

# Your Data Body

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## Abstract

This paper delves into the aesthetics and ethics surrounding the collaborative virtual reality artwork, *Your Data Body*. Made using medical scan data as a metaphor for our ever-expanding bodies of intimate personal data, *Your Data Body* seeks to challenge how we interact with the data of others, questioning the etymology of the word data, meaning “given” and questioning whether in many cases, data is rather “taken”. Using the gaming device of moving through a sequence of scenes, users first encounter open-access anonymized scan data and later donated data given with active and ongoing consent of the subject. Each scene situates the medical scan data within LiDAR scans, is accompanied by poetic elements, and has a complex sonic composition that combines field recordings, choral composition and data sonification as a way to situate the data geographically, temporally and emotionally.

## Keywords

Virtual reality, personal data, data consent, data privacy, sound, composition, LiDAR scanning, data sonification.

## Your Data Body

We are constantly warned that our personal data is vulnerable. We are told that it is used and abused by artificial intelligence, giant tech corporations, and controlling governments [1, 2]. But do we really understand what “our data” consists of and what can be done with it by both ourselves and others? Is it possible to unravel the complex entanglements of data gathering and automated processing technologies in order to see and understand what sociologist Deborah Lupton terms our “human data assemblages” in meaningful ways? [3] Can virtual reality (VR) be used as a creative space to explore and situate our data bodies temporally, geographically and emotionally?

The research project *Know Thyself as a Virtual Reality* (KTVR) has focused on these questions since 2019 through a series of interdisciplinary symposia, publications, and research-creation projects. The central research creation project is a diptych of VR artworks titled *My Data Body* and *Your Data Body*. *My Data Body* focuses on the data we generate and are responsible for as individuals, whereas *Your Data Body* questions how we interact with, understand, and are responsible for the data of others. Both the works use high resolution volume rendered medical scan data (such as MRI and CT scans) as well as other personal data, LiDAR

scans, poetry and unique sonic compositions to create immersive and affective VR experiences that invite the user to think deeply about the data bodies they are seeing, hearing and touching, albeit mediated by a VR headset and controllers [4].

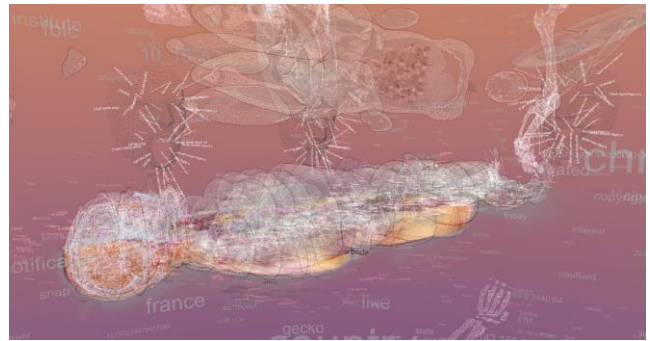


Figure 1. screen shot of *My Data Body*

This paper focuses specifically on *Your Data Body*, the most recent of the two projects. As with *My Data Body*, medical scan data is used in the project both as a literal and metaphorical symbol of intimate personal data. Unlike *My Data Body* [5] however which uses MRI scan data of the artist acquired especially for the work (fig.1), *Your Data Body* is made using a combination of open-access anonymized datasets and donated medical scan datasets with varying levels of information about, and consent from, the subject of the scan. *Your Data Body* employs the gaming device of a series of progressive levels that the user moves through as a way to think through different levels of consent and data ownership, starting with open-access anonymized data and ending with data donated with active and ongoing consent and authorship. The different levels also situate the data within increasingly intimate and emotive virtual spaces, from the artist’s home office to a series of old log cabins from a family property belonging to the scan subject and collaborator Liz Ingram. This paper will explain the aesthetic choices made in each of the scenes and share the many social, ethical and emotional questions that were raised by working with the personal data of others in virtual reality.

