know
thyself
AS A VIRTUAL REALITY

Ethics e_Symposium Proceedings
05 May 2021

Land Acknowledgement

The University of Alberta respectfully acknowledges that we are located on Treaty 6 territory, a traditional gathering place for diverse Indigenous peoples including the Cree, Blackfoot, Métis, Nakota Sioux, Iroquois, Dene, Ojibway/ Saulteaux/Anishinaabe, Inuit, and many others whose histories, languages, and cultures continue to influence our community.

Table of Contents

INTRODUCTION/BACKGROUND

Know Thyself as a Virtual Reality (KTVR) is an interdisciplinary project that focuses on the ethics and aesthetics of the use of medical scan data and virtual reality. This is an exciting, emerging field which holds huge creative potential and striking opportunities for producing new medical knowledge. Hyper-personal forms of data, such as medical scan data and biometrics, are however fraught with issues related to personal privacy and human rights, especially in relation to artificial intelligence.

To start to unpack these issues, a one day online workshop, funded through the KIAS and AI4Society e-conference grant program, was designed to explore the thorny and controversial issues related to the use of our healthcare in order to spawn debate, dialogue and discussion. The outcomes of this session, including this report, will be used to develop a set of ethical guidelines that will be published alongside software tools being created by the KTVR team for working with medical scan data in virtual reality which will help students, creatives and healthcare workers and the public better understand risks associated with medical data in the age of machine learning and artificial intelligence.

The workshop was hosted online (Zoom) on May 17th. Approximately 50 people registered for the workshop, with actual attendance varying from between 25-40 people throughout the day.

The day began with a focus on legal perspectives related to the use of medical data. Dr. Remegius Nwabueze's talk focused on a UK legal perspective and the laws (or lack thereof) governing the use of imagery of the deceased. The presentation raised a number of questions surrounding the rights of not only the deceased, but also the family of the deceased and served to highlight legal limitations and loopholes.

This presentation was followed by Dr. Ubaka Ogbogu who discussed the issue of legal ownership of human biological materials. From a legal standpoint, if human ingenuity alters the biological materials, the resulting new material can become the property of the creator. This allows for much latitude in patenting human biological materials, which in turn raises questions regarding privacy vs property law not only for human biological tissues, but also, within the bigger context of healthcare data.

Both Dr. Nwabueze and Dr. Ogbogu used a case law approach in their presentations which served to demonstrate precedents in law to illustrate key points and present legal precedents.

After the lunch break, the workshop shifted from legal to ethical considerations. Dr. Susan Cox shared her work on creating ethical guidelines for visual research methods. Dr. Cox touched on the historical context of research ethics and suggested a less adversarial and more collaborative approach between researchers and REBs.

This was followed by Fahim Hassan's presentation on facial recognition technologies. Fahim covered the history of facial recognition, ways in which the technology can harm people and some proposed ways forward to address ethical issues.

Finally, Katrina Ingram presented a case, The Circle of Healthcare Data, which highlighted Google's expanding role in the healthcare industry. This was followed by three facilitated breakout group discussions on the topics of Medical Scan Data, Privacy and Consent, and Data and Patient Rights.

SCHEDULE AND SPEAKERS

The workshop opened with a presentation by Marilène Oliver and then featured several guest speakers. Full biographies can be found on page ***. In order of appearance:

Dr. Remigius N. Nwabueze, Associate Professor of Law at the School of Law of the University of Southampton, UK.
Dr. Ubaka Ogbogu, Associate Professor in the Faculty of Law at the University of Alberta and a Pierre Elliott Trudeau Foundation Fellow.
Dr. Susan Cox, Associate Professor in the W Maurice Young Centre for Applied Ethics and the School of Population and Public Health at the University of British Columbia in Vancouver, Canada.
Fahim Hassan, Ph.D. student at the School of Public Health at the University of Alberta.
Katrina Ingram, MA, recent University of Alberta alumna and CEO of Ethically Aligned AI.

In addition to live presentations, pre-recorded videos were featured during breaks and intermissions featuring the work of the following students (in order of appearance):

Walter Ostrander, 3rd year Computer Engineering CO-OP Student from Jasper, Alberta. Loading Medical Scan Data into Unity, a behind the scenes look at the tools used in the KTVR project.
alissa rossi, MFA candidate at the University of Alberta in Printmaking. Data Privacy Laws in the EU, UK and Australia, a presentation exploring the legal aspects of medical scan data, and Our Digital Lives, looking at cellular location data and privacy.
Erin Ratelle, PhD student in the Faculty of Kinesiology Sport and Recreation at the University of Alberta, Canada. The Art of Forgetting, a short story exploring our "digital children" and the role of forgetting.

The workshop also showcased a number of artful provocation videos including Playing the Body, My Data Body and Your Data Body. Descriptions and examples of these works are available on the Know Thyself as a Virtual Reality website.

RECORDINGS

All recordings can also be found on the Ethics e-Symposium, Know Thyself as a Virtual Reality website.
Marilène Oliver, Welcome and Opening Remarks
Dr Remigius Nwabueze, Privacy Protection of Death Images in England and Wales
Student Short: Walter Ostrander, Loading Medical Scan Data into Unity
Artful Provocation: Scott Smallwood, My Data Body / Hear Thyself Work in Progress
Dr Ubaka Ogbogu, Do You 'Own' Your Health Data?
Student Short: alissa rossi, Privacy and Consent Across Jurisdictions and Our Digital Lives
Artful Provocation: Marilène Oliver, My Data Body (WIP)
Know Thyself as a Virtual Reality, Introduction Presentations Summer 2020
Dr Susan Cox, Emerging Ethical Challenges in Innovative Visual Methodologies
Fahim Hassan and Katrina Ingram, Navigating Data Dilemmas Workshop
Student Short: Erin Ratelle, Art of Forgetting
Artful Provocation: Marilène Oliver, Your Data Body (WIP)

PRESENTATION SUMMARIES

DR REMIGIUS NWABUEZE, PRIVACY PROTECTION OF DEATH IMAGES IN ENGLAND AND WALES

Dr Nwabueze used case law to explore how privacy laws for living and deceased individuals have developed in England and Wales since the adoption of the European Convention on Human Rights (ECHR) in 1998. He used cases from England and the United States that involved the publication of images—moving and still—of living and deceased individuals. Death images were typically produced through the investigation of their death (crime scene and autopsy documentation) that were then leaked beyond those that had authority and legitimacy in viewing the images.

Dr Nwabueze explained that until 2004, privacy was protected in the courts indirectly through things such as copyright infringement. The ECHR was developed in the 1940s and 50s and within it, Article 8 Protection of Privacy, provided for some protection of privacy. It was ratified in the UK, but it was never adopted into domestic law, so there was no legal requirement for judges to consider it in court cases.

The first case Dr Nwabueze began with was Reklos and Davourlis v. Greece (2009). The case involved a photojournalist who photographed a dead baby without permission and published those death images. The parents brought an action against the photojournalist claiming a violation of the baby's privacy rights. The courts agreed and ruled in the parents' favour.

Human Rights Act of 1998 introduced the ECHR into UK domestic law, and included Article 8, Protection of Privacy. But, while it provided for protection of privacy, it was necessary for the law to be litigated in court in order to facilitate its enactment. For the first five years, privacy was protected through a cause of action known as breach of confidence. But this course of action was very limited as it addresses instances of unlawful disclosure of information but does not address privacy violations that fall outside of this.
In Campbell v MGN Limited (2004), Naomi Campbell brought an action of violation of privacy against MGN newspapers for publishing photographs of her. The courts sided with her, ruling that by publishing images of a living person without consent, MGN had violated her privacy through the misuse of private information. This ruling was reinforced in the courts in the cases of Douglas v. Hello Limited (2005) and Murray v Express Newspapers (2008). Both were cases in which photographers took and published photos without consent, and both publications were found to have violated privacy law in the misuse of private information.

Dr Nwabueze then went on to cases that involved images of the dead and how privacy legislation applies differently—if at all—to deceased individuals.

In the first case, Éditions Plon v France (2004), involved the former French President, President Mitterrand. During his presidency, Mitterrand had kept private that he had been diagnosed with a serious form of cancer. After his death, one of his doctors got a publishing contract to produce a book about Mitterrand's illness and treatment, and the Mitterrand family brought an action against the publisher to prevent the publication of the book. They brought two courses of action: that the doctor had violated patient-doctor medical confidentiality, and that the publication of the book was a violation of President Mitterrand's privacy. The courts ruled that the patient-doctor medical confidentiality does not end with the patient's death and that the doctor was in violation of confidentiality, but that privacy, in the case of the second action, does not extend beyond a person's death. While health information remains private, other private, personal information of a deceased person is not protected by privacy law and can be used without any legal consequences. Dr Nwabueze pointed out that while the dead person cannot be embarrassed or otherwise compromised by the publication of death images, the family can be, and that is a very serious issue.

Dr Nwabueze then discussed how there is no privacy protection for the dead in Europe. Under the General Data Protection Regulation (GDPR), privacy protection is not limited to the living, but each member state is free to decide whether to extend that protection to the dead or not. In England and Wales, that protection is not extended to the dead. Even the privacy of medical information of the dead is limited. In a case involving workers at a nuclear power plant, Lewis v Secretary of State for Health (2008), it was established that medical privacy would be respected unless it was in the public interest for the medical information to be made public.

This issue came up in Catsouras v Department of California Highway Patrol (2010), when it was established that the publication of death images had a negative impact on the family of the deceased. In this case, a young woman was killed in an automobile accident in which she was decapitated. Two of the officers on the scene distributed the forensic photos to their friends and family, which were then posted on over two thousand websites. The courts ruled that because the publication of such photos caused harm and suffering to the family, the law should extend the protection of privacy of the dead to the deceased's family. Dr Nwabueze pointed out that there is no uniformity in American law, referring to an earlier, similar case, Smith v City of Artesia (1989), in which the courts did not recognize the family's right of privacy, ruling that the privacy of the individual ended with their death. Dr Nwabueze argued that this is the old way of looking at privacy, and that, with the proliferation of social media and other technology, the risk of harm and suffering to the family is now greatly increased, and the courts should follow the ruling of Catsouras.

Dr Nwabueze gave three sources for how privacy protection could be structured in regards to the dead. The first is case law from the Supreme Court of Florida, Weaver v Myers (2017). It determined that private information collected during the individual's lifetime should be protected; information collected after the individual has died should not. He then cites two philosophical theories. The first is Joel Feinberg's 1984 theory that certain interests extend beyond death and that those interests should be protected.[1] Dr Nwabueze pointed out that in practice, it is not clear who would claim violation of privacy on the part of the deceased, and that there is no practical differentiation between a living and a dead person. The second is philosopher John Harris' theory of 'persistent critical interests' which should be protected beyond the death of the individual.[2] Dr Nwabueze pointed out that this is based on property ownership and is thus its scope is narrow. However, a combination of these three approaches could be used to develop legal protection for the violation of the privacy of the dead.

Dr Ubaka Ogbogu, Do You 'Own' Your Health Data?

Dr Ogbogu used case law in Canada and the US to illustrate how privacy law and property law intersect with the ownership of health data and excised human biological tissue.

Dr Ogbogu began his talk by describing a biobank. He cited a 2012 paper out of the University of Minnesota [3] that described what kinds of excised human biological tissue a biobank stores, how it is stored, who has access to it, what kinds of data can be extracted from the material, and how that data is stored. The material itself can be grouped into three main categories: the excised human tissue (the samples), the materials that are derived from the samples which are unaltered from the original state, and the data that is derived through analysis which may be considered altered from the original state.

From a legal standpoint, Dr Ogbogu discussed the two main questions: who owns the material and what rights does the owning entity have over the material? Ownership implies the ability to decide what happens to it, and the rights and responsibilities of the owning entity change whether it is a custodial institution or the person from whom the tissue was taken. Even when a person does not own their own tissue, they still have rights regarding privacy and to the use of and disclosure of the information or materials. In Canada, rights of control are more settled than ownership over excised human biological material.

Legally, excised human biological tissue is classified by the reason for which it is being used. This—the purpose for which material has been collected, used, shared, or controlled—is an area that is frequently litigated, and it is through these litigations that Dr Ogbogu discussed the issues of ownership of excised human biological tissue.

There are two main reasons why tissue is typically removed: one is for diagnostic purposes, as part of a clinical procedure; the other is for research purposes. Dr Ogbogu refers to a 2013 paper in the Canadian Medical Association Journal that traces these two paths and how the law regulates the tissue depending on the reason for excision.[4]

Tissue that has been altered falls under a different legal classification. Tissue that has been altered by applying 'human ingenuity' is not owned by the person from whom the tissue was removed from, but by the person or entity that applied the human ingenuity to alter it. Dr Ogbogu asks: what does it mean to alter human biological materials? Why does the application of human ingenuity create, under the law, a new kind?

Dr Ogbogu started with the case of Moore v. Regents of University of California (1990). In the course of treatment, John Moore had samples taken from his body for which he had given consent to UCLA for use in the diagnosis and treatment of cancer. One of his doctors, Dr David Gold, found something unusual in Moore's blood and derived the cell line from it, then sought to commercialize it. Moore had not authorized this and brought an action against the university for violation of property rights. The courts said that excised human tissue is not property in the strict sense, and that the person from whom the tissue was taken cannot claim property rights over it. As well, once human ingenuity has been applied to alter it, the altered kind has property rights, and it belongs to the creator, the person or entity that performed the alteration. In this case, the Regents of the University of California and Dr Gold became owners of that tissue, not Moore. Dr Ogbogu challenged the idea that property rights are created in the process of altering tissue and doubts that this legal decision stands up well to scrutiny.

Dr Ogbogu then discussed the exceptions that exist to property rights over human tissue. In Hecht v. Superior Court (Kane) (1993) and in York v. Jones (1989), a deceased person retained ownership over preserved biological material (semen and pre-zygotes, respectively) and, via contract law, the ownership was transferred to another person. But, as Dr Ogbogu pointed out, it is not clear why contract law applies in some cases, but not in ones that involve diagnostic procedure and treatment.

The next case Dr Ogbogu discussed was Piljak Estate v. Abraham (2014). The outcome of this case has many flaws, but it is the only ruling on ownership of human biological materials and the associated health data that exists in Canada. This case revolved around the diagnosis of Mrs Piljak, who died of cancer. Her estate claimed that Dr Abraham was negligent in the performance of his duties by misdiagnosing the tumour as benign. The defendant brought a motion to have the samples re-examined to confirm the original diagnosis, which was denied. The case then went before a master who ruled that, referring to an earlier decision that health records belong to the owning institution, because the samples contained health data, it was analogous to a medical record. Therefore, the material was the personal property of the institute that was holding it—Sunnybrook Hospital—and that they held authority over the use and access of the material. The court also recognized that the person from whom the tissue was taken has rights over the tissue, but only within privacy law.

Taken with Moore, the two cases make three propositions. One, in an unaltered state, human biological materials are owned by the person who collected them. Two, once altered, material is owned by the person or entity that altered it. And three, the person from whom the material was taken retains some rights over the material, but that those rights are founded not in property law but in other areas of law including privacy, fiduciary, and consent law.

Dr Ogbogu then outlined how ownership is still not settled, and that the rulings in these cases have consistently avoided commenting on the issue of ownership of human biological tissues. The ruling in Piljak is particularly flawed because it analogizes tissue to a medical record, which is, in Dr Ogbogu's opinion, completely wrong. It also relies on another case, McInerney v. MacDonald (1992), that ruled on access to information, not on ownership. In that case, the collecting institution's role was defined as custodial, not as an owning entity, and that as a custodian, the institution is bound to rights and responsibilities in the maintenance of those tissues.

McInerney v MacDonald was the case that prompted the creation of access-to-information and health information laws in Canada. In it, McInerney asked her doctor for a copy of all the records in her medical file. The doctor agreed to provide any file that she had obtained or that she had created themselves but claimed that it would be unethical to provide records that were created by other medical professionals the patient had seen. McInerney disagreed, claiming that since the records contained her health information, then she should have access to them. The court in this case agreed with the patient. Health data belongs to the patient. Because of this, the patient has the right to control the data that is held in medical records; a patient has the right to consent to its use or disclosure, and they can ask for information to be corrected. However, the court made a distinction between the health data that is held in a record and the record itself. Patients control the information, and not the records themselves. In regards to the Piljak ruling, Dr Ogbogu disagreed with analogizing tissue to medical records. While they do both contain health data, they are fundamentally different.

In McInerney v MacDonald, ownership was not addressed. The ruling clarified that collecting institutions are custodians of material obtained to provide healthcare. The patient has control over the use and disclosure of the health information contained in the material, and the custodial institution has an obligation to facilitate the direction of that control. It also has an obligation to respect and protect the privacy and confidentiality of that information.

In respect to the application of human ingenuity and the alteration of human biological material, Dr Ogbogu questioned the ways in which the law classifies material. It does not classify material based on its constituent parts or characteristics the way that science does, but on legal artifacts and forms of reasoning that may not make sense with the material itself. Dr Ogbogu asks, how much manipulation is required to render a new kind? Data rendered from material describes the material itself, so why is it a new kind? Why and how does human ingenuity change it? The idea that human ingenuity alters biological material comes from case law which posits that discoveries that possess markedly different characteristics from any found in nature are considered to be new kinds. But I medicine, altered kinds—DNA, stem cells, cell lines—are all the same kind in terms of constitutive properties as their unaltered source material.

In closing, Dr Ogbogu discussed the limits of privacy protections. While the person from whom material is taken retains rights of privacy and confidentiality, privacy protections are dependent on the identifiability of the data. If the data is non-identifiable—if the person is not identifiable through the data—then there is little or no privacy protections and little time has been spent in the courts to determine the legal consequences of use of non-identifiable data. This is becoming an issue since emerging technologies are able to re-identify individuals through de-identified data.

Dr Susan Cox, Emerging Ethical Challenges in Innovative Visual Methodologies

Dr Susan Cox work focuses on the social and ethical impacts of arts-based research that brings together health researchers and artists. In her lecture she gave an overview of research ethics in Canada, an overview of her own work as it related to ethics in arts-based research, and then discussed future directions for the further development of ethical practices.

Dr Cox discussed how all human research done in Canada falls under the Tri-Council Policy Statement (TCPS), and that it operates under an honor-code system in which once a researcher has passed an REB review, there is minimal monitoring or follow up. Because the TCPS was developed in order to establish ethics in medical research, its structure is not well fitted to arts-based research and can seem adversarial at times, operating as a way to reduce institutional liability. In the arts setting, Dr Cox discussed the need to avoid this adversarial model and to think of it more as an alliance between the REB and the community of researchers and artists. But research ethics in the arts is still underdeveloped.

Dr Cox describes how the TCPS was developed out of a variety of principles that include autonomy, beneficence, non-malfeasance, and justice. In 2008, a chapter on arts-based research was proposed but was never included in any of the TCPS updates.[5] In it, they express the need for ethical guidelines and the desire to avoid unnecessary restraint or censorship of artists.

Dr Cox went over some of the projects she has been involved with and discusses the findings from each in relation to ethical research practice. Some of the research showed how different research participants' experiences are from what researchers expect, leading them to advocate for more researcher and research participant involvement in the REB process. She noted that REBs tend to have a paternalistic view towards research, when, in the arts research field, participants expect and accept that theater or art gallery experiences may be slightly provoking or distressing.

Dr Cox referred to a paper written by Marilys Guillemin and Lynne Gillman on institutional (big 'E') ethics, those that are discussed on the level of the REB, and every day (small 'e') ethics, those that come into play when the research is being carried out and which are much messier.[6] It is the messiness of small 'e' ethics that requires researchers to be reflexive in their research and to continually assess and address emergent issues.

Dr Cox also brought up the tension in arts-based research between the desire for fidelity to realistic representation and for creative impulse.

Dr Cox went over the six key issues from the Guidelines for Ethical Visual Research Methods (2014) and elaborated on each with experiences from her own research projects.[7] Those six key issues are confidentiality, consent, representation and audience(s), fuzzy boundaries, authorship and ownership, and minimizing harm.

Consent. She found that consent was an ongoing process, not a single event that occurred at the beginning of the research project. This was negotiated between participants during the creation of the project, and between participant-creators and researchers during the installation of works for exhibition.

Confidentiality. She observed the difference between what participant-creators are willing to divulge in artist statements and what visitors to exhibitions what to know about the participant-creators when viewing the work.

Fuzzy Boundaries. Fuzzy boundaries are when expertise becomes inverted, and it is important to recognize when participants are the experts and to incorporate their knowledge into a project.

Authorship and ownership. Authorship and ownership are less clear-cut when participants are part of the research creation and/or when works is created collaboratively. It is important to work with the participants to determine how authorship and ownership of such work is communicated.

Dr Cox acknowledged the importance of being reflexive and responding to the kind of “gut feeling” when something doesn’t seem quite right and responding to it as it comes up.

She emphasized the importance of researchers sharing their experiences, both at conferences, in papers, and with REBs. She stressed the importance of making sure that people with appropriate knowledge and experience are part of the REB process.

Going forward, Dr Cox suggested that, when developing guidelines, it is important to survey artists and visual researchers in order to identify the issues and challenges they have encountered.

Fahim Hassan and Katrina Ingram: Navigating Data Dilemmas Workshop

Hassan presented an overview of how AI and facial recognition technology have evolved, the issues and biases embedded in it, and some of the projects that challenge its development and use.

AI-based facial recognition systems have been around since the 1960s. In the 60s and 70s, researchers used key facial indicators including hair and eye colour, and the distance between the eye and nose in order to develop a system that automatically or semi-automatically recognized different faces. Since then, researchers have used principal component analysis to improve the technology. In the 90s, federal agencies began developing the technology, including Defense Advanced Research Projects Agency (DARPA) and the National Institute of Standards and Technology (NIST). In the mid-2000s, they made their platform available to researchers and companies to encourage development of automatic facial detection.

Hassan pointed out that as the datasets became larger and the computational techniques or algorithms became more complicated and difficult to interpret, the ethical boundaries and issues of privacy and consent became very blurred. This came to a head when Facebook published DeepFace, their research which used 120 million parameters on user data for which they did not have consent to use.

After Facebook published DeepFace, other companies began showcasing their development of facial recognition technology. Apple released a facial recognition-based ID lock on their phones, and, more egregiously, Clearview AI used publicly available images to develop facial recognition technology which they then sold to law enforcement agencies, including the RCMP. Shortly thereafter, a federal investigation found that Clearview AI violated privacy laws and that stricter legislation was needed on AI and facial recognition technology.

Hassan pointed out that there is a range of uses for facial recognition technology, including ones that are less problematic than surveillance and law enforcement. One example is film studios like Pixar and Disney who use it to improve their animations.

One of the biggest issues with facial recognition technology is the gender and racial bias that programmed into it. Hassan discussed the Gender Shades project which evaluated three commercial gender classification systems and found that the software performs much better on male than female faces, and much better on lighter skin, which means that the software misclassifies women of colour the most. He also discussed AI Now, a research article that found that there is a lack of diversity in computer vision research, and that AI systems are highly flawed when it comes to race and gender and found issues with the training data sets, labelling, and the algorithms. To illustrate, Hassan pointed out some well-known cases of algorithms misidentifying famous black women as men and not recognizing people of colour as human. These examples seem trivial compared to more serious cases, such as that of Robert Williams who was arrested and jailed because facial recognition technology incorrectly identified him as the perpetrator of a crime.[8]

Hassan asked, what can we do about it? There are technologies that have been developed such as Fawkes, a digital image cloaking technology that makes pixel-level changes to photos that make facial recognition algorithms unable to read the faces in the image. There are other groups that are using special face masks to avoid public surveillance.

Hassan then discussed legislation and regulations around privacy and facial recognition technology, including GDPR, PIPEDA and the Privacy Act in Canada, and provincial legislations. In Alberta, he observed that there is a large knowledge gap between the policy makers and the developers of facial recognition technology. He also acknowledged that it is difficult to enforce legislation that seeks to restrict this kind of technology. But he expressed hope because government bodies are paying more attention to facial recognition technology companies and to tailoring legislation to address the issues.

He also mentioned groups that advocate for protections from facial recognition technology, including the Algorithmic Justice League, and local University of Alberta groups such as AI for Impact and AI Arts and Culture Salon. He pointed out that it is important for us as individuals to be aware of the technologies we are using and how they use our data, from social media to cell phone software. Hassan pointed out the importance of discussing these issues beyond the academic realm.

Hassan ended with the quote, "Don't ask if AI is good or fair, ask how it shifts power." There are many guidelines and best practices that evaluate whether technology is fair, but it is more important to think about how it shifts power. He referred to a Nature article from 2020 in which Pratyusha Kalluri cites Ruha Benjamin, who pointed to the major imbalance in power.[9] Hassan believes we need people from many disciplines to come together and look critically at facial recognition technology.

Katrina Ingram began the workshop with two clips. The first was from the movie, The Circle, where a CEO is presenting a surveillance technology which has the capacity to be ubiquitous. The second was a presentation given by Sundar Pichai on Google Health. In it, he presents Google Health's use of AI to provide diagnosis for diabetic retinopathy, and the use of AI in predicting medical events.

Ingram gave a short history of Google's forays into the health care market, beginning in 2006 when they wanted to be the digital location for patient medical records. Due to lack of interest, the plan was abandoned in 2012, but Google continued to develop technology for the health market. In 2014, they acquired DeepMind, a UK company that included a health division, DeepMind Health. It had partnerships with the UK's National Health Services and were responsible for much of the retinal scan technology that Sundar Pichai referred to in the second clip. In 2018, Google launched Google Health.

Ingram then detailed some of the most recent projects. Project Nightingale is a US project that partners Google with universities and a healthcare organization called Ascension, giving them access to patient health data. The project was a secret until 2019 when the Wall Street Journal broke the story. Lawsuits were subsequently filed against Google, but they were not found to have violated any laws. Care Studio is Google's software that aggregates electronic health records to facilitate physician access to all of a patient's records. This is a very useful tool when health regions do not have unified standards for medical records.

Ingram then detailed how the issue with Google is not with any one of its companies or technologies, but when they are considered as an ecosystem, each collecting and feeding off consumer data. Nest has a sleep-tracking app that integrates with Fitbit. Sleep is one way to predict adverse health events, so sleep data would be of use to Google's health insurance company, Oscar. Google is now recruiting Android users to be part of the beta version of its patient portal, introducing patient health data into its ecosystem.

In contrast to Google's culture of secrecy as a company and considering the wealth of data Google has access to, Ingram pointed out that they have a single privacy policy which treats all data equally. Finally, when we die, although Google claims to have an expiry date for inactive accounts, it isn't clear what gets deleted or when.

Transcripts

Marilène Oliver, Welcome and Opening Remarks

Hello and welcome to the Know Thyself as a Virtual Reality Ethics Symposium. My name is Marilene Oliver and I am an assistant professor of printmaking and media arts at the University of Alberta, my pronouns are she/her. This event is being hosted in amiskwacîwâskahikan, Edmonton, Alberta. Edmonton is on Treaty 6 territory, a traditional gathering place for diverse Indigenous peoples including the Cree, Blackfoot, Métis, Nakota Sioux, Iroquois, Dene, Ojibway/ Saulteaux/Anishinaabe, Inuit, and many others whose histories, languages, and cultures continue to influence our community.

As an artist I have been working with medical imaging data such as MRI and CT scans for almost 20 years. One of my earliest works was Family Portrait, a sculptural installation for which I arranged to have each of my family members MRI scanned. Later I screen printed the scans onto sheets of clear acrylic and stacked them to create this installation. I was drawn to the MRI scan then, as I am now, because it is one of the most intimate and precise ways of capturing and digitizing a human being. MRI, CT and other scanning technologies resemble photographs, in that they are indexical, and they promise access to interiority by making our invisible interior visible. They literally convert flesh to pixel, flesh to voxel, and flesh to xyz coordinate, offering what I believe to be a potent metaphor to think, see and know with in the Digital Age.

Figure 1. Family Portrait, 2003. MRI scans silkscreen printed onto acrylic.

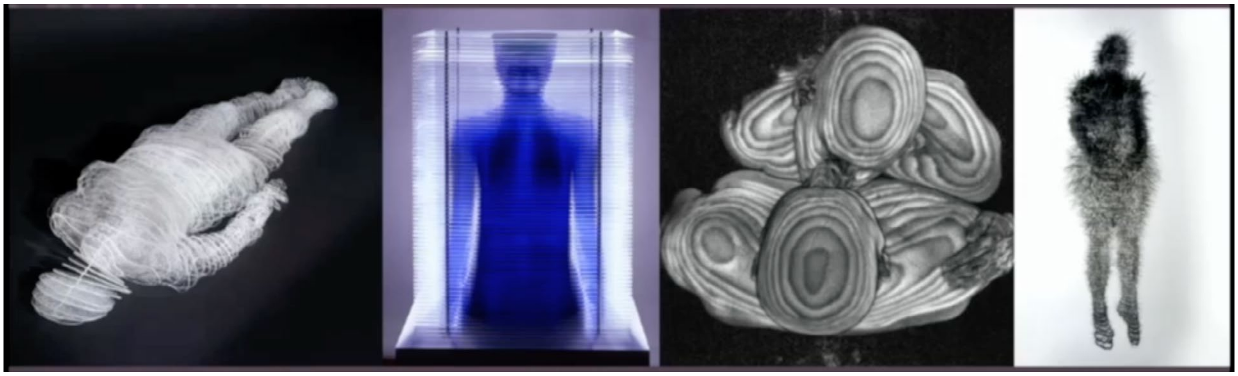


Figure 2. Selection of artworks made with MR/PET scans 2001-2007

The digitized individual is quantified, fragmented, reformatted, aggerated, duplicated and cross referenced so that it can be read and processed by machines. Here we see Facebook's facial recognition software tagging a volume rendering of my MRI data.

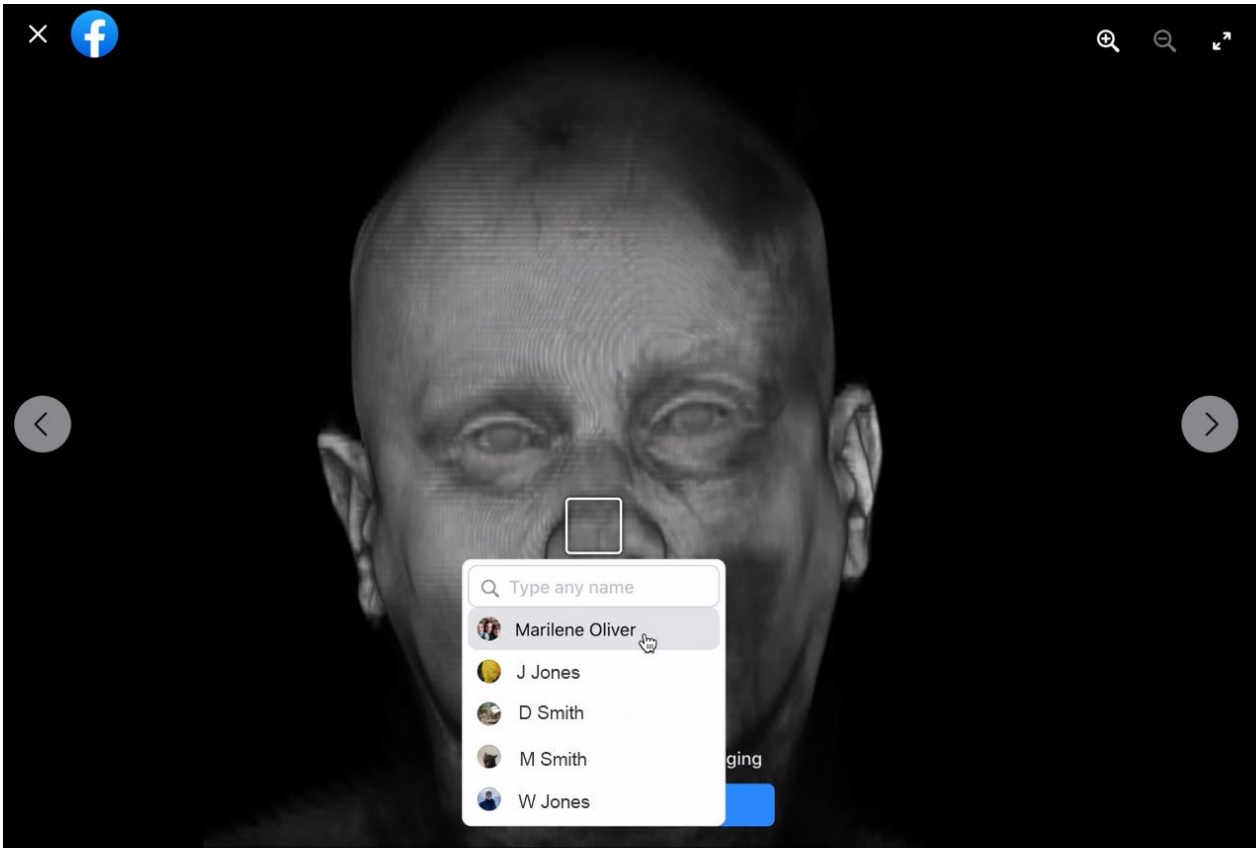


Figure 3. Facebook's facial recognition identifying the artist's medical scan.

After making Family Portrait I continued reworking the scans to make other works, but I was always searching for more scans to work with. I wrote letters to radiology researchers and scanning centres who generously supported this work by helping me acquire data or sharing anonymized data with me but I constantly wanted to be able to process the data myself, both to lessen the burden on my collaborators and also to understand the material of the digitized body better through play and experimentation.

In 2007, on one of my quests for data I was told by a radiographer about Osirix – open source radiology software that also included a repository of open access scan datasets.

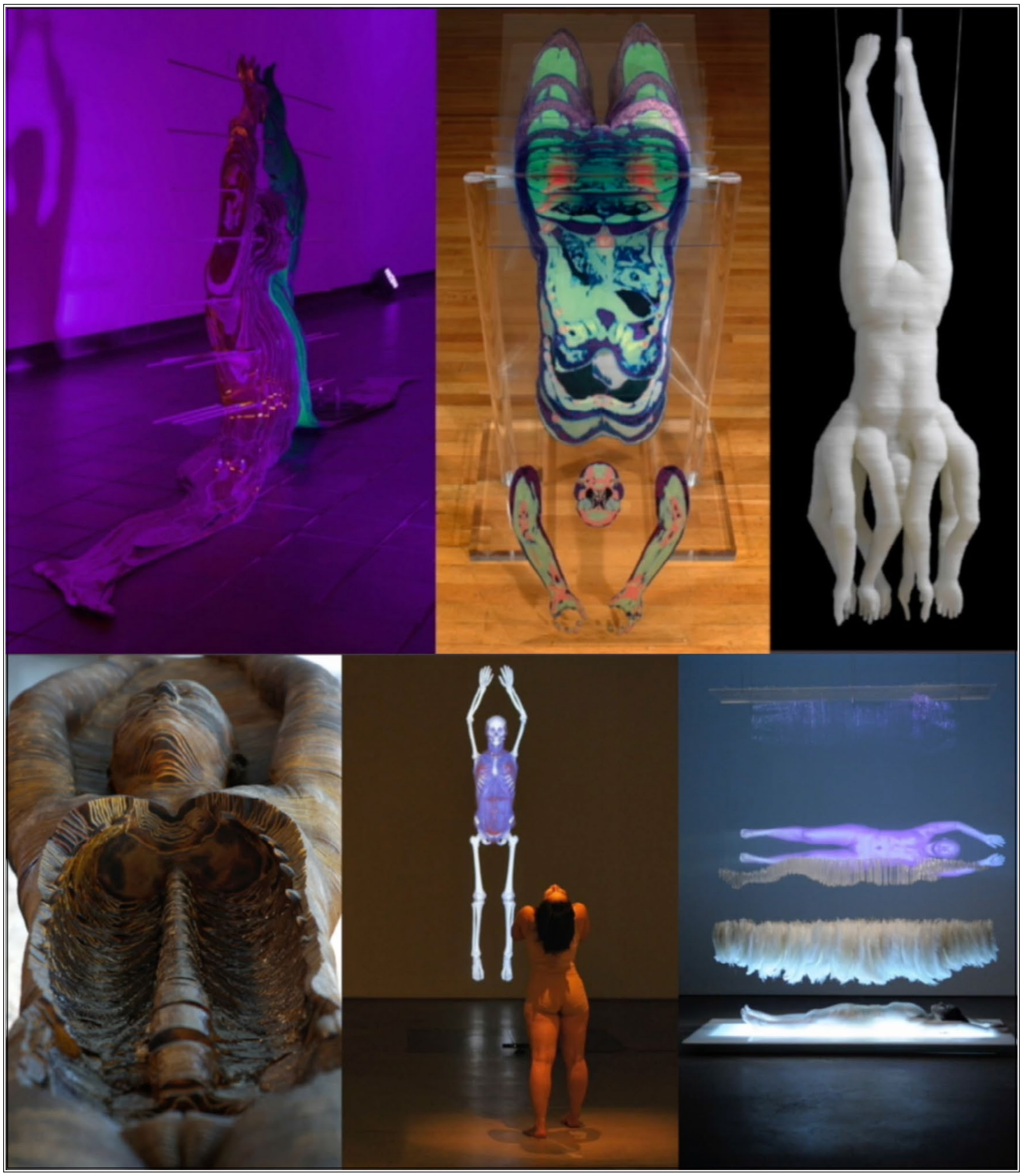


Figure 4. Sculpures, installations, and interactive artworks made using open-source anonymized CT dataset MELANIX 2007-2019.

This discovery which gave me direct and open access to both easy to use software tools and range of datasets that transformed my practice. It allowed me to play, experiment and push the scanned body in multiple directions and forms.

From Flesh to voxels
Voxels to pixels
Pixels to vectors
Vector to vinyl
Vinyl to copper
Copper to to overstretched, devoured, constantly connected figure

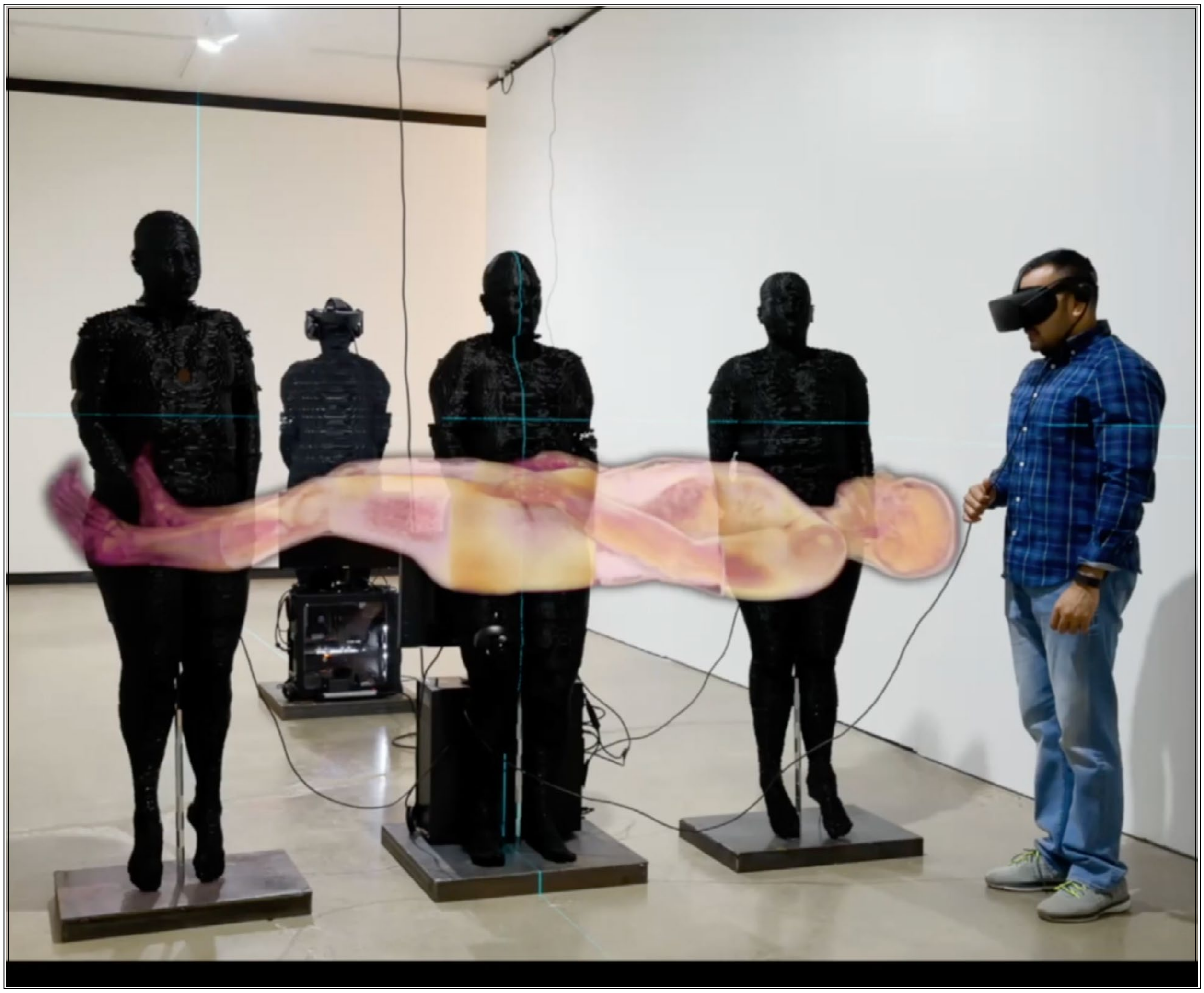


Figure 5. Deep Connection, 2019. Visual Art: Marilène Oliver, Sound: Gary James Joynes; Data processing and development of virtual reality application: Kumar Punithakumar, Pierre Boulanger, Madhavi Nimalaratne, Preet Giri; Radiology: Richard Thompson, Chris Hanstock Petere Seres.

Almost 20 years since Family Portrait, technology has advanced and been brought to market so rapidly that we are able to work with this scan datasets in virtual reality.

If we don virtual reality hardware, our physical embodied selves can interface with these digitized copies of ourselves, of our loved ones, of anonymized strangers.(1) We can literally dive deep into the data body and explore it, activate and animate it as we did in Deep Connection, the virtual reality artwork that we made here at the University of Alberta made in 2019.

This symposium is part of 'Know Thyself as a Virtual Reality', an interdisciplinary and collaborative research project that continues to explore working with medical scan data in virtual reality. As part of the project we are making two new VR projects, My Data Body which focuses on the data of a single individual and Your Data Body, which focuses on working with the data of others. Medical scan datasets are foundational components of these projects for they digitize the prone, passive, obedient human body at an intimate cellular level. The resulting datasets can be translated into high resolution volume renderings that in VR can be weightlessly held, penetrated, explored and colonised. Into, onto and around these medical scan datasets can be overlaid and embedded the many data corpora we all now consciously and unconsciously generate (2) such as social media data, health data, biometric data, social security and banking data.(3) In addition to teaching us just how much data we generate, these works are also allowing refine open source software tools to optimise the aesthetic control of volumetric scan data in VR which we in turn want to share with others. During the lunchtime break we will be streaming Walter Ostrander's student short which gives an overview of these tools that give us more aesthetic control and freedom when working with medical scan data in VR.

In partnership with creating these aesthetic tools that have the potential to help us know ourselves better in the digital age, there is also an urgent need to create ethical guidelines as to how we as artists, scientists and researchers work with this data. Furthermore, as digital charters such as the EU's GDPR now advocates that patients have 'access to their personal data',(4) there is the additional responsibility to provide guidance and context when releasing digital tools and app that could potentially be used with personal data. In 2002 when I made Family Portrait there were no ethics boards as far as I was aware. Now of course every research institution has rigorous ethics procedures and ethics training is an important part of medical education and research.(5) When I applied to get ethics approval for my projects as an artist however, they were deemed out of the remit of the ethics board.(6) Consulting the Tri-council guidelines states "Creative practice activities do not require REB review but they may be governed by ethical practices within the cultural sector." Of course as an artist I appreciate and fully support creative practice having this freedom, but as visual data culture is changing so rapidly in the digital age, there is a need to be as informed of the potential harms of working with our own data and the data of others.

As an artist, creative researcher and educator I been searching for ethical guidance on the use of personal data in our 'cultural sector' and although there are many great resources, such as the Guidelines for Ethical Visual Research Methods (2014) by Susan Cox's team who will be delivering our afternoon keynote, as visual data is evolving and expanding so rapidly there is a need for us all to be involved in contributing to guidelines ourselves and consulting and seeking advice from our colleagues in other disciplines such as digital humanities, law, public health and radiology.

In preparation for this symposium, our research assistant Alissa Rossi has been doing a literature review of the various digital charters and privacy acts in order to understand them better and how they can apply to creative research that works with personal data.

Alissa has prepared two presentations that will be streamed during the lunch break that explain in more detail the differences between these charters with relation to privacy, consent, anonymization and exceptions. This slide gives you a sense of how complex it is to try and navigate! At a high level however we have found a number of key points.

- Digital charters do not move with data; data is governed by the legislation of the location where the data is being accessed.
- New technologies and improvements to processing create the need for new or updated legislation, which is often slow to develop.
- Different cultural and spiritual relationships to data and privacy.(7)

Why does is matter? Who cares?
What are the potential harms? Who is most at risk and why?

- Control over one's own data and privacy (sense of autonomy, consumer manipulation, gamefication)
- Biometric control by the state (i.e China's social credit system)
- Insurance companies / future employers could use this data to decide whether to insure / hire you
- What is the risk of the secondary use of data if it can be de-anonymized?

We also need to ask the question of Why does all this matter? Who cares? What are the potential harms? Who is most at risk and why? There are moves, especially in the pandemic for states to exert increasing biometric control of citizens and we know that facial recognition is part of China's social credit system. Likewise, large tech companies are developing systems that aggregate data and we are learning more and more that anonymization is fallible. Some of these questions will be unpacked and discussed in our Navigating Data Dilemmas workshop by Katrina Ingram and Fahim Hassan this afternoon.

- Biometric control by the state (i.e China's social credit system).(8)
- Insurance companies / future employers could use this data to decide whether to insure / hire you.
- What is the risk of the secondary use of data if it can be de-anonymized?

This morning however will learn lessons from history and related forms. We will start with a presentation about legal ethics and privacy in relation to photography of the dead and living in England and Wales from our morning keynote speaker Dr. Remigius Nwabueze from the University of Southampton. This will be followed by a workshop led by Professor Ubaka Ogbogu that will focus on the question of who 'owns' health data from a Canadian legal perspective. During the breaks we will be streaming videos of *My Data Body and Your Data Body*, the virtual reality projects we are currently working on and also a series of student shorts I mentioned earlier.

We will have a one hour break for lunch before Dr Susan Cox's presentation on the "Emerging Ethical Challenges in Innovative Visual methologies" at 1pm and at 2pm we will start the "Navigating Data Dilemmas" workshop run by Fahim Hassan and Katrina Ingram. Again during the break we will have a student short this time by Erin Ratelle on the Art of Forgetting. These videos are also available on the Know Thyself website for you to view at anytime. I would like to make sure that everyone is aware that we will be recording our presentations today so please do turn off your cameras if you do not want to be captured. Our discussions and break out rooms will not be recorded although we will be making notes of main discussions points that arise as they may inform our guidelines. We will also be saving the chat. As you will have seen the chat will be used by us to link to further reading and resources throughout the day. We will also be playing sounds created by Scott Smallwood in our waiting rooms.

I would also like to take this opportunity to thank all those who have been working so hard make this event happen, it has been a lot of work at a very challenging time. Thank you to our speakers who have created the content for today's symposium, thank you to Katrina, Alissa and Chelsey for all the preparation and organisation, thank you Clare and Grant who are taking care of the technical side of today's event and Gillian Harvey for her wonderful visual identity that holds the event together and of course I thank everyone who is taking the time to be with us today any pay attention to these issues. This interdisciplinary symposium is one that requests that all participants think outside of their discipline which comes with a certain amount of vulnerability and I thank all our speakers, contributors and guests for being willing to do that with us. I hope today can be an opportunity for positive sharing and lively discussion where no one feels intimidated to voice their opinion.

As you will have seen in today's promotional materials, this symposium is funded by the Kule Institute for Advanced Study (KIAS) and AI4Society and we thank them for their ongoing support and encouragement. Today's symposium focuses less on AI and more on the data we are generating, interacting with and responsible for. AI needs the data we and society produces. We can make choices about whether we create it and share it and for what purposes. To do that we need to know ourselves as virtual realities.

I am honored now to welcome Dr. Eleni Stroulia, Professor in the Department of Computing Science who will tell us a little more about AI4Soceity.

NOTES

1. Road to VR article on Vive Studios VR recreation of a deceased girl for her mother. Vive Studios project webpage. Interspectral's Ben Body.

2. Zongyu Lin et al. "HealthWalks: Sensing Fine-grained Individual Health Condition via Mobility Data." Proc. ACM Interact. Mob. Wearable Ubiquitous Technol. 4, 4, Article 138 (December 2020). https://doi.org/10.1145/3432229 "...individual mobility features can help infer fine-grained individual health risks. As an increasing number of devices can collect user mobility data, e.g. cellphone, and wearable devices like smart watches, we envision future mobile health sensing applications which leverage such collected user mobility data, along with other useful user social demographic information, to reveal the potential health risks to the user. This would provide much more accessible and timely health alerts to users, as a complement of traditional medical examination, which is more accurate yet more expensive and time-consuming. Moreover, we envision that our sensing techniques can be combined with gamification systems to promote individual user positive behavior changes." (22)

3. Privacy Project, Fall 2019; New York Times, "One Nation, Tracked."

4. European Society of Radiology (ESR). "The new EU General Data Protection Regulation: what the radiologist should know." Insights Imaging. 2017;8(3):295-299. doi:10.1007/s13244-017-0552-7

5. The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans was adopted in 1998. A separate chapter addressing creative practice was drafted in 2008 but was not included in later updates.

6. As the KTVR project involves the acquisition of new human scan data, it did benefit from an

ethics review process which prompted rigorous consideration of how consent, data privacy and potential harms would be addressed during the research project. Typically, though, projects do not undergo ethics review. PIPEDA, UK GDPR, and GDPR all include exceptions to privacy rules for journalistic, academic, literary, or artistic works. Anonymized or de-identified data is excluded from PIPEDA, UK GDPR, GDPR, and HIPAA regulation, with some exceptions, though with increased amounts of data, it is becoming uncertain that anonymizing data is actually possible. Activities Not Requiring Research Ethics Board Review, Article 2.6: Creative practice activities, in and of themselves, do not require REB review. However, research that employs creative practice to obtain responses from participants that will be analyzed to answer a research question is subject to REB review. Application: Creative practice is a process through which an artist makes or interprets a work or works of art. It may also include a study of the process of how a work of art is generated. Creative practice activities do not require REB review, but they may be governed by ethical practices established within the cultural sector.

7. Karen S. Rommelfanger et al. "Neuroethics Questions to Guide Ethical Research in the International Brain Initiatives." Neuron 100, n.1(10 October 2018): 19-36. "It is necessary to ask how the prevalent Western approach—largely conceived as a matter of obligations to individual rights bearers rather than the often more globally prevalent communitarian concerns—applies to the moral aspirations and requirements of a broader global community, a community characterized by diverse values and beliefs."

8. Raffi Khatchadourian. "Surviving the Crackdown in Xinjiang." The New Yorker 12 April 2021. Details how biometric information on the Uyghur population is being collected by the Chinese government and the "Uyghur alarm" tech companies have developed using facial-recognition software. Wong KLX, Dobson AS. "We're just data: Exploring China's social credit system in relation to digital platform ratings cultures in Westernised democracies." Global Media and China. 4, 2 (2019):220-232.

Dr Remigius Nwabueze, Privacy Protection of Death Images in England and Wales

Introduction by Marilène Oliver:
I'm delighted to be able to move on and start with our day. When we were planning this workshop, we asked Ubaka to recommend a speaker. There was no hesitation that the person we wanted to invite was Dr Remigius Nwabueze. So, we're so delighted that you are joining us today Dr Remigius Nwabueze, as our first keynote speaker.

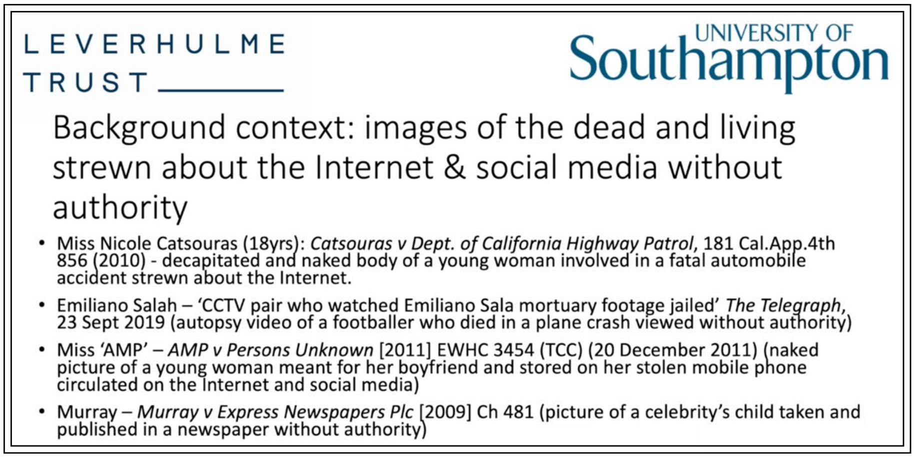
Dr. Remigius Nwabueze is Associate Professor of Law at the School of Law in the University of Southampton in the UK. His primary areas of scholarship are the legal regulation of the biotechnological utilization of human body parts and dead bodies, the ethical and legal regulation of biomedical research involving human participants, and equity and trust law. He is the author of numerous journal articles, his books and his works have been cited by the US Federal Court of Appeals Second Circuit, Nigerian Court of Appeal, the Federal High Court of Nigeria, and the High Court of Kenya. Welcome and thank you so much for being here.

Dr Remigius Nwabueze:
Thank you very much, thank you for the introduction. Thank you, Ubaka and Katrina, for inviting me. I'm going to talk about the protection, if at all, of the law of privacy in the jurisdiction where I work, England and Wales, with respect to digital images. Talking about the living, my emphasis will be the digital images of the dead.

It is right that I acknowledge my funder. Leverhulme Trust has funded my research in this area for three years.

Let me give you some sort of background to the legal discussion that follows. I have picked as my factual basis, cases that actually took place or were litigated in the courts, both in the United States and in the UK to bring home to you the sort of issues and difficulties that, from the use of digital images, can arise, not only socially, but legally as well.

The first case involved Miss Nicole Catsouras.[10] It was decided in 2010 by the Californian State Court of Appeals. That case involved a young girl, 18 years. She was known as the "party" type. She went to a party and on her way home, she was involved in a horrible, fatal automobile accident. As a result, she was decapitated.



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Background context: images of the dead and living strewn about the Internet & social media without authority

- Miss Nicole Catsouras (18yrs): *Catsouras v Dept. of California Highway Patrol*, 181 Cal.App.4th 856 (2010) - decapitated and naked body of a young woman involved in a fatal automobile accident strewn about the Internet.
- Emiliano Salah – 'CCTV pair who watched Emiliano Sala mortuary footage jailed' *The Telegraph*, 23 Sept 2019 (autopsy video of a footballer who died in a plane crash viewed without authority)
- Miss 'AMP' – *AMP v Persons Unknown* [2011] EWHC 3454 (TCC) (20 December 2011) (naked picture of a young woman meant for her boyfriend and stored on her stolen mobile phone circulated on the Internet and social media)
- Murray – *Murray v Express Newspapers Plc* [2009] Ch 481 (picture of a celebrity's child taken and published in a newspaper without authority)

Not long after the accident, the California Highway Patrol officers came to the scene and marked off the scene for investigation. Because of the investigation, they took pictures of the naked and decapitated body of the girl for investigation purposes. Unfortunately, two of the officers later sent those digital death images to friends and family members of theirs on Halloween day just for shock effect. These people had no connection with the investigation, and minutes or just hours after these pictures were sent to friends and family, they appeared on more than 2000 websites around the world. The Internet throws standard taunting at the father of the girl, who was already bereaved, calling him a father of a whore.

That was not the only case of this kind. There is a similar incident here in the UK, involving Emiliano Salah. Emiliano Salah, for any of you that are interested in the English football--in Canada and the US they call it soccer--Emiliano Salah was a professional footballer in France. He was bought by an English club called Cardiff, which was in a relegation. They bought this player from France to help them fight relegation. This was, I think, in 2019. He left France for Cardiff and unfortunately, his plane crashed into the sea. The body was only recovered days later. An autopsy was performed on the body; the autopsy was video'ed. Unfortunately, two security officers who were in charge of the mortuary, without authority, viewed the recorded autopsy film and disclosed it to some other people. Eventually, they were prosecuted under the Computer Misuse Act, but Emiliano's Family did not bring a civil action against them.

It highlights some of the social problems, in addition to now, that could be raised by unauthorized use of digital images and recordings.

Following that is the case that is called Miss AMP. That was a legal way of anonymizing the girl involved in that case for purposes of protecting her privacy. So what happened in Miss AMP was that this young woman took a naked picture of herself on her mobile phone. She intended to send her nude photograph to her boyfriend. Unfortunately, she lost her phone. I think it was stolen, and hours later, her nude picture appeared on thousands of websites all over Europe and the UK. Then she rushed to get a sort of emergency injunction to remove those pictures from those offending websites. Luckily, the Court granted an injunction in that case. Some of the people involved chose not be identified.

Lastly, there is the case of Murray.[11] Murray is a well-known [writer, JK Rowling], she was having an evening out including members of her family, including her younger children. A covert photographer took pictures of Murray's younger child. The photographer is a journalist; the picture later appeared in the newspapers. Ironically, when it happened, Murray became aware of the film photographer and got an assurance from him, or at least told him, warned him not to publish the photograph, but the photographer still went ahead and published the picture.

Then Murray brought an action on behalf of his child to vindicate the violation of the child's privacy.

In all of this, there is a common thing which resonates with the theme of this conference. That is: privacy. All of these cases involve privacy requirements. So, how does the law go about protecting privacy within the context of England and Wales?

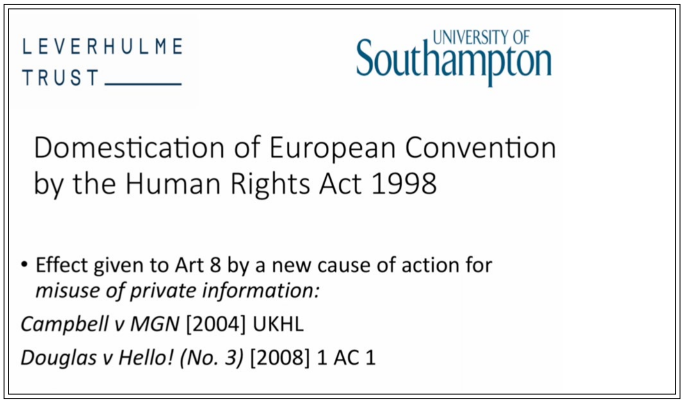
Privacy is such a well-known concept even outside the legal realm, so it should come as a shock to non-lawyers that this very ingrained principle is not directly, or at least until 20 years ago, was not directly protected under the law of England or Wales.

Until 2004, the only way to protect your privacy in this country was for the judge to do it indirectly, not directly. For instance, if somebody crossed over your fence, and then watched you without your knowing when you were taking a shower, the main offence here would be privacy. The person violated your privacy: the person watched you taking a shower without your permission. But until recently, an English court did not grant you any remedy in privacy. They went around that problem, around that issue, and held that the offense was a violation of your copyright. And therefore, you were entitled to compensations for trespass against your premises.

That wasn't actually what we were looking for. We are looking for a vindication of your right to privacy. Until 2004, that was how English courts protected privacy indirectly. But it was insufficient because there were so many circumstances in which no indirect way of protection could be found. And in those cases, the victim of the privacy violation got no legal remedy at all. And we could see a restatement of the English law Protection of Privacy by the highest court--the then House of Lords--by Lord Hoffmann. He said there is none, that the right of privacy as a general idea is not recognized in this country.

But things started changing gradually, faced with the development of the European Convention on Human Rights.

The Convention was developed in the late 40s and early 50s, and the UK was one of the countries that originally ratified the Convention. But it never became part of domestic law. Because the UK ratified the convention in the early 50s, the UK courts gave it respect, but it had no direct force here.



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Domestication of European Convention by the Human Rights Act 1998

- Effect given to Art 8 by a new cause of action for *misuse of private information:*

Campbell v MGN [2004] UKHL

Douglas v Hello! (No. 3) [2008] 1 AC 1

Judges were free to ignore the provisions; it was not allowed to override provisions of domestic law. But interestingly, the European Convention, particularly as a convention, left specific provisions for the recognition and protection of the right of privacy. You can see it in Article 8, which says everyone has the right to respect for his private and family life, his home, and his correspondence. Of course, Article 8.2 shows that it is not an absolute right as it could be overridden in certain specific circumstances.

So, you can see the kind of contradiction that existed here in the UK, privacy as a legal right was not required, was not recognized. But within Europe, and under the convention, that was the government legislation to which the UK was a party. The right of privacy was recognized. So, for many decades this sort of uncertainty and conflicts were open in this jurisdiction until 2004.

It would be very important to emphasize that within Article 8, Protection of Privacy, the specific issue that I'm concerned with here--that is the protection of death images, living images, or digital identity--it is very clear to ascertain that these are covered within the bounds of Article 8, Protection of Privacy. And I think they are emphasize by the European Court of Human Rights, which is the highest judicial authority in relation to the interpretation of European Convention on Human Rights.

Reklos v Greece [12] was a case that originated from Greece. In Reklos, a baby was in the hospital. After the baby's death, a photojournalist photographed the baby without the consent of the parents. The photographer did it with a view to publication of the picture, which was eventually published. The parents of the baby brought an action in a Greek court saying that what the photojournalist did in taking and publishing the picture of the baby without authority amounted to violation of the baby's privacy. Ultimately the case came to the European Court of Human Rights, which decided in favor of the baby and the baby's parents, and you can see, giving you protection from the courts.

On this slide as you can see from the emboldened portion, the concern of the privacy violation here involves two issues. One, the taking of the picture without authority, and the publication of the picture without authority. So, the European court of human rights said that both violated the privacy right of the baby, and that even the mere taking of the picture without authority was sufficient to violate the privacy rights of the baby. You can see, at the level of the European Court of Human Rights and the level of Europe, at the level of the convention, there was no uncertainty at all, as to the existence, the content, and the enforceability of the rights of privacy. This sharply contrasts with the position in England and Wales until recently.

But, nevertheless, things started changing. The momentum from the European Convention, cases like Reklos as we saw, started inspiring the cause of legislators here to make a difference, which was made in 1998 when the Human Rights Act was passed.

Now, the essence of the Human Rights Act of 1998 was to domesticate the European Convention on Human Rights. That is the legal speak for saying that the Human Rights Act of 1998 was intended to make the European Convention on Human Rights, particularly Article 8 or including Article 8, to become part of UK domestic law. That was a fundamental legislative move, and that meant from 1998--actually it come into force in 2000. From 2000, Article 8, which provides clearly for the protection of privacy, became part of English law. But there was a problem as to the vehicle, the modality for actually enforcing the rights conferred by Article 8. Yes, Article 8 confers the right of privacy, but it does not immediately translate into local law. So, you still have to find a vehicle for bringing it into operation under which citizens who are victims of privacy violations can actually go to court and complain.

Initially, within the first five years of the domestication of the convention, they decided that the best vehicle for translating Article 8, Right of Privacy, into domestic law was a cause of action known as Breach of Confidence, which has always been recognized in this country. But it is the lone cause of action, it is the law under which you can sue somebody who disclosed a secret. You confided in them with that shield. So, the English Courts said that, that course of action could be used to actually effectuate Article 8 of the convention which have been received into domestic law by the Human Rights Act of 1998.

That worked for a while until judges began to see that even that cause of action for Breach of Confidence was not expansive enough to accommodate all instances of breach of privacy. For instance, if the complaint of a victim of privacy violation was that somebody video'ed them without their consent when they were taking a shower, or as in the case I showed you a few slides ago,[13] where the victim, the claimant, the woman, went to the prison to visit her son, and she was strip searched, according to the drug law policy of the prison, before she could see her son. She pursued the prison authorities for violating her privacy. Her complaint there was that she was strip searched, she was embarrassed, she suffered from mental distress. So, these kinds of situations are not something that an action for breach of confidence speaks to. Breach of confidence or the need to deal with situations of unlawful disclosures of secret, but not privacy violations at this time. So that was the problem that arose. English judges quickly realized that they really had to find a better vehicle for enforcing the right of privacy, which had been given by Article 8 and which English courts were required to protect following the Human Rights Act 1998.

The opportunity for squarely meeting with that concern came in 2004 in the House of Lords case of Campbell and MGN (MGN is newspapers).[14] The House of Lords then was the highest judicial authority in the UK, but now it has been renamed the Supreme Court of this country. This case, that gave them the opportunity to develop an ethical vehicle, an ethical modality or framework, or course of action for the enforcement of privacy, involved Naomi Campbell.

Everybody knows Naomi Campbell, the Black supermodel. In fact, in that case, Baroness Hale, the only female member of the House of Lords joked that even the male judges, her colleagues, knew who Naomi Campbell was.

Naomi Campbell, the case arose because she sued a newspaper for publishing an article alleging that she was a drug addict. The background was that before the publication, Naomi Campbell had on several occasions given newspaper interviews praising herself for not abusing drugs. This paper came out with the bombshell that she was a drug addict. And, maybe to make the story more credible, they published a picture of Naomi Campbell taken by a covert photographer as she was coming out of a meeting of NA, Narcotics Anonymous. Naomi Campbell brought the action the very next day against the newspaper, making a violation of her privacy.

I'm very mindful of the audience that I'm not a lawyer, so I'm trying not to use technical terms. The judges, five judges, they were split for the majority three to two, decided in the favour of Naomi Campbell. They didn't agree on the legal precedent; they disagree on how the law applies to the facts of that particular case. The reason I'm mentioning it here is that it was the first time in this country that the judges developed a cause of action known as the misuse of private information as the proper modality for suing a defendant who violated your privacy. That should have brought considerable clarity into the law of privacy in this country.

Four years later, in another case involving celebrities, Douglas and Hello, Michael Douglas. Michael Douglas and Catherine Zeta-Jones, celebrating their wedding. The complaint was that a photographer slipped into their wedding, took pictures without their authority, and sold those pictures to Hello Limited. They sued. And again, the House of Lords decided in that case that misuse of privacy information was a proper course of action under which the Douglases could complain about the violation of their privacy. So, we have some clarity from 2004 on the law of privacy in this country.

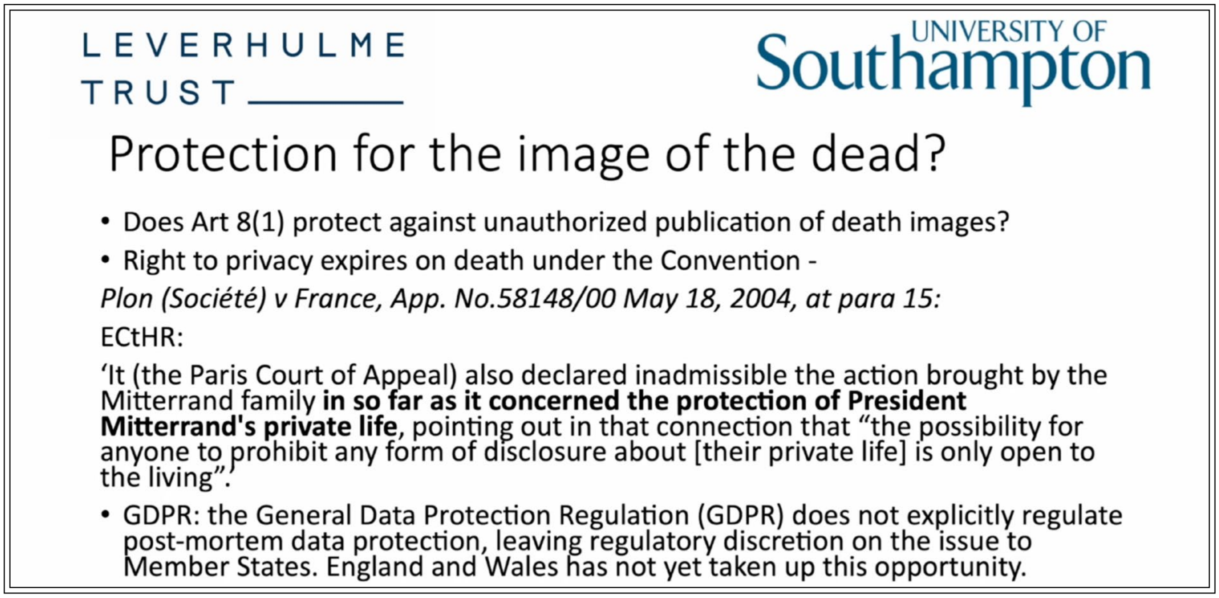
Just to give you a little bit of comparative context here, the Canadian press is similar now to the UK. It goes back to the colonial period. I should say that the Canadian law of privacy, I mean apart from more recent statutory innovations. Apart from those, the Canadian law of privacy is still the English common law of privacy. At least until 2012, [Canadian law had] all the same uncertainties and problems that I told you in relation to English and Welch law. It was, if I remember, in a relatively recent Canadian case called Jones and Tsige, that the Ontario Court of Appeal started recognizing some of the privacy courses of action developed in the US. In talking about privacy, it equally applies to the Canadian Common Law to some extent.

In England and Wales, we seem to be out of the waters, and now we know how to go about that. That water was tested in the Murray case I mentioned at the beginning. Murray brought that action against that photographer under the new course of action called the misuse of privacy information. The case was decided at the level of the Court of Appeals, by Anthony Clarke who, in this quotation, gave a list of factors that a judge must take into consideration before coming to the conclusion whether or not the action of a defendant violated a claim on his privacy. So, you can see, as it should be, privacy is not an absolute right.

So far, we're talking about the living. The course of action for misuse of private information, or the prior course of action or breach of confidence, all I've said so far, mostly applies to the living. What about the dead? Can you use the same course of action, developed by the English House of Lords into government for misuse of private information, to vindicate the unauthorized publication of a death image?

At the beginning I mentioned the Catsouras case. If that had occurred here, how would the family have gone about it? The family was likely to have lost and then, as now as I'm going to explain, English Law does not recognize the right of privacy of the dead. To see how the law applies to digital images of the dead, we go back to the European Convention, Article 8, which is now part of UK Law, which, as I said, clearly recognizes and enforces the right of privacy at least for the living.

Now, what about the dead? Not many cases have come to the courts for relation to the privacy rights of the dead, but a very crucial case is the one I'll show you there on the second bullet point, Plon and France. [15] This is an important case not just because of the personality that was involved.



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Protection for the image of the dead?

- Does Art 8(1) protect against unauthorized publication of death images?
- Right to privacy expires on death under the Convention -

Plon (Société) v France, App. No.58148/00 May 18, 2004, at para 15:

ECtHR:

'It (the Paris Court of Appeal) also declared inadmissible the action brought by the Mitterrand family **in so far as it concerned the protection of President Mitterrand's private life**, pointing out in that connection that "the possibility for anyone to prohibit any form of disclosure about [their private life] is only open to the living".'

- GDPR: the General Data Protection Regulation (GDPR) does not explicitly regulate post-mortem data protection, leaving regulatory discretion on the issue to Member States. England and Wales has not yet taken up this opportunity.

It involved the former president of France, President Mitterrand. The case revealed that--he served two terms of office. The first application showed that, right from the beginning, he was diagnosed with prostate cancer, which was serious, which threatened to destroy his presidency. But he got some very good doctors led by his personal doctor. The diagnosis and the prognosis for the disease was very dire. But that information was kept away from the public. Members of the public didn't know the President's medical condition. And regular health related news released to the public about the President's health did not include anything about his cancer illness.

So that was the position. President Mitterrand managed to finish his two terms in office without anybody knowing about that.

And then he died.

Within ten days, in fact one week after his death, his doctor who took care of him during his illness got a publishing contract with a publisher to publish a book, which made detailed, explicit disclosures about President Mitterrand's cancer illness and treatment. President Mitterrand's family was totally distressed. They brought an action in court to stop the circulation of the book, to injunct the publication of the book, and to recommend compensation from the doctor.

Okay, now, the action: they brought the claims under two courses of action. A course of action, by the way, for those that are not lawyers, when you go to court, you must find a particular legal category under which courts will listen to your complaint and grant a remedy. That category has a cause of action. So, if you don't establish a cause of action, then your case will not succeed. In the case of Plon and France, President Mitterrand's family brought two courses of action. Number one, they said, what the personal doctor did amounted to a violation of the patient-doctor medical confidentiality. And number two, that what the doctor did in publishing a very revealing book amounted to a violation of President Mitterrand's privacy. So, very interesting in that regard.

This is, so far as I'm aware, the only case at the highest European level raising an issue as to the privacy of the dead. The Council of Human Rights ultimately accepted that what the doctor did breached the patient-medical confidentiality, and that the President's family succeeded and was compensated, because the rights of medical confidentiality stay beyond, death does not extricate it. Which is very crucial in comparison to the claim in privacy brought by the family.

In relation to the claim from privacy--that's the one I'm giving you from the court. The decision of the Court of Appeals, on that ground which held that publication violated his privacy, that his rights to privacy did not exist beyond his death. In other words, once you die your privacy dies with you. It is not protected or protectable beyond death. That simply means you can use private information of a dead person. You can use private data of a dead person generally, without any legal consequences. And that is very sobering and frightening as well. Because, take for instance death images. The dead are dead. It's embarrassing but they're no longer alive to feel it. But who feels it more? Survivors. If you publish a death image, or publish embarrassing private information about the dead, the family suffers. And that is a very serious problem. The law says the rights of privacy dies with the dead, and that's what I've considered here.

Basically, there is no protection for the dead. I tried to find any other way that data could be protected. Marilène in the introduction mentioned the GDPR, (General Data Protection Regulation) which since 2017 replaced the Data Protection Act 1998 of England and Wales. Now. The thing is that GDPR is a European wide regulation, and, under that regulation, the European states are free, they have a discretion whether or not to include the dead in the provisions of the regulation. A few European countries have accepted this opportunity and included provisions that protect the data of the dead, but not in England and Wales. The GDPR, as applicable here, still has nothing to say about the dead. It applies specifically to the living, because the definition of data subject is defined as to exclusively referred to the data of the living. That should have been the easiest way to protect death images or information and data related to the dead. But not in this country. So it seems that the dead are not protected in terms of privacy.

I've already mentioned when discussing President Mitterrand's case in France, it should not be forgotten that medical information of the dead in the possession of the dead's private practitioner or medical doctors is still protected on medical confidentiality. But even then, the medical confidentiality could be ignored if it is in the public interest to do so. As we saw in Lewis and Secreteary of State for Health, [16] the medical files of patients who worked in a nuclear facility were ordered to be release to a public inquiry investigating their deaths. The doctor who triggered the biopsy initially resisted a request to release their medical files but eventually the court ordered that those files should be released in the public interest. But that is the only kind of situation, as I'm aware, under which information relating to the dead would be protected, but in other circumstances it wouldn't.

So, you can see the grim, the very devastating and sad picture of privacy protection of the dead in this country. I keep emphasizing this country because, if I still remember perfectly, Alberta might be different because under the Alberta privacy acts, the data of the dead is included. It is actually the kind of openings that can shield if resorted to. But the picture here is so dark. So, how would English courts go about reconsidering this position by trying to recognize and enforce the privacy of the dead, knowing of the incomparable harm and distress survivors suffer when death images, embarrassing death images of the deceased, or private information which might be embarrassing, related to the deceased, gets published? What frameworks could inspire the law?

The first thing here or other countries with