_MedicalOfficer_Health_Creating_Engaging_Communities

The communities we live in play an important role in our health and wellbeing. By providing us with opportunities to get active, to access healthy foods and to make new friends, our communities have an impact on our health.

The physical aspects of communities, such as the amount of park space, walking trails, and proximity to stores that provide healthy food options are just as important to our health as the social aspects such as knowing our neighbours and those around us. Communities that provide opportunities to be active and to make connections with one another enhance residents’ quality of life.

The physical aspects of communities can positively influence how we live, work and play. By providing us with the ability to make healthy choices such as paths that allow us to walk instead of drive and parks that encourage active play, our communities help us feel a sense of well-being in our daily lives.

Albertans can foster healthy communities by advocating for the development and maintenance of paths, parks, arenas, and community centers.

Parks and arenas are important to our health because they promote physical activity as well as social connections. Parks give children the space to make new friends and to exercise. Arenas allow parents to connect with one another and form support networks during their children's hockey games. Curling rinks give people the opportunity to maintain social circles and remain active. High levels of community involvement can be achieved when communities have livable neighbourhoods that encourage people to form connections.

A community with high levels of social involvement is one where residents can participate, contribute and access opportunities. When people are engaged in their community, they care about and participate in sports teams and neighbourhood watch; they make connections with their neighbours and create strong social support networks. Communities with high levels of social interaction are places where people are safe and included. Having strong social connections with those in our communities has been shown to make people feel healthier and to actually protect against chronic disease and mental illness.

It is important to ensure that communities are built with our health in mind. Creating engaging communities cannot be achieved through any one organization, business, or government, but requires all of us working together.

Examples of Responses to the Blog:

“One social aspect of our community that keeps me healthy is the availability of recreational activities at community leisure centers including swimming, hockey and team sports. A physical aspect of our community that keeps me healthy is the presence of sidewalks that allow us to stay healthy by engaging in activities like walking and running safely. Another activity I enjoy is using bike trails that allow people to engage in physical activity in a safe environment. There are many opportunities to create healthy engaging communities. One idea I think is interesting would be the creation of outdoor eating areas that will allow people to enjoy eating

while spending time outdoors. These plazas can be created in the community as well as in urban centers on sidewalks or on the road during certain parts of the year, for example on Whyte Avenue or off Jasper Avenue.” —Albertan

“Thank you for your comments and for sharing your ideas on how we can make our communities healthier for all Albertans. We agree that safe outdoor spaces provide Albertans with opportunities to engage in physical activity and meet their family and friends. I encourage you to continue to take part in discussions that will guide the development of Alberta’s Social Policy Framework.” —Dr. James Talbot

Colorectal Cancer Outcomes in Alberta

Jennifer Windsor, Geoffrey Rockwell, Chris de Gara, Marcy Winget & Joanne Duebel

Colorectal Cancer Outcomes in Alberta represents a collaborative convergence of graphic design, healthcare, digital technology, and data analysis. As a visual and narrative expression of complex aggregated provincial data, brought to life and accessible by utilizing current internet affordances, it is at once a method of data delivery, a learning resource, and a meaningful tool for self-reflection for colorectal cancer physicians. Engaging with the visualization is intended to inform, and ultimately transform, a healthcare community of practice. The visualization provides a confidential forum to measure not only one's practice with the practice of others, and also with projected outcomes. But perhaps more meaningfully, it also offers an engaged method of exploring, and thinking about, colorectal cancer outcomes in Alberta, not as charts, columns and rows of numbers, but as an unfolding story, the ultimate ending of which the user has the power to improve upon.

Colorectal cancer outcomes in Alberta

From 2002 – 2005 only 50% of Albertans with advanced stage colorectal cancer received guideline recommended care. Explore the visualization to see what mortality rates looked like during this period and what they would have looked like had patients had received recommended care: in the province, in your hospital and in your practice. Original articles outlining methods and results of studies can be found [here](#) and a draft analysis of study results can be found [here](#).

CURRENTLY IN →

Alberta

OPTIMIZED

CURRENTLY IN

my practice

OPTIMIZED

CURRENTLY IN

my hospital

OPTIMIZED

Patients who
did not receive
adjuvant therapy



Blue-Green Elixir

Suzanne Wood

It is my aim to express creatively my experiences, thus making tangible through artistic expression my emotions, thoughts, and memories involving illness. The work is a sampling of documentation of my search for “well-being”, when “being well” is not an expected outcome. In addition to the insight producing the art has provided me, it is my desire that it may also provide the community at large, other patients, and especially health professionals, with insight and understanding of what one patient may experience during their medical journey. Improved mental well-being throughout the course of incurable, chronic illnesses has become viable for me because of my engagement in artistic endeavors. Hopefully my positive experience will resonate with other patients, and also encourage health professionals, if not to “prescribe” at least perhaps to “advise” their patients of the possibilities of art and medicine working hand in hand.



Connecting With the Community: Using Art to Raise Awareness and Communicate About the Health Effects of Climate Change

Caroline Wellbery

Background

In a series of projects linking health, art and the environment, Georgetown University medical students and residents have defined a role for art as a means of bridging the gap between academic scholarship and the broader community through interdisciplinary collaboration. This work derives its inspiration from many demonstration projects exploring collaborations between artists and scientists. Notable collaborations include the work of Liz Lerman, who engaged in lengthy dialogues with molecular biologists over the period of one year to choreograph *Ferocious Beauty*, a meditation on the human implications of molecular genetics; and an Australian project fostering interdisciplinary work between artists and scientists in a Centre of Excellence in Biological Arts established for this purpose.² These projects explore on a technical level underlying commonalities between disciplines but more importantly, emphasize how science complements art and vice versa, particularly in the medical field. While medical technology and scientific facts are essential ingredients in medical care, art gives the patients and populations they serve a human face and voice. Conversely, art and narrative as applied to the medical setting acquire credibility through the methodological rigor and substance science provides.³ Art-science collaborations facilitate the give-and-take between reflection and action, creativity and relevance, joy and purpose, journey and outcome.

Our work also draws on a longstanding observation that the arts span a dual function, aesthetic pleasure and instrumentality. The arts are potentially both expressions of creativity and a means to an end.⁴ Which part of the spectrum art emphasizes—the aesthetics or the educational message—depends on the artist, the artist's intentions, and his or her milieu. In the health humanities, the institutional home for our projects, and in most art-science collaborations, the Horatian *utile* tends to carry as much weight as the *dulce* of aesthetic pleasure. Indeed, education and practical application are essential ingredients of the aesthetic enterprise in these interdisciplinary contexts.

An aesthetic that integrates meaning with message and feeling with fact defines for the medical establishment a preliminary approach to community engagement.⁵ As is well known in the world of community-oriented primary care and service education, when working with audiences comprising the local and broader community, it is important to avoid imposing unilateral lessons of any kind.⁶ Our work in environmental health and health of the environment has been especially careful to take the community's potential resistance to outside agendas into consideration because in the US, climate change-related issues have polarized constituents largely for political reasons both within and outside medicine.⁷ In this contentious context especially, we have regarded art as an ideal intermediary between arts educators and community members because art provokes and asks questions without dictating answers. From the standpoint of political non-confrontation, we have also emphasized the health effects of climate change.⁸⁻⁹ Our premise is that health affects all: most people have health concerns and are able to understand the relevance of health matters as they might affect them individually. In sum, our projects seek to meld viewer autonomy with emotional engagement, provocation with an opportunity to learn.

The procedural caveats just mentioned raise an important question about outcomes. If art is to be relevant to the community, it is presumed to have some sort of impact. Yet this has typically been difficult to measure. Therefore, before introducing our projects, I would like to offer the reader yet another perspective within which to situate our work, namely, ecological art, in particular its most community-oriented branch, “ecoventure.” Ecoventure highlights through its many hands-on facets the limitations of more conventional socially conscious art, including our own, and points to potential directions for intensifying community engagement. Ecoventure projects entail collaborations between artists, community members, zoologists, botanists and other scientists but tend to place an even greater emphasis

on practical outcomes (the instrumental end of the aesthetic spectrum to which I previously alluded) than strictly art-centered projects. Using a definition hard to improve upon, “ecovention describes an artist-initiated project that employs an inventive strategy to physically transform a local ecology.”¹⁰ Ecovention projects often actively engage community members to replant a barren landscape, detoxify plots of land and rebuild habitats. These communities can be real or virtual. Several examples below link to illustrative websites (see “Web Resources” listed at end). A major challenge posed by the ecovention movement for those who pursue interdisciplinary educational projects is the focus on purposeful transformation of architectural or geographical sites rather than on merely provoking the viewer into startled reflection. As will be discussed in the section on future directions, community-geared art projects containing interactive components or action directives might ultimately be more successful in turning viewers into active participants, an enhanced form of community engagement conducive to lasting, identifiable outcomes.

Our Art-Science Projects: Art, Health and the Environment

Our projects serve as a platform for reflecting on art activism and its role in public health and community engagement, using environmental health as the fulcrum for discussion. In both projects, scientific research gave rise to an artistic interpretation of factual findings. The first art-science project had as its instigation a larger funded project designed to pair artists with scientists to collaborate on an artwork.¹¹ For our project, we chose to address the problem of medical waste. First, we conducted a focus group with medical students, which elicited the views of students on whether environmental/climate change concerns had any role in medical education and on the extent to which art could be a useful medium for communicating to the public about climate change. Our focus group participants identified medical waste as an important topic for medical education. Also, while students agreed that art could make a powerful statement they warned that overexposure could jade viewers into ignoring the artworks’ intended messages. Following up on the focus group, faculty presented a lecture to medical students and residents on scientific evidence regarding the carbon footprint of the US health care sector, covering such topics as hospital waste and waste disposal, pharmaceutical groundwater contamination andesthetic gases as major contributors to environmental pollution. Participating learners then viewed a community artist-led presentation on climate change and environmental art. These

introductory sessions prepared the medical trainees for enrolment in a glass workshop, conducted under the community artist’s tutelage, as a means of reflecting on and interpreting artistically the problem of medical waste. Each participant created a glass panel, which the lead artist assembled in a frame, as depicted in Figure 1. Some individual panels were more directly didactic than others, for example, one panel depicted a single-use plastic speculum with teeth, connecting the bodily invasiveness of the instrument with the environmental invasiveness of plastic waste. The finished sculpture was exhibited first in a community gallery, the Smith Center for Healing and the Arts (<http://www.smithcenter.org>) and after several months was transported to an outpatient family medicine clinic’s outpatient waiting room where its display is accompanied by an explanatory notice intended to raise awareness of medical waste. Thus, the project’s process taught participants the scientific and human implications of medical waste, while the project’s product intends to bring medical waste to public consciousness emphasizing patient-oriented action items such as proper disposal of unused pharmaceuticals.

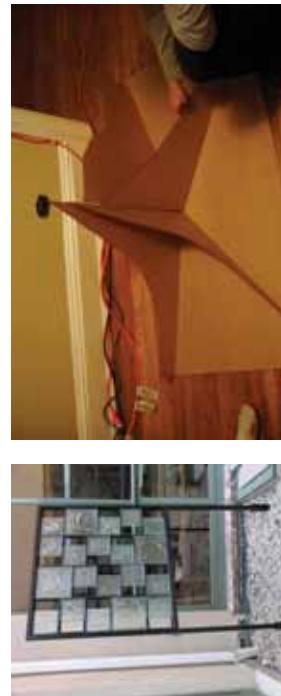


Figure 1
Figure 2

In a second project, three groups of undergraduate students, each led by a medical student, selected respective topics focused on environmental health. Group 1 focused on various graphical correlations showing connections between the logarithmic rise of the earth’s temperature, carbon emissions, and population growth (Figure 2). Group 2 addressed the effects of pollution on respiratory health, and Group 3 focused on water contamination/toxicity (Figures 3-4). In an initial phase of this project, students investigated the topic under the tutelage of a science mentor and presented their findings at a medical student science symposium entitled “Climate change and health.” In a second, overlapping phase, each group worked with a professional artist mentor to interpret their scientific findings artistically. The small budget available for the creation of their artworks felicitously underscored through

low impact (for example, through the use of found and recycled items) their themes and environmental messaging. These works were completed and presented at a university-sponsored event (March 16, 2013), in conjunction with a panel addressing the role of art in communicating about climate change. Journal entries, a pre- and post-questionnaire and a poster presentation gave the students an opportunity to reflect on the learning process that connects art and science, head and heart, formal scientific presentation and artistic installation. Various activities and platforms have been devised to ensure the longevity of this project, including the works' presentation with accompanying posters at Georgetown University's 2013 National Undergraduate Bioethics Conference, as well as a proposed website linking to the university's Environmental Initiative website which will allow user interactions and postings. Most importantly however, the project has led to further insights into the potential for deeper community engagement, setting the stage for an art-science collaboration that targets interactive participation in a two-phase process involving both the academic community and the local Washington, DC community and beyond (see below).

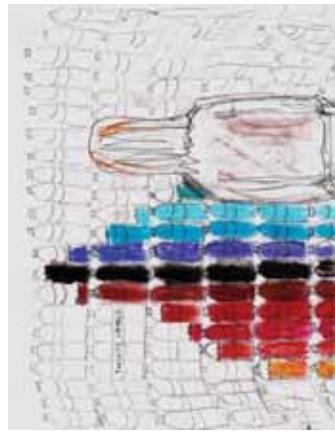


Figure 3
Project 1: Erwin Timmers



Figure 4
Project 2: Lena Bichell

Future Directions

As discussed in the background section of this article, new modalities of community engagement such as ecovention have encouraged interdisciplinary teams to work together to maximize the social value of their efforts.¹² Artists can play a seminal role in these interdisciplinary projects through creativity and aesthetic enhancements. In addition, an important

potentiating resource some artists have begun to embrace is that offered through social networking.¹³ To these ends, we have devised a third project building on the two projects just described. Our new project plans to engage 30–50 students from two campuses respectively, to create and disseminate posters featuring provocative environmental health questions in their schools and local communities. These questions will link to educational messages as well as simple recommendations for actions that can improve both personal health and the environment. Student learners are tasked to engage with their academic and local communities to explore the barriers and opportunities involved in placing these environmental health posters. The project thus takes on the challenge of communicating effectively with the public about climate change, both by physically situating educational posters about climate change which have health impact as the primary focus; and by linking posted health education questions to interactive opportunities, including a web-based blog, Facebook and/or Twitter. In particular, it asks two questions: 1) Can students effectively achieve an educational campaign by engaging with their local communities?; and 2) Can an artistically-driven poster campaign effectively serve the purpose of communicating environmental public health content?

The answer to these questions has implications for integrating health-related climate change topics into clinical curricula and educational programs, and more importantly, for understanding how arts-driven experiential learning combined with social media might be useful in disseminating scientifically sound messages about pressing environmental and health matters. If successful, these modalities could add to current resources for developing far-reaching and widely accepted methods of raising public awareness about the health impact of climate change.

Readers are invited to sign on as potential participants in the later expansion of this project.¹⁴

Project 1: Erwin Timmers
Project 2: Jesse Chen, Sarah Chang, Danielle Llanos, Katherine Adams, Maiko Mori, Joseph Raevis, Jee Won Park, Carmen Hernandez, Celeste Chan, Michelle Stearns, Lena Bichell, Greg Oliva

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4. McNaughton, J. 2000. "The Humanities in Medical Education: Context, Outcomes and Structures". *Med Humanities*. 26: 23-30
5. Cole, A.L., Knowles, J.G. 2008. "Arts-informed Research". In: Knowles, J.G., Cole, A.L., eds. *Handbook of the Arts in Qualitative Research*. Los Angeles: Sage. 55-70.
6. Cashman, S.B. et al. 1999. "Carrying out the Medicine/Public Health Initiative: The Roles of Preventive Medicine and Community-responsive Care". *Acad Med.* 74(5):473-83.
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10. Spaid, S. 2012. "Green Acres: Artists Farming Fields, Greenhouses and Abandoned Lots." <http://www.greenmuseum.org/c/ecovention/sect1.htm>
11. "SOFALAB (Science of Art Laboratory): Science Talks to Art/Art Talks to Science." Funder: Center for Consciousness and Transformation, George Mason University
12. White, T. and Rentschler, R. 2005. "Toward a New Understanding of the Social Impact of the Arts. Presented at the International Conference on Arts and Cultural Management, Montreal, Canada. Retrieved from http://neumann.hec.ca/aimac2005/PDF_Text/WhiteTR_RentschlerR.pdf
13. http://theatrebayarea.org/Programs/programDocuments/upload/LSM_Tangled/Web-SocialMediaintheArts_by DevonVSmith.pdf
14. Contact Dr. Caroline Wellbery at wellberc@georgetown.edu.
- Web Resources
- http://artscoolcfacmu.edu/~bingham/archive/hmr_arch.html
- <http://www.guerrillagardening.org/ggseedbombs.html>
- <http://greenmuseum.org/c/ecovention/tredrawing.html>
- <http://weadartists.org/ecoart-as-performance>
- Figures
- Figure1: Glass panel metal frame: Interpreting medical waste
- Figure2: Group1 Graphic climate change plexiglass mock-up
- Figure3: Group2 Wire lungs
- Figure4: Group3 Water bottle gloo sketch



Take a Leaf from My Book

Marlena Wyman & Chris Westbury

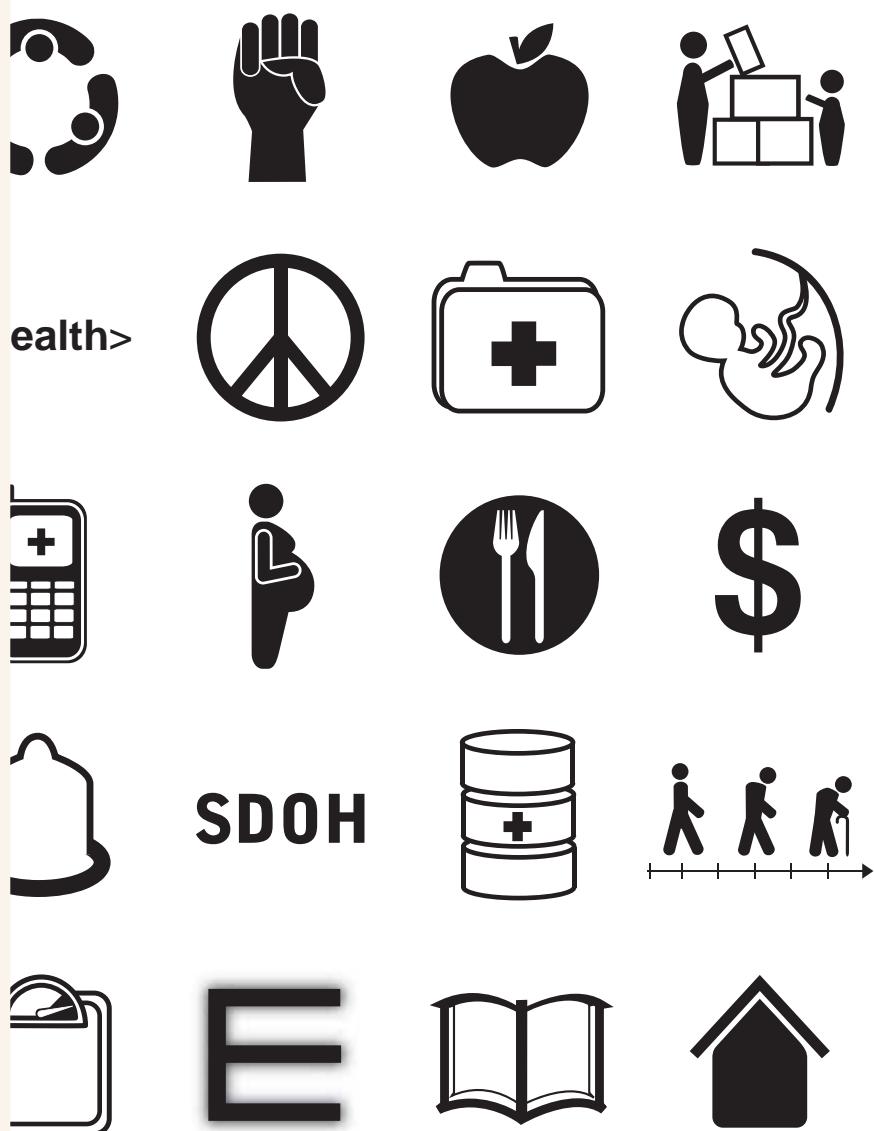
Many health benefits are attributable to a positive attitude. We invite spectators to experiment with this idea by offering them 999 computer-generated descriptions of art to serve as 'projective surfaces' for transformative positive thinking. Spectators are encouraged to remove the description that inspires them and build the described piece. The 1000th description has been removed in advance by artist Marlena Wyman, and transformed into the work displayed. Rather than presenting 'our viewpoint', this piece enables viewers to actively experiment with their own epistemology. In challenging viewers to find positive inspiration in random texts, we remind them of the wide variety of things that can serve as positively transformative symbols. Our work draws from health psychology, Dadaism, visual art, poetry, hermeneutics, and semiotics. The use of nonsense to inspire deliberate positive thinking raises broad questions about the meanings of things, and the extent to which we ourselves can improve those meanings.



Public Health Iconathon

Andrea Yip

Public Health Iconathon is a visual summary of an 'icon marathon' completed in October 2012 in response to the lack of recognizable, universal and usable imagery conveying complex public health concepts. Over a one-month period, twenty-five public health concepts were iconized, with personal Twitter followers and peers of the illustrator, involved in helping brainstorm terms to visualize. Icons were created in less than one hour in order to encourage rapid ideation, iteration, and prototyping. The iconathon represents a type of visual design 'jam' or 'charrette' that I believe is important to incorporate into public health practice. Through ongoing and creative collaboration and a participatory co-design process, we can create new visual imagery in order to expand the public's understanding of health and well-being, and improve health literacy, signage, and wayfinding. The ultimate goal is to create a more robust visual vocabulary for health.



Public Health Iconathon
OCTOBER 2012

Photovoice and Rural Nursing Education: Impressions from the Field

Olive Yonge

“When I was sixteen,” says my research assistant from behind the wheel, “my stepdad took me duck hunting out this way. Definitely not my thing.” We pass farms streaked with late March snow, ditches full of rippling, icy meltwater, copses of trees, and old granaries. I remember my brothers proudly returning home, soaked and filthy, with their brand new twenty-two and a sackful of dead ducks. The boys had to do their own retrieving—Ricky the dog was more of a live duck early warning system—and, as it turned out, their own dressing and cleaning. Mother never let a teachable moment pass, and my brothers learned that day that the payoff sometimes doesn’t equal the effort.



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Today is also about rural teaching and learning, only our destination is not the Saskatchewan farm of my childhood, but a hospital in a small town outside Edmonton. My assistant’s late model Honda is burning more oil than fuel, and we’re miles from the nearest service station. Next time we’ll bring my car.

This is nursing research unlike any I’ve done before. Our participants—nursing students and their rural nurse preceptors—have been busily snapping digital photos of their day to day routine, and our role is to watch, listen, and query. Later on we will clean the data and draw our own conclusions, but for now, it’s their show. We’re early, so we explore the town. It’s a mix of newer bungalows and older, wood-clad houses with verandas and caragana hedges, totally unlike Edmonton’s cookie-cutter suburbs. On the main street at the Co-op

store we see an elderly farmer in a ball cap and a young woman with a baby stroller. At “Mona’s Pot” across the way, homemade cinnamon buns and coffee for two, plus tip, run us the same as a single cinnamon bun in the city. It’s a seat-yourself kind of place, run by a grey-haired, bib-aproned lady (Mona, possibly). In our black business attire, we are clearly out of our element; the regulars wear plaid, cotton, and wool blends, and they are here more for the company than the coffee. That’s rural Alberta.

Hospital parking is plentiful and free, another reminder we are not in the city. The entrance is spotless, smelling faintly of disinfectant, and the floor is shined to a high gloss. We don’t need to be reminded to take off our boots. From her nearby post, the all-knowing unit clerk greets us warmly. While we set up shop in the conference room, a nurse comes by to offer tea, coffee or water. We’re treated as guests and friends, not least because everyone here has a stake in our project; it’s their town, their hospital, their story.

And what a story. Over the following two and a half hours, we get a nurse’s-eye view of the rural landscape, from patient care to powwows, through wheat fields, oil fields, ball fields, hockey rinks, highways and hospital corridors. Through it all run the parallel tracks of community and caregiving. Learning to nurse in a small town means learning about resourcefulness, pride, thrift,

We are bursting with ideas on the trip home. What does this all mean? What can urban hospitals and policymakers learn from our findings? Our brief experience as outsiders has already transformed our perception, so much that we nearly miss our turnoff. It's a welcome reminder of the journey nursing students take, and I feel grateful for having chosen the right profession after all. On this particular hunting trip, the payoff has been well worth the effort.



mutual trust, and fellowship. Most of all, the preceptorship journey is about becoming a community insider—knowing the injuries a thresher or a falling hay bale can cause, for instance, or knowing that rural patients seek care only when absolutely necessary, or that a housecall after hours is worth a bagful of garden produce.





Through Their Own Eyes: Images of Rural Nursing

Olive Yonge, Florence Myrick, Linda Ferguson, Quinn Grundy & Jim Cockell

Over an eighteen-month period between 2009 and 2010, we recruited fourth year nursing students and their rural nurse preceptors to tell the story of teaching and learning in a rural health care agency using digital photography. Our research method invested participants as genuine stakeholders with the power to broaden the scope of the project and influence its outcomes. The participants enlisted their colleagues, clients, family, and friends on both sides of the lens to produce over 800 images. Group discussion and thematic analysis of these data revealed stories encompassing not just the health care setting but the entire rural landscape and community. We found travel, industry, history, and a community spirit of making do and mutual support informed their identity and clinical practice. Rural nurses live and work according to a highly integrated professional and community ethos, requiring flexible professional boundaries. Living the rural life can be grinding but by pulling together, giving comfort, sharing humour and having courage, the community pulls everyone along.



Stuart Adams & Jim Davies
Edmonton, Canada
Heartland Project (pg 16)

River Ice Drama
2009
Watercolour on paper and digital print on parchment
H: 30" W: 49 1/4"

Credits/acknowledgements:
On loan from the University Hospital Collection

Feet, Miles and Fahrenheit
2009
Watercolour on paper and digital print on parchment
H: 37 1/2" W: 41 1/4"

Credits/acknowledgements:
On loan from the University Hospital Collection

The Trees Have Grown
2009
Watercolour on paper and digital print on parchment
H: 37 1/2" W: 41 1/4"

Credits/acknowledgements:
On loan from the University Hospital Collection

Alberta Health, Office of the Chief Medical Officer of Health
Edmonton, Canada
Let's Talk... (pg. 20)

Let's Talk about the Early Years
2011
Report
H: 10" W: 8"

Let's Talk about Aging
2013
Report
H: 11" W: 8.5"

Rachael Allen
Gateshead, UK
Narratives of Medical Miniatures (pg. 21)

Untitled (hospital bed and NG feeding pump)
2009
Digital print
H: 31.4cm W: 42cm

Untitled (operating table)
2009
Digital print
H: 42cm W: 31.4cm

Untitled (incubator)
2008
Digital print
H: 42cm W: 31.4cm

Untitled (black wheelchair)
2008
Digital print
H: 31.4cm W: 42cm

Untitled (obstetric labour table and Entonox cylinder)
2010
Digital print
H: 31.3cm W: 42cm

Untitled (chemotherapy chair)
2012
Mixed media
H: 8cm W: 4.7cm D: 7.7cm

Artivists & collaborators
Artivists Quilting Across Cultures: Building Community and Exploring Health (pg. 22)

Artivists Quilting Across Cultures: Building Community and Exploring Health
2013
Digital projection

Credits/acknowledgements:
University of Alberta design classes:
Des 395, Des 593 + Des 595 (fall 2012)
activists 4 life: Jitta Maurice, Kakome Paul, Kalungi Frank, Kisitu Joseph, Kizito Joseph, Mukasa Vincent, Muwanga Joel, Musisi Charles, Nalubowa Aidah, Nampanga Miriam, Namulondo Deborah, Obol Andrew Jackson, and Robinson Leslie.
Other participants: Jamie Courtorielle, Nikki Webb, Lyubava Fartushenko, Aidan Rowe, Kurt Young, and Bonnie Sadler Takach

Sarah Aziz
Edmonton, Canada
Truth Serum (pg 26)
2013
Installation
H: 8cm W: 20.3cm D: 10.5cm

Susan Bleakley
Peninsula Medical School, UK
Nobody's Home (pg.27)

Nobody's Home
2010
Video

Series of Mortuary Photographs
2010
Digital prints
H: 28cm W: 42cm (each)

Laura Boffi
Rome, Italy
Weaving Relationships (pg.28)

Weaving Relationships: Nesting Dolls
2010
3D prototyping
H: 21cm W: 7cm D: 7cm

Weaving Relationships: Symbols Set and Case
2010
Textile, acrylic, wood
H: 22cm W: 9cm D: 1cm

Weaving Relationships: Messages Station
2010
Wood, ceramic, iron, textile
H: 55cm W: 45cm D: 20cm

Weaving Relationships: The Tree Blanket
2010
Textile
H: 300cm W: 200cm

Weaving Relationships: The Experience Prototyping Video
2010
Video

Weaving Relationships: The Concept Video
2010
Video

Credits/acknowledgements
for the last five works:
Joachim Halse (advisor), CIID Copenhagen Institute of Interaction Design (school), Laura Boffi & CIID Copenhagen Institute of Interaction Design (funder), Antea Hospice, Rome, Italy (collaborating hospice), Istituto Maestroni, Cremona, Italy (contributing institution)

Blair Brennan

Edmonton, Canada

Collecting the Wounded (for Nelson Algren) (pg. 32)

2004

Embroidery on cotton army-surplus stretchers (cotton, wood and metal stretcher hardware)
H: 58cm W: 226cm (two pieces, each piece)

Credits/acknowledgements:

Courtesy of the artist and dc3 art projects

Paul Chamberlain

Sheffield Hallam University
(Art & Design Research Centre), UK
engagingdesign: 'Stigmas' (pg. 33)

Stigmas: 'Rest of your life'

2012

Artefact (chair)

H: 80cm W: 40cm D: 40cm

Credits/acknowledgements: Designer:
Paul Chamberlain ('Art on Chairs', International Design award, Parades Portugal)

Stigmas: 'Adjustable chair'

2012

Artefact (chair)

H: 80cm W: 40cm D: 40cm

Stigmas: 'Danger! Chair'

2012

Artefact (chair)

H: 80cm W: 40cm D: 40cm

Stigmas: 'Wayfinder'

2012

Artefact (chair)

H: 80cm W: 40cm D: 40cm

Stigmas: 'This is a chair to sit on'

2012

Artefact (chair)

H: 80cm W: 40cm D: 40cm

Credits/acknowledgements
for the last five works:

Paul Chamberlain ('Art on Chairs', International Design award, Parades Portugal) (designer)

Stigmas

2012

Digital print

H: 84.1cm W: 59.4cm

Credits/acknowledgements:

Paul Chamberlain (designer)

Sue Colberg

University of Alberta
(Department of Art & Design,
Visual Communication Design), Canada
gratitude / I feel lucky (pg. 34)

gratitude / I feel lucky

2013

13 hand-bound books

H: 7" W: 9" D: 2"

gratitude / I feel lucky

2013

Digital print

H: 17" W: 102"

Kate Collie & Mia Weinberg

Edmonton, Canada

Will You Be My Hands? (pg. 39)

Anthophore

2012

Mixed media on board

H: 30" W: 24"

Gynoecium

2013

Mixed media on board

H: 30" W: 24"

Daffodils in Three Parts

2012

Mixed media on board

H: 24" W: 20"

Winged Tulip

2012

Mixed media on board

H: 24" W: 20"

Will You Be My Hands?

2013

Digital print

H: 17" W: 12.5"

Jannie Edwards, Bob Lysay & Agnieszka Matejko

MacEwan University, Edmonton, Canada

adrift (pg. 40)

2013

Video installation

H: 96" W: 150" D: 288"

Credits/acknowledgements:

Alberta Foundation for the Arts &
MacEwan University (funders)

Lyubava Fartushenko

University of Alberta
(Department of Art & Design,
Visual Communication Design), Canada
Understanding Bipolar Disorder (pg. 41)

2013

Digital print

H: 23" W: 30"

Credits/acknowledgements:
Salim Azzam (photography),
Maryn Sommerfeldt, Mathew Letersky,
Xin Yu Mao, Lindsay Goff and Bridget
Budzak (student collaborators)

Friends of Darren Zenko

Edmonton, Canada & various locations

Quilting with Love (pg. 42)

2012

Fabric

H: 90" W: 55"

Credits/acknowledgements:
Colleen Allen, Anna Classen, Karen Chow,
Christine Chomiak, Cindy Couldwell,
Paul Coutts, Tory Culen, Gavin Dunn,
Tash Fryzuk, Lori Gavrylyk, Fish Grikowsky,
Dara Humniski, Smokey Johnson, Candice Kelly, Lisa Lunn,
Colleen Martin, Dwayne Martineau, Brett Morrison, Steve Notley, Leanne Olson, Shannon O'Toole, Jon Pelster, Krista Polley, Darren Radbourne, Lisa Rezanoff, April Schoonmaker, Kyla Sentes, Jody Shenkarek, Julie Skrepnek, Kyla Tichkowsky, Amy van Keeken, and Brianna Vere (quilters), Joanne Flamand, Diane Fryzuk, Marilyn Tichkowsky, and the Zenko family

Michael Frishkopf

University of Alberta (Department of Music), Canada

Giving Voice to Health: "Sanitation" in Liberia (pg. 46)

2013

Video

Credits/acknowledgements:
Samuel Morgan aka Shadow (composer, lyricist and rapper), Teconblah Morris/J-Cop V (rapper), Chiller Coolhanee (rapper), Timothy F. Bomah /5ya (singer), David Mell (singer), SHADOW's ENTERTAINMENT, Monrovia, Liberia (beats). RED EYE ENTERTAINMENT, Monrovia, Liberia (vocal, mixing and mastering), FARON FILMS, Monrovia, Liberia (video production), Ari Mastoras and Rhodes Recordings, Edmonton (AV post-production), Nora Rahimian and Camilla Hermann, Ground Up Global (consulting), Rotary Club of Calgary (funding), Michael Frishkopf (concept, project direction and production)

Marie Gojmerac, Akua Gyambibi, Crystal Zhou, Michele DuVal, Eric Chan Tai Kong, Amanda Vanderhoek, Danielle Gabert, Mahsa Kamali, Kirsten Marshall, Jennifer Ortynski & Jesse Stach

University of Alberta
(Art in Medicine Club), Canada
What We Learn When We See People (pg. 47)

2013
Mixed media on textile
H: 45" W: 60.5"

Credits/acknowledgements:
Art In Medicine Club

Darian Goldin Stahl

University of Alberta
(Department of Art & Design), Canada
DisEase: Living on the Brink of Disability (pg. 48)

Immobile
2013
Photographic silkscreen on Mylar
H: 34" W: 31.5"

Numb
2012
Photographic silkscreen on Mylar
H: 41.25" W: 29"

Viscosity
2012
Photographic silkscreen on Mylar
H: 35.25" W: 30"

Catherine Kmita

University of Alberta
(Department of Anthropology), Canada

Mongolian Shamanic Ritual: Ensuring Community Balance Through Intercession with Ancestral Spirits and Masters of the Mountains (pg. 51)

Mongolian Böö Mörgöl (Shamanic Practice): Offerings Lake Baikal, Irkutsk Oblast, South Siberia

2013
Photographic digital print
H: 17.5" W: 11.5"

Mongolian Böö Mörgöl (Shamanic Practice): Prayer Lake Baikal, Irkutsk Oblast, South Siberia

2013
Photographic digital print
H: 17.5" W: 11.5"

Mongolia Böö Mörgöl (Shamanic Practice): Ritual Lake Baikal, Irkutsk Oblast, South Siberia

2013
Photographic digital print
H: 17.5" W: 11.5"

Mongolian Böö Mörgöl (Shamanic Practice): Daily Practice Binder, Khentii Aimag, Mongolia Ust-Orda, Ust-Orda Autonomous Region, South Siberia

2013
Photographic digital print
H: 17.5" W: 11.5"

Mongolian Böö Mörgöl (Shamanic Practice): Sacred Sites Bogd Khan Sacred Mountain, Ulaanbaatar, Mongolia Binder, Khentii Aimag, Mongolia

2013
Photographic digital print
H: 17.5" W: 11.5"

Credits/acknowledgements
for the last five works:
Kevin Zak and Salim Azzam (designers)

Kaisu Koski

Utrecht, The Netherlands

Four lessons in anatomy (pg. 52)

2013
Video

Credits/acknowledgements:

Kerry Atkins, Melanie Bodnar, Chantelle Bowden, Pamela Brett-MacLean, Sarah Forgie, Marie Gojmerac, Sachin Rathee, Shirlee Ren, Lynora Saxinger, Urooj Siddiqui, Trish Sigurdson, Jonathan White and Tim Winton (participants in the arts-based inquiry, "Representations of the body in medical education")

Hamit Kuralkan

Monash University (Department of Design), Melbourne, Australia

Preventative Design: Designing for Music Induced Hearing Loss (pg. 53)

2013
Digital print
H: 42cm W: 59cm

Pierre Leichner

Vancouver, Canada

Nothing is Created, Nothing is Lost, All is Transformation (pg. 54)

grassroot worker 1
2012
Mixed media
H: 24" W: 24"

grassroot worker 1
2012
Dried wheatgrass sculpture
H: 13" W: 5" D: 3"

Compendiums of Pharmaceutical Specialties--The Canadian Drug Reference for Health Professionals/ (CPS)
Alberta Tar sands-Canada

2013
Altered book
H: 29cm W: 24cm D: 6cm

Compendiums of Pharmaceutical Specialties—The Canadian Drug Reference for Health Professionals/ (CPS)
Argyle mine-Australia open pit gold and diamond mine

2010
Altered book
H: 29cm W: 24cm D: 6cm

Connaisances—The New Encyclopedia Britannica

2011
Altered book
H: 28cm W: 15cm D: 4cm

Earth—(Venus of Willendorf)—
The New Encyclopedia Britannica
2011
Altered book
H: 28cm W: 15cm D: 4cm

Metamorphosis—The New Encyclopedia Britannica
2010
Altered book
H: 28cm W: 15cm D: 4cm

Multiple artists

Aklavik, Fort McPherson and Old Crow, Canada
University of Alberta, Canada
Community-Driven Research in Northern Canada: Visual Representations of a Health Research Project (pg. 56)

2007, 2010, 2012
Multiple media
H: 24" W: 17"

Credits/acknowledgements:
community members from Aklavik, Northwest Territories; Fort McPherson, Northwest Territories; or Old Crow, Yukon (drawings), Amy Colquhoun (PhD student, School of Public Health, University of Alberta), Sally Carragher (PhD candidate, Faculty of Social Sciences, McMaster University), Monika Keelan (Associate Professor, Faculty of Medicine and Dentistry, University of Alberta) and Karen J. Goodman (Professor, Faculties of Medicine and Dentistry and School of Public Health, University of Alberta) (exhibition design), Matthew Fagnan (image digitization), Canadian Institutes of Health Research, Alberta Innovates Health Solutions, ArcticNet and Canadian Circumpolar Institute (funders), Laura Aplin, Rachel Munday and other members of the Canadian North Helicobacter pylori Working Group (facilitating generation and collection of drawings)

NYIT Center for Global Health

New York, USA
Malaria Education of School-Aged Children in the Kwahu-Eastern Region, Ghana (pg. 57)

Malaria Education of School-Aged Children in the Kwahu-Eastern Region, Ghana

2012
Two framed photographs
H: 18" W: 22" & H: 12" W: 15.5"
Credits/acknowledgements: Karen Chandler (photographer)

Anansi Tricks Mrs. Mosquito
2012
Illustrated cartoon book, report & DVDs
H: 8" W: 4.5" (cartoon book)
H: 10.5" W: 8.5" (report)

Credits/acknowledgements: Susan Warner (director, publications), Karen Chandler (illustration and design), David Shaw (2D animation), Dr. Deborah Lardner and Dr. Miachael Passafaro (NYIT CGH faculty), Dr. Zehra Ahmed (NYIT faculty), Dr. Janice Sawyer (story)

Malaria Education of School-Aged Children in the Kwahu-Eastern Region, Ghana
2012
2 printed posters
H: 36" W: 24" (each)

Credits/acknowledgements:
Susan Warner (director, publications), Diego Rios (art director), Edward A. Gotfried D.O., FACOS, Director, Center for Global Health (author)

Janet Roseman

Nova Southeastern University School of Medicine (College of Osteopathic Medicine), Fort Lauderdale, USA
Honoring the Medicine: Medical Students Create Personal Code of Healing (pg. 58)

2013
Video

Credits/acknowledgements:
Arif Rana (PhD technical coordinator)

Adolfo Ruiz & Megan Strickfaden
University of Alberta
(Department of Art & Design, Visual Communication Design and Department of Human Ecology), Canada
Light in the Borderlands (pg. 62)

2013
Video

Credits/acknowledgements:
Eleanor, Shafi and Carol (stories and videography)

Helen Sanematsu & collaborators

Herron School of Art and Design, New York, USA

For Real Journals for Pregnant and Parenting Teens (pg. 64)

2012
Printed booklets
H: 8.75" W: 6.75"

Credits/acknowledgements:
Helen Sanematsu, Visual Communication Design, Herron School of Art and Design, Indiana University; Courtney Kuhstoss, Dustin Lynch and Andrea Haydon (primary design team), Brandon Cockrum, J Brian Crain, Eric Gray, Cheryl Harnishfeger, Bridget Hawryluk and Ross Shafer (design research team, 2011), Jennifer Bute, Assistant Professor, Communication Studies, Indiana University, Indianapolis; Neale R. Chumbler, Professor and Department Head of Health Policy and Management, Department of Public Health at the University of Georgia; Kathryn Lauten, Associate Director, Indiana Center for Intercultural Communication; Karen Fredrickson Comer, Director of Collaborative Research, Polis Center; Michelle Derr, GIS Analyst, Polis Center; and Jennifer Wright, Graduate Intern, Polis Center (research team), Indiana State Department of Health, Division of Maternal and Child Health, Mary Ann Galloway and Mary Weber (partners)

Jeremy Shellhorn

University of Kansas (School of Architecture, Design and Planning, Visual Communication Design), USA
You Put What In My Mouth? (pg. 65)

2013
Digital print and laser cut board
H: 40" W: 30"

Credits/acknowledgements:
Randall Moore (writer)

Eleni Stroulia, Shayna Fairbairn, Blerina Bazelli, Dylan Gibbs, Robert Lederer, Greig Rasmussen, Robert Faulkner, Janet Ferguson-Roberts & Brad Mullen
University of Alberta, Canada
Socially Engaging Apps (pg. 66)
2013
Tablets displaying apps

Geo Takach
MacEwan University (Edmonton) and University of Calgary, Canada
Voices from the Visual Valley: Filmmakers, Tar Sands and Public Health (pg. 71)
2013
Video

Credits/acknowledgements: Anonymous, Warren Cariou, Travis Davies/CAPP, David Lavallee, Peter Mettler, Matt Palmer, Gerry Potter, Tom Radford, Shannon Walsh and Charles Wilkinson (interviewees), Alberta Fish and Wildlife/Todd Powell, Iwona Faferek and Greenpeace/Eamon MacMahon (photographers), Iwona Faferek (visual designer), Allan Gilliland (composer), Perry Thomas (video editor), Kristel Harder, Carmen Nieuwenhuis, Patrick Maloney, Sarah Ormandy, Jordan Sabo, Krista Skwarok, Peter Takach and Charlotte Wray (voice actors), Grant MacEwan University, Centre for the Arts and Communications, and Social Sciences and Humanities Research Council of Canada (funders)

Andrea Van Der Ree
University of Alberta
(Department of Art & Design, Visual Communication Design), Canada
A Customized Board Game: Visualization as a Tool for Teaching Social Skills to a Child with Autism Spectrum Disorder (pg. 72)
2013
Digital print and game prototype
H: 50cm W: 70cm (print)
H: 20cm W: 60cm D: 60cm (game)

Patrick von Hauff, Arya Sharma, Christian Rueda-Clausen, Geoffrey Rockwell & David Holmes
University of Alberta, Canada
Conversation Cards for Obesity Management (pg. 76)
2013
Paper playing cards, poster & digital toolkit
H: 3.5" W: 2.5" (cards)
H: 36" W: 24" (poster)

Credits/acknowledgements:
Canadian Obesity Network (producer of toolkit)

Jennifer Windsor, Geoffrey Rockwell, Chris de Gara, Marcy Winget & Joanne Duebel
University of Alberta, Canada
Colorectal Cancer Outcomes in Alberta (pg. 81)
2013
Digital visualization & poster

Credits/acknowledgements:
GRAND (Graphics, Animation and New Media); Physician Learning Program; Faculty of Medicine and Dentistry, University of Alberta

Suzanne Wood
Bonnyville, Canada
Blue-Green Elixir (pg. 82)

Healing Garden
2012
Acrylic painting
H: 8" W: 8"

Eternity
2012
Acrylic painting
H: 5" W: 7"

Revelation
2012
Acrylic painting
H: 18" W: 18"

Embrace
2012
Acrylic painting
H: 20" W: 16"

The Appointment
2012
Printed poem
H: 24" W: 8"

Autumn Evening in the Healing Garden
2012
Printed poem
H: 10" W: 8" (each)

Icicle
2012
Printed poem
H: 14" W: 8"

Scar
2012
Printed poem
H: 14" W: 8"

Marlena Wyman & Chris Westbury
University of Alberta, Canada
Take a Leaf from My Book: 1000 Original Artwork Ideas You Can Take Home in Your Pocket. pg. 87)

Take a Leaf from My Book
2013
Mixed media
Three pieces:
H: 30cm W: 25.4cm D: 20cm (five books)
H: 31 cm W: 23 cm (framed text)
H: 30.5 cm W: 61cm (encaustic, image transfer & mixed media on birch panel)

Credits/acknowledgements:
Johwanna Alleyne (photo)

Andrea Yip
Toronto, Canada
Public Health Iconathon (pg. 88)
2012
Digital print
H: 22" W: 17"

Olive Yonge, Florence Myrick, Linda Ferguson, Quinn Grundy & Jim Cockell
Various locations
Through Their Own Eyes: Images of Rural Nursing (pg. 91)
2011
Book
H: 22cm W: 28.5cm D: 1.5cm

Credits/acknowledgements:
Lorris Williams (page layout)

Images provided by contributors unless otherwise noted. Studio photography was provided by Sima Khorrami and David Roles

Wendy Austin, Pamela Brett-MacLean, Daniel Garros, Timothy Anderson & Erika Goble

Various institutional affiliations, Edmonton, Canada
Using Transmedia to Promote Dialogue about the Moral Distress of PICU Teams (pg. 17)

Alan Bleakley

Plymouth University (Peninsula School of Medicine), UK
Transitions in Health Humanities – Towards a ‘Critical’ Health Humanities that Embraces Beauty (pg. 10)

Louise E. Boyle

University of Glasgow (School of Geographical and Earth Sciences), UK
Systems of Panic: Negotiating Boundaries of Social Anxiety Disorder (pg. 23)

Edward Gotfried & Deborah Lardner

New York Institute of Technology (Center for Global Health), Old Westbury, USA
Malaria Education of School-Aged Children in the Kwahu-Eastern Region, Ghana (pg. 29)

Carol Hodgson

University of Alberta (Faculty of Medicine & Dentistry), Canada
End of the Never Day (pg. 34)

Arno Kumagai

University of Michigan (Medical School), USA
Ways of Knowing, Ways of Seeing: Creative Arts in Medical Education (pg. 43)

Alex Donaghy & Sara Neil.
Family Centered Experience Interpretive Project: Two Worlds Apart (2011).
Oil combine. Featured in Academic Medicine 87(12) December 2012.

Lianne McTavish

University of Alberta (Department of Art & Design), Canada
Selected Encounters with Health and its Definition within Diverse Communities, 2010–2013 (pg. 49)

Alan Peterkin

University of Toronto (Health, Arts & Humanities Program), Canada
LIMP (pg. 55)

Robinson Leslie, Jitta Maurice, Kakome Paul, Kalungi Frank, Kisitu Joseph, Kizito Joseph, Mukasa Vincent, Muwanga Joel, Musisi Charles, Nalubowa Aidah, Nampanga Miriam, Namulondo Deborah, Obol Andrew Jackson & Robinson Leslie.
Various locations
Designing for a Better World – Across Boundaries and in Partnership with Communities (pg. 59)

Bonnie Sadler Takach, Aidan Rowe, Pamela Brett-MacLean

University of Alberta (Department of Art & Design, Department of Dentistry), Canada
At the Nexus of Design, Health Humanities and Community (pg. 8)

Helen Sanematsu & Sarah Wiehe

Indiana University (Herron School of Art & Design, School of Medicine)
How Do You Do? Design Research Methods and the ‘Hows’ of Community Based Participatory Research (pg. 67)

Eleni Stroulia, Shayna Fairbairn, Blerina Bazelli, Dylan Gibbs, Robert Lederer, Greig Rasmussen, Robert Faulkner, Janet Ferguson-Roberts & Brad Mullen
University of Alberta, Canada
Socially Engaging Apps (pg. 73)

Alysha Visram, Gillian Birmingham, Tricia Morris, Louise Forest, Annette Lemire & James Talbot

Alberta Health, Office of the Chief Medical Officer of Health
Let’s Talk about Health (pg. 77)

Caroline Wellbery

Georgetown University (Family Medicine), Washington, USA
Connecting with the Community: Using Art to Raise Awareness and Communicate about the Health Effects of Climate Change (pg. 83)

Figures

Figure 1 Glass panel metal frame: Interpreting medical waste

Figure 2 Group 1 Graphic climate change plexiglas mock-up

Figure 3 Group 2 Wire lungs “Lungcatastrophe”

Figure 4 Group 3 Water bottle igloo sketch

Credits:

Project 1: Erwin Timmers

Project 2: Jesse Chen, Sarah Chang, Danielle Llanos, Katherine Adams, Maiko Mori, Joseph Raevis, Jee Won Park, Carmen Hernandez, Celeste Chan, Michelle Stearns, Lena Bichell, Greg Oliva

response to Alberta Health blog texts

Katrina Whiteman

Spruce Grove, Canada
If Your Heart Knocks, It Beats Hard (pg. 101)

Olive Yonge

University of Alberta (Faculty of Nursing), Canada
Photovoice and Rural Nursing Education: Impressions from the Field (pg. 89)

This section has been prepared based on information provided by contributors.

Please send any corrections to info@healthhumanities.ca, and we will do our best to update the online version of this publication.

Engaging with Learners

In our Visual Communication Design program at the University of Alberta, we involve our students in interdisciplinary, collaborative projects for clients and community partners. Students tell us that these types of innovative, explorative and sometimes experimental projects are educational, meaningful, engaging and prepare them for professional practice, graduate study and life-long learning.

InSight 2: Engaging the Health Humanities extends the *InSight: Visualizing the Health Humanities* project to engage learners in a number of ways. In preparation for the *InSight* last year, design students worked together to visually represent the interdisciplinary connections in the emerging field of health humanities. This year, during a participatory workshop, learners in health sciences and medicine were invited to collaborate with senior design students to imagine scenarios for working with communities (of all sorts) while engaging the health humanities to enhance individual and societal responsiveness to the human aspects of medicine and healthcare.

Participants responded to the visual concepts design students developed for branding the *InSight 2* project. A final concept was chosen from several strong designs created, combining the ideas of Kayla Callfas and Katya Worbets. The design utilizes a multi-voice logotype, quadrants with images that challenge boundaries and a circle signifying a spotlight or magnifying glass to focus on and frame different connections across disciplines and communities.

“[It was] very interesting to be able to interact with/collaborate with design students. I’d be very interested to be able to work with ‘arts’/design people in the future to help create more positive and ‘human’ environments for patients and healthcare workers.” (Medical resident)

We continued our connections with design, medical/health humanities and the community, through a collaborative educational project, “Designing for Health,” that involved medical students/professionals working with design students and community members to identify critical issues and visualise design concepts and solutions for health problems. This pilot project was part of an interdisciplinary Spring

Session course called “Radical Imagings and Imaginings: Social Design and the Health Humanities.” Participants responded to emerging themes in the *InSight 2* exhibition and publication, and attended the “Design, the Health Humanities and the Community” symposium, May 24 and 25, 2013.

Allied with these *InSight 2* activities, design student Kim vanderHelm undertook the design research project, “Design Interventions and Activations: Communicating Visual Messages to Provoke Public Action About Elder Care Issues.”

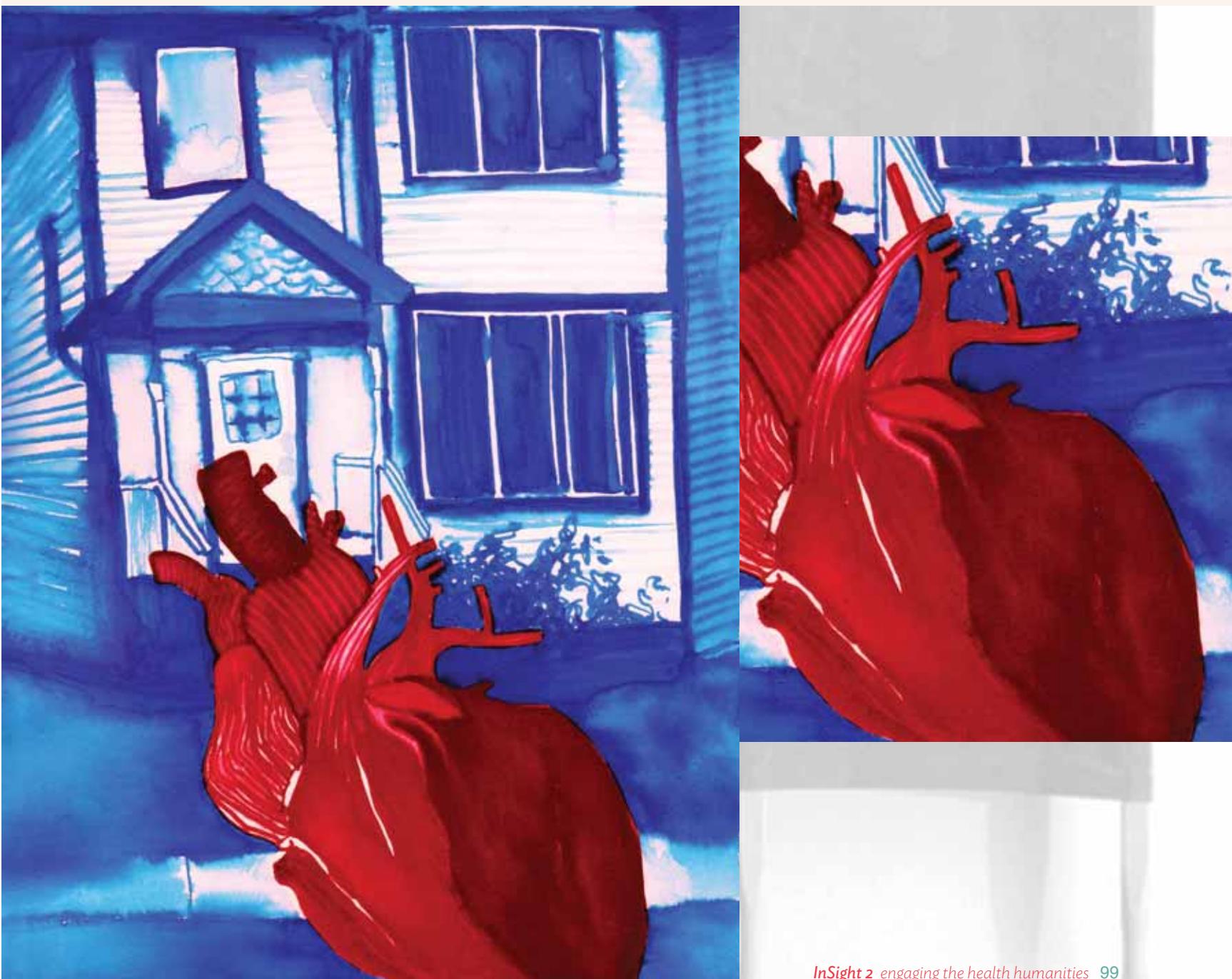
Feedback from these experiences will be used to inform shared learning and interdisciplinary practices that engage communities through design and the health humanities, and open up ongoing opportunities for inter-professional and public involvement in envisioning medicine and health for the future.

Design student Katrina Whiteman created a written and visual personal response about health and well-being.

If Your Heart Knocks, It Beats Hard

Katrina Whiteman

As an artist and as a person, I approach the idea of health with an open curiosity and a desire to obtain a better understanding. Through some of my previous and current work, I have explored the body as it exists, observing skin and muscle and looking to anatomical references to study the skeleton and the organs that lie beneath. I do not shy away from realities concerning the body, or questioning these realities in my work. In this particular piece, I feel the approach was honest. The heart is not overly simplified, and the ties to reality through colour and form are strong. On one level, the colour red speaks to health, passion, and vitality. On a more elemental level, it speaks of blood. I do not find this troubling, however, as I know that blood is red as a result of oxidized iron being contained within the hemoglobin. If my blood is red then I know it is efficiently carrying oxygen. I know I am healthy. Through open curiosity, honest observation, and artistic exploration, I am continually obtaining a better understanding of how the body works. It is through this continued exploration and pursuit of knowledge that I am ultimately better able to care for myself, my family, and those around me.

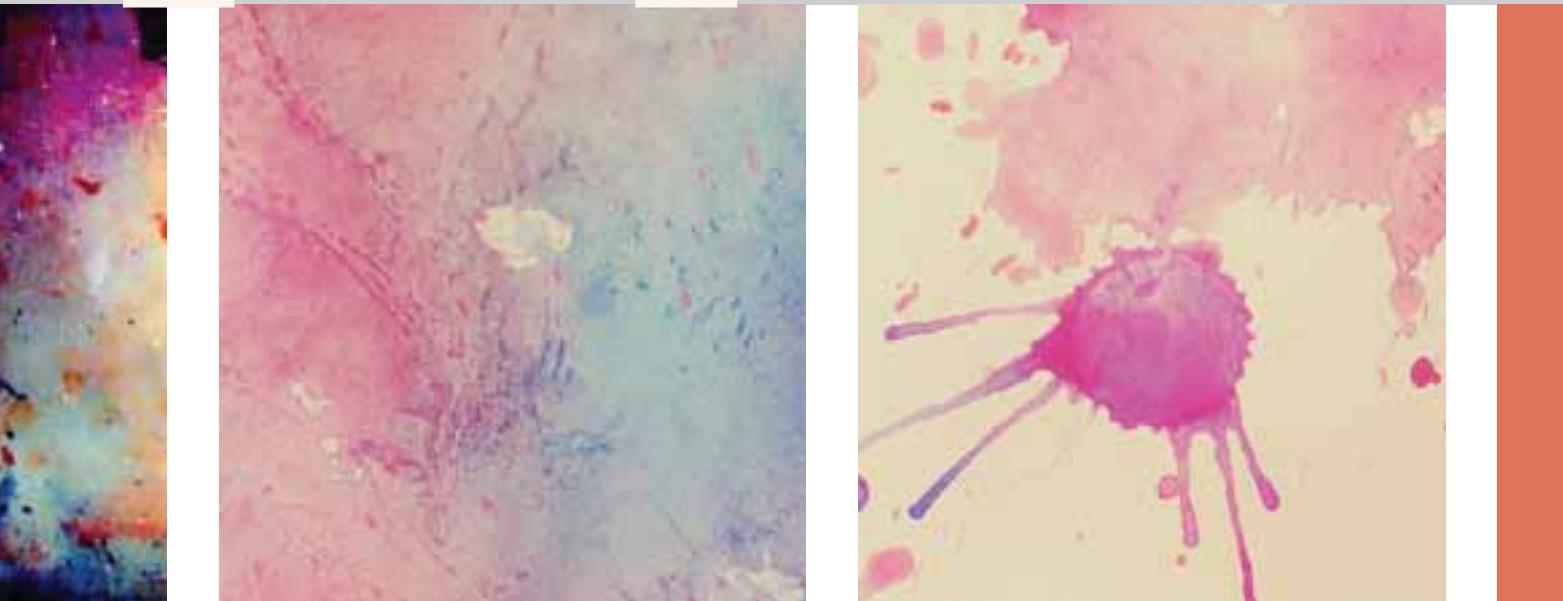


DES 593 *InSight 2* Identity Project

Instructor: Bonnie Sadler Takach

Kayla Callfas
Cindy Chen
Herri Choi
Jenna Clarahan
Janet Ferguson-Roberts
Andrea Hartoyo
Kiersten Marchand
Sarah Oberik-Olivieri
Justin Pritchard
Katya Worbets

An international exhibition and publication offering frameworks for examining linkages, experiences, visualizations and productive imaginings at the nexus of the health humanities, design and community engagement.



IN SIGHT 2

engaging health humanities

Exhibition dates: May 14 to June 8, 2013.
Fine Arts Building Gallery, University of Alberta
Edmonton, Alberta, Canada

An international exhibition and publication offering frameworks for examining linkages, experiences, visualizations and productive imaginings at the nexus of the health humanities, design and community engagement.



InSIGHT 2

Engaging the
Health Humanities



This international exhibition offers a framework for examining linkages, experiences and productive imaginings at the interface of health humanities and community engagement.

May 14 - June 8, 2013
Fine Arts Building Gallery

<http://www.insight.healthhumanities.ca>

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Bryan Kulba
Piyush Mann
Lianne McTavish
Leslie Robinson
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Jane Sadler and (in memory of) Lloyd Sadler
anyone else we may have missed inadvertently
- This work is supported in part by the President's Grants for the Creative and Performing Arts from the Killam Research Fund at the University of Alberta.
- In memory of our friend, Marc Brisbourne (BDes & MDes, University of Alberta; Chair of Design Studies, MacEwan University) whose inspiring and influential work in design education and the design of media for medical education connected across design, the health humanities and community.

Dr. Alan Bleakley is Professor of Medical Education and Medical Humanities at Plymouth University Peninsula School of Medicine, UK. He has a background in biological sciences, psychology, psychotherapy and medical education. His recent work has focused on improving surgical teamwork; communication in medicine; medical education curriculum reform; and the medical humanities in medical education. He is an internationally respected figure in medical education and is a founder member of the Rogano group, committed to innovation in medical education theory and practice. He has published widely, including many papers and six books most recently *Medical Education for the Future: Identity, Power and Location* (Springer 2011). A book on communication in medicine—The Heart of the Matter: Patient-Centred Medicine in Transition—is due in 2014 (Springer). He is a widely published poet (most recently *Striking Blows for Drummers and Other Poems, Acts of Language*, 2012) and a keen surfer.

Pamela Brett-MacLean is Assistant Professor and Director of the Arts & Humanities in Health & Medicine Program in the Faculty of Medicine & Dentistry (FoMD) at the University of Alberta. She is committed to enhancing teaching and learning by infusing arts and humanities perspectives in curricular and co-curricular activities within health professions education. She is also committed to collaborative explorations into the scope and possibilities of an expanded medical/health humanities field, both within the University of Alberta and beyond. A recipient and co-recipient of University of Alberta Teaching and Learning Enhancement Fund grants in support of innovative approaches to medical education, she was also recently awarded a 2013 Canadian Association for Medical Education “Certificate of Merit” for her contributions to medical education.

Lianne McTavish is Professor of the History of Art, Design, and Visual Culture in the Department of Art and Design at the University of Alberta, where she offers courses in early modern visual culture, the history of the body, and critical theory. She has published two monographs, *Childbirth and the Display of Authority in Early Modern France* (Ashgate 2005), and *Defining the Modern Museum* (University of Toronto Press, 2013), as well as numerous scholarly articles on the history of medicine, vision, and museums. Her recently completed manuscript, *Feminist Figure Girl*, stems from an auto-ethnographic project for which she trained and dieted to compete in a bodybuilding/figure competition (feministfiguregirl.com). She also curates and writes about contemporary art, including Janice Wright Cheney’s installation called *Cellar* (2012). Lianne’s current work addresses the numerous illnesses of French King Louis XIV, shifting conceptions of micro-organisms, and the history of the human microbiome.

Aidan Rowe is Assistant Professor of Design Studies (Interactive New Media) at the University of Alberta. He holds degrees from the University of Alberta, University of Westminster and Goldsmiths College, University of London. He teaches design fundamentals, interactive media, design theory and information design. His research, curatorial and practice interests are in design and education. Recent practice-based work explores human-computer interaction, net.art and information aesthetics. Written and pedagogic work revolves around understanding and improving design education in practical and theoretical forms. He has lectured and taught design in Canada, Japan, Korea, Germany, Hong Kong, France and the UK.

Bonnie Sadler Takach is Associate Professor of Design Studies and Coordinator of Visual Communication Design in the Department of Art & Design at the University of Alberta. Her work involves the visual translation of knowledge, and the collaborative design and evaluation of health messages. She was co-investigator of a CIHR Knowledge Translation Grant to study strategies for critically appraising children's health-information websites. She integrates research into teaching, involving participatory methods with community partners. She is a co-recipient of a Teaching and Learning Enhancement Fund grant to explore alternative approaches in design education. She has researched and presented her work locally and internationally.



A note on the design:

The visual identity for *InSight 2* was originally designed as part of a senior design class project. Those involved in the evolution of the visual identity for *InSight 2* are: Kayla Callfas, Katya Worbets, Bonnie Sadler Takach, Aidan Rowe, Salim Azzam and Cindy Couldwell.

A note on the publication:

The layout of this book embraces the theme of engagement by using subtle cues to see what is coming in the pages ahead but also to show that each work in the show is connected. The written articles are set an unorthodox manner to get the reader to, not just visually, but physically engage with the book, lending to the notion of engaging with health humanities. It may seem difficult to engage in the health humanities at first glance but taking a different approach or changing perspective may encourage those connections.

Engage and enjoy the show.

colophon

Book design by Iwona Faferek, www.iwonafaferek.com

The typeface used throughout this book is Ideal Sans, designed and distributed by the type foundry Hoefler & Frere-Jones.

This book is printed on 80lb text Cougar opaque smooth in the interior and 100lb cover Cougar opaque smooth—both FSC-certified papers.

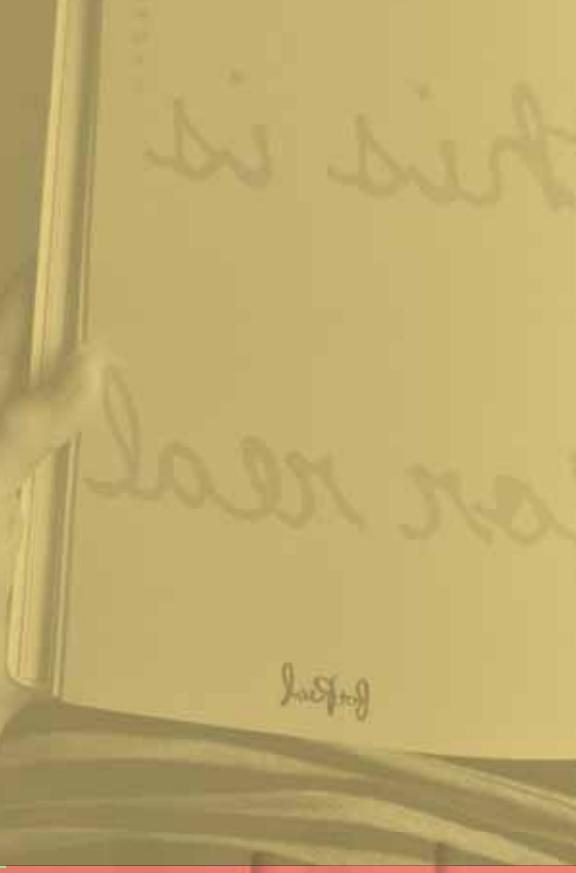
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