## Scene 1: Anonymized open-access data

The first scene in *Your Data Body* collects open-access medical scan data that was originally acquired for scientific and medical research but has now been anonymized, so it can be used for secondary research with creative commons licensing. Since personal information has either been removed or obscured, consent from the scan subject is not required for use of these anonymized datasets. For *Your Data Body* computer tomography (CT), magnetic resonance imaging (MRI) and positron electron tomography (PET) data were easily and freely downloaded from multiple research open access databases; The Cancer Imaging Archive (TCIA), National Library of Medicine, Embodi3D and Open Neuro. Additionally, openly available sample data for working in open-source radiology software (3D Slicer, OsiriX-Viewer and medDream) was also downloaded.

Once downloaded, the scan data was processed so that it could be imported into VR, where it was placed in a web like pod, much like insects caught in a spider's web (fig. 2). The pod was then nested within a LiDAR scanned mesh of the home office of artist Marilène Oliver in which the virtual reality project was largely developed using the gaming software Unity. In early iterations of the scene, the data was placed in what looked like a storage facility or museum display case, but these structures felt strangely impersonal, resembling a science fiction computer game. In an attempt to acknowledge that it is the artist/researcher who is ultimately responsible for treatment of the anonymized data, as well as present where the data was being downloaded, transformed and rendered, it was decided to self-consciously place the data within a scan of the office in which the work was being developed.

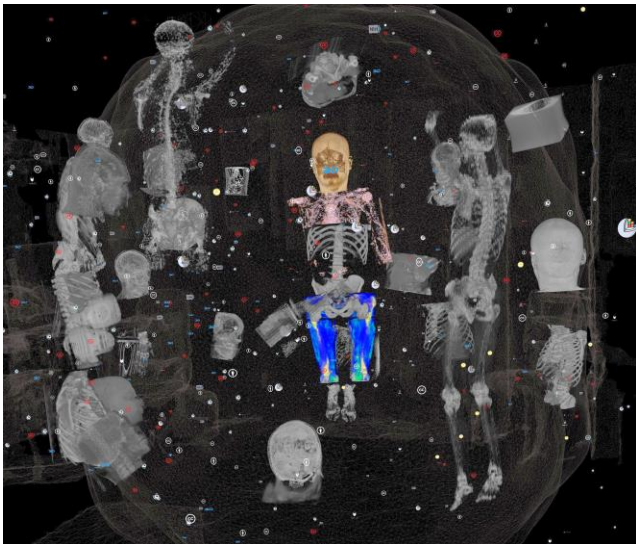


Figure 2. Screenshot of scene 1

A medical data (DICOM) loader script was written for the gaming software Unity so that using the VR controllers grabbing function, the user can pull scanned body parts out

from the web structure, place them elsewhere in the scene, resize and recolour them. The invitation is to use the scanned body parts like building blocks to create a Frankenstein like figure. As the user brings the scanned body part closer to them, and then to their ear like listening to a shell, they hear an automated voice reciting the information about the original research project and why the data was originally acquired. Each body part has a different automated voice, but the information about each of the datasets is very scientific and objective, giving no information about the subject of the scan. Datasets which don't have this information are silent. An additional layer of sound in the scene created by composer Scott Smallwood is an abstract sonification of the data usage agreements for each of the databases (which range in length from a few lines to 18 pages long). Each body part also emanates logos and icons from them like confetti, which relate to the institutional or commercial database identity and the usage agreements attached to them.

The intention with this first scene is to invite users to reflect and question their relationship to open-access personal data. When the user is in the first scene of *Your Data Body*, they are able to hold the virtual head, chest, torso of another person in their own virtual hands. The body part is to scale so the user can relate to it with their own body, they can manipulate it and combine it with another anonymous body parts. But they know little about the subject, where or when the data was acquired, where the subject is now and of course the subject has no idea that a virtual copy of themselves is being held by another person somewhere, somewhere in the world. Although arguably more uncanny and more embodied, this echoes many of our virtual interactions on social media where we consume, comment, like/love posts from strangers sharing very intimate information and images of themselves from everywhere and everywhen. Or, as another example given by Laurence Scott in *The Four-Dimensional Human*, how platforms such as Airbnb allow intimate access into the interior home spaces of millions of strangers around the world at a time when we are increasingly socially distanced from our 'real' neighbors [5].

The ethical difference of course is around consent and hopefully most people who share on social media and on Airbnb are doing it somewhat knowingly and actively. As explained earlier, consent is not legally required for anonymized data as the data has been de-identified and cannot be connected to the subject. Anonymization however has become less reliable in an age of big data, smart devices, and social media and anonymized datasets no longer offer the protections they once did. Smart devices and social media make a wealth of information publicly available [6,7] and this big data can undermine the methods for protecting human subjects represented in anonymous datasets. Furthermore, as machine learning algorithms work by finding patterns in data, there is no assurance (or even way of knowing) if anonymized datasets are cross-referenced and thus reidentified. In order to test the theory of cross-referencing, a volume rendering of a team member's own MRI scan was uploaded to Meta and it was tagged instantly (fig.3).

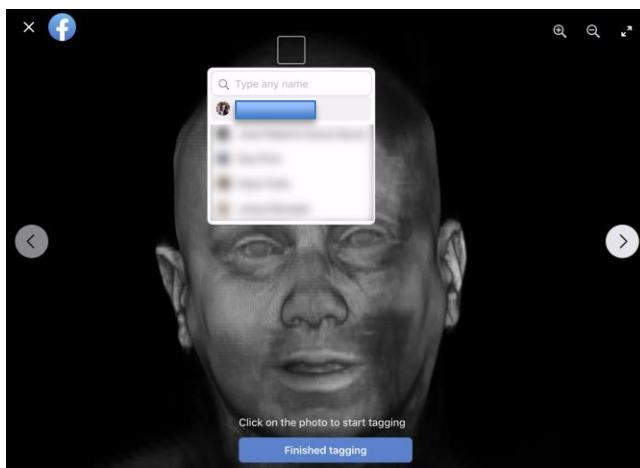


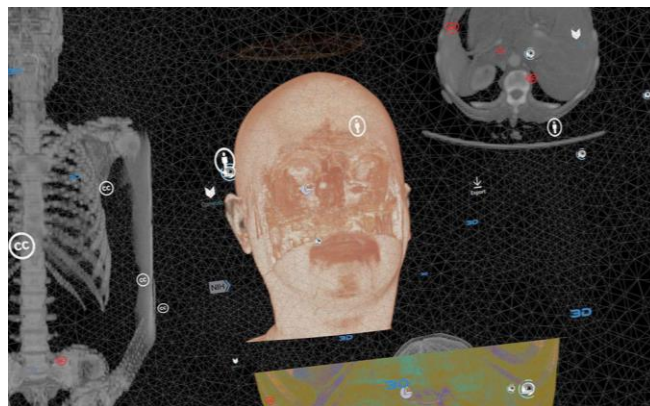
Figure 3. Facebook/Meta tagging rendering of MR scanned head

The potential for harm to the re-identified data subject is not equal for all data subjects and depends on the kind of data, its age, and a myriad of other local social, legal, political, and economic factors. The possibility of reidentification is particularly troubling when we consider that social media giants such as Google and Meta are establishing lines of business in the health care domain. For example, 23andMe is a Google venture (via Alphabet) that became a publicly traded company in early 2021 and is now using the DNA from millions of Americans to produce pharmaceuticals [8]. 23andMe is part of a Google health portfolio that includes insurance companies, medical record apps, and home health monitoring technologies that collect biometric data. Google's Project Nightingale, which gave Google access to health care data through research partnerships, has already raised privacy concerns and lawsuits [9].

A solution developed in the radiological community for the re-identification of scan data is "defacing", which literally involves cutting away the face from head scans [10]. Defacing is mandatory for a dataset to be uploaded to the Open Neuro database, but as of writing, not to Embodi3D, nor 3D Slicer, other open access scan databases. Again, there is considerable debate over the efficacy and ethics of defacing. Many, however, are horrified when they first encounter a 3D rendering of a defaced dataset for it resembles a head with its face violently axed off. Aesthetically, a defaced 3D volume rendered dataset brutally symbolizes the crude (and typically automated) attempts to de-personalize and de-humanization data (hence the choice to include it in this scene (fig. 4)).

In an attempt to re-humanize and re-personalize the data in this scene and indeed the whole of the *Your Data Body* artwork, the project composers Scott Smallwood and Mari Alice Conrad wrote a choral composition that envelopes the user when they are within the data nest. The composers worked with the University of Alberta Madrigal Singers to make a multichannel recording of the choir chanting "Anon, Anon, Anon." This layer of beautiful harmonious human voices is intended as a gratitude to all the anonymous data

that makes so much contemporary research and medical advancement possible. As the sound is so crucial in *Your Data Body*, the sound engine Wwise, was integrated by Catherine Bevan into Unity to allow more spatial control of the data



sonification, automated and human voices.

Figure 4. screenshot of Scene 2 showing a defaced dataset.

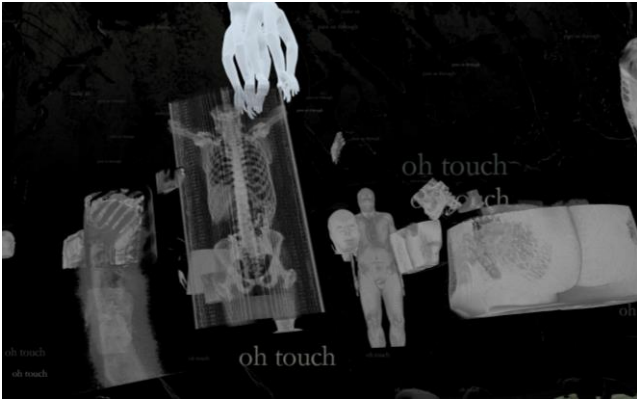
## Scene 2: Rings of Familiarity and collective data ownership



Figure 5. Screenshot of Scene 2, *Your Data Body*

The next level or scene in *Your Data Body* is made up of MR and CT scans "donated" or "given" to the project specifically for creative purposes. Following academic research ethics procedures, an open call for scan data was disseminated through various academic email lists, as well as through direct requests to friends and family. In "Consent to Our Data Bodies: Lessons from Feminist Theories to Enforce Data Protection," Paz Peña and Joana Varon bring a feminist lens to thinking through consent to data usage [10]. They explain the problematics of binary consent options and the illusion that consent can be a free, rational, and individual choice. When a simple click can give access to a website, or, in the case of some medical research projects, to a potentially life-saving study, is there really a choice? In the same way that terms and conditions for social media sites are unreadable, is there a risk that research ethics information sheets and consent forms are equally unintelligible, prompting us to click through rather than meticulously scroll

through the entire text? Peña and Varon suggest that the act of consent needs to be a) active, meaning actively agreeing with body and words to do so (not only the absence of no); b) clear and intelligible; c) informed, fully conscious; d) freely given, out of choice and free will; e) specific to a situation, therefore f) retractable and g) ongoing. With these healthier qualifiers of consent in mind, those who donated their data were shown the project during its many stages and given the option of retracting their permission or suggesting



changes and being credited as an author.

Figure 6. Screenshot of Scene 2 showing text falling

The intention in the second scene is to suggest a collective and consensual ritual of offering and receiving data. When the user enters the scene, they are surrounded by rings of data that swirl around them and they are beneath a virtual sculpture of an eight-armed figure hanging from above seemingly reaching to catch or release data (fig. 5). There are three concentric rings of swirling data around the viewer. Data from close family and friends of artist Marilène Oliver is in the first ring, then known colleagues in the second ring, and less familiar colleagues of colleagues or friends of friends in the outer ring. The rings float within a 360-degree video sphere of a forest of trees shedding their autumn leaves captured close to where the VR artwork was made, signifying being in a time of harvest. Inside the dome are various LiDAR scans of circular structures; a topiary trained tree, a stone circle and a large lily pond. These structures were all scanned by Oliver in locations near her father's home and chosen because of their relationship to time, tradition and ritual. From above fall words from another chant like poem called *Touch* written by J.R. Carpenter about the desire for embodied connection in a virtual world (fig.6). If the user grabs/touches any of the data, it starts to glow with a warm pulsing light. As the user moves closer to the scans, they hear human voices either reciting or singing the *Touch* poem that then wash through them as the scans swirl around the scene. The people who donated the data were given the option of either reading/singing the poem themselves in their own voice, or allowing a trained choral voice or musical instrument to be attached to their data. Most of the people who donated the data did agree to record in their own voice, but made the recordings in different places and at dif-

ferent times. In VR however the user is surrounded by a circular chorus of the scan subjects reciting or singing the poem at the same time.

The idea of placing the data in concentric circles around the viewer developed from learning about examples of collective, rather than individual concepts of data ownership. In "Neuroethics Questions to Guide Ethical Research in the International Brain Initiatives," neurotech ethicist Karen Rommelfanger and her colleagues explain how work done by International Brain Initiative, to coordinate brain mapping initiatives in China, Japan, South Korea, Australia, and the EU, highlighted important differences between Western and Buddhist and Confucian societies in relation to data collection and ownership [11]. Rommelfanger explains that as Chinese, Japanese, and Korean societies are typically more collectivist, medical decisions and ownership of a person's data is collective and family-based rather than individualistic.

Katherine Hayles famously argued that the tech industry continually revels in the fantasy of a disembodied future where we can cast our feeble bodies and become ostensibly omnipotent and omnipresent bytes of information [12]. But our data is hardly objective and acts instead like an expression of what Donna Haraway called our situated knowledges. It is full of the same biases, privileges, limitations, and historical locatedness as our physical bodies; no matter how much one might want to dissolve into nothingness, there are always traces that lead us back to our bodies in the here and now [13]. This 'limitation' is not only inescapable, but the source of our hopes and fears, individuality, and sense of collectivity. VR offers a unique opportunity to challenge this post humanist logic by showing how our personal data continues to be sensorial, affective and highly relational, offering the ability to be surrounded by and immersed in it.

### Scenes 3, 4 & 5: Situating data aesthetically, physically and emotionally



Figure 7. Screenshot of Scene 3, *Your Data Body*

One participant, Liz Ingram responded to the call for scan data with a donation of over twenty datasets is herself an artist. Liz Ingram has created several artworks with her own medical scans, which have been acquired for diagnostic reasons since 2014 as part of her ongoing oncological care. In 2019 for instance, she worked with her husband and long-term collaborator Bernd Hildebrandt to create *Light Touch*, a large silk fabric tent printed with images of her brain scan held tenderly in both her own and her husband's hands. In this and subsequent works, Ingram and Hildebrandt have made strong aesthetic choices about how the artist's scans are presented; typically fragile, transparent, and intermingled with images of flowing water and poetic text. Through conversations and experimentation, it became clear that Liz Ingram who donated the data and her husband Bernd Hildebrandt should collaborate on the *Your Data Body* project, be offered aesthetic control of the scenes that feature her data (3, 4 & 5) and become co-authors of the work.

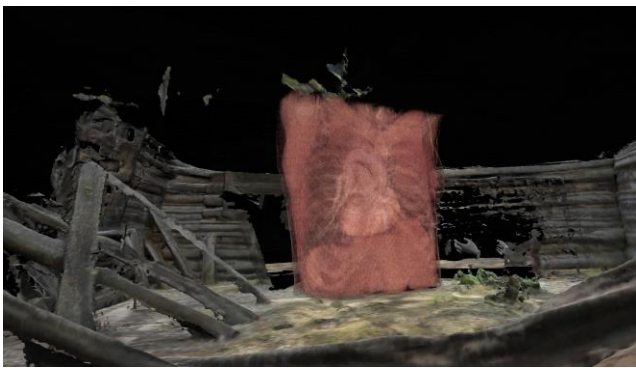


Figure 8. Screenshot of Scene 4, *Your Data Body*

The final three scenes of *Your Data Body* Ingram's medical scans within LiDAR scans of disintegrating pioneer wood cabins in the boreal forest of Alberta, a location that has been central to Ingram's past and present as a beloved second home. Originally a homestead property and then a fishing camp, the location is now a collection of wooden cabins in varying states of decay and repair as the artist and her family are committed to 'rewild' the property. In the third scene, rows of Ingram's head scans sit within the ruins of the "homestead" cabin (fig.7). In the fourth scene, a CT scan of the artist's chest and lungs rotate slowly within the "Miller" cabin (fig.8), and in the fifth and final scene, the artist's fiery PET scan data is cradled within the "tent" cabin (fig.9). In each scene is a poem written by Hildebrandt that either floats above her data, is nestled within it, or as in the final scene, sways through it back and forth. Hildebrandt wrote after first seeing renderings of his wife's data and feeling a deep sense of lack in them, a lack of recognition, a lack of ownership, a lack of meaning. The poems are tender, mournful, sensuous and full of longing, recalling shared intimate memories of each other's bodies in a very specific location steeped in personal and socio-political history.

Once again, sound is crucial in these scenes for which the composer went to the lake site and made a library of field recordings of water, fire, wind in trees, birds and animals,

and distant trains and traffic for the project. Smallwood also used the cabins and found objects as instruments, capturing their resonances. With his students and working with Wwise, the composer placed the captured sounds in the scenes to guide and envelop the user. Inside the rotating chest of the Miller cabin is the sound of water (fig. 8), in the cradled PET scan, the sound of fire (fig. 9). In other parts of the scene are recordings of the forest and the lake. In addition to the spatial composition of field recordings, there is also a layer of choral singing and spoken word based on the husband's poems. To the right of the cabin which holds the PET scan for instance, there are scanned trees in which whisperings of poems can be heard.

When reflecting on their experience of making these scenes, both Ingram and Hildebrandt said they found the process surprisingly therapeutic and positive. What once had been scans that conjured fear and anxiety, now felt loved and cared for. Working with the scans in VR and making aesthetic decisions about them gave them agency and ownership of their data. Interesting, having worked for so long in virtual reality with the medical data within the LiDAR scans of the cabins, when they now return to the cabins in real time and space, they almost feel the data within it.

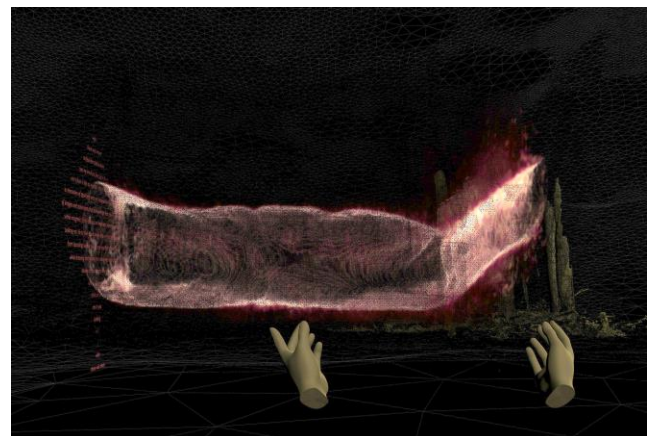


Figure 9. Screenshot of Scene 5, *Your Data Body*

## Know Thyself as a Virtual Reality exhibition, resources and future work

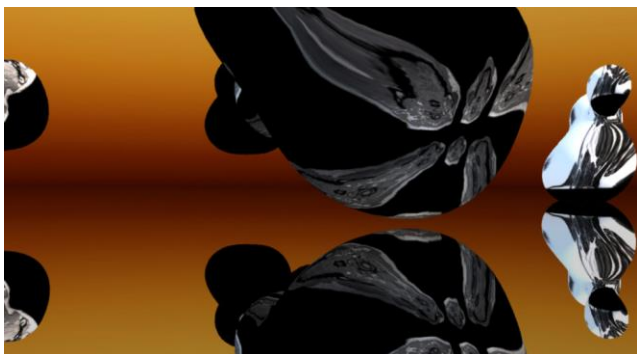


Fig. 10 Screenshot of *mirror with no reflection* by Nicholas Hertz

*Your Data Body* was first exhibited at an exhibition titled *Know Thyself as a Virtual Reality* in February 2023, alongside *My Data Body*. Many novel technical resources and workflows were created in the making of *My Data Body* and *Your Data Body* that have been made openly available via research project website [14] such as a GitHub repository of Unity projects and codes, as well as step-by-step videos and PDFs. This was done in the hope therefore that other artists and researchers would also work with this fertile medium to explore and situate their own data bodies into their own virtual worlds.



Fig. 11 *A vase, a vessel, a body, a home* by Chelsey Campbell

As a way to expand and diversify the *Know Thyself as a Virtual Reality* exhibition, five guest artists were invited to work with the KTVR team and these resources to create their own VR artworks with their own medical scan datasets and situate them in their own diverse emotional, social, spiritual and political realities. Each of the artists made very different works focusing on a variety of themes, further demonstrating the potential of working creatively with medical scan data in VR to question how we know and see ourselves as human data assemblages in the Digital Age. Artist aAron Munson acquired functional MRI scans of his brain after extended periods of meditation and then intensive social media use to question how addictive social media platforms are changing the way we place and hold attention (fig. 12).

Chelsey Campbell who works through the lens of critical disability theory, placed her MR scan into a LiDAR scan of her own bedroom, a site of rest and care (fig.11). Dana Dal Bo hid her data in a large empty office space full of desks with unattended computers that display views from the windows of Amazon's Mechanical Turk workers. Lisa Mayes created a virtual world based on her genetics report from 23andMe, which provided her with a quantitative breakdown of the geographical origins of her ancestors. Nicholas Hertz's VR artwork, *A mirror with no reflection*, focused on the experience of the MR scanning itself, exploring the MR imaging machine as liminal space that exists in between knowing and not knowing about the dangers that might be hidden within the body (fig.10).

The phrase *Know Thyself as a Virtual Reality* is based on the Greek philosophical maxim *Nosce te Ipsom*, which first appeared in the Temple of Apollo in Delphi, where it was a reminder to know one's place within a social hierarchy [16]. Later, *Nosce te Ipsom* was included in anatomical engravings as a reminder to know thyself as divine creation of God [16]. Nodding directly to this history of anatomical art, the *Know Thyself as a Virtual Reality* project encourages us to know ourselves as digital subjects and objects [17] *everywhere* and *everywhen*. The five scenes of *Your Data Body* and the five artworks made for the KTVR exhibition described briefly here, we believe demonstrate the huge potential of working with medical scan data in virtual reality. The ability to situate what is typically considered cold and scientific data within meaningful and emotive virtual environments allows us to better know and ultimately care for our own data bodies and the data bodies of others.

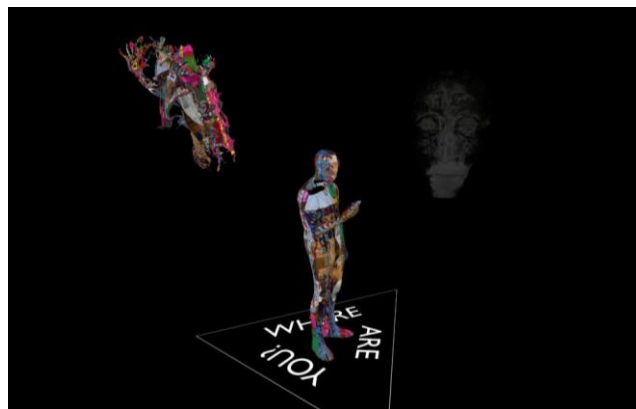


Fig. 12 *Where are you?* by aAron Munson

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## Author Biographies

Marilène Oliver is an associate professor of printmaking and media arts at the University of Alberta. Marilène works at a crossroads between new digital technologies, traditional print and sculpture, her finished objects bridging the virtual and the real worlds. Oliver uses various scanning technologies, such as MRI and CT to create artworks that invite us to materially contemplate our increasingly digitised selves. Marilène currently leads two art & science research projects: *Dyscorpia: Future Intersections of the Body and Technology* and *Know Thyself as a Virtual Reality*.

Scott Smallwood is a sound artist, composer, and performer who creates works inspired by discovered textures and forms, through a practice of listening, field recording, and improvisation. Much of his recent work is often concerned with the soundscapes of climate change, and the dichotomy between ecstatic and luxuriating states of noise and the precious commodity of natural acoustical environments and quiet spaces. He performs as one-half of the laptop/electronic duo *Evidence* (with Stephan Moore) and teaches as an associate professor of composition at the University of Alberta, where he also serves as the director of the Sound Studies Institute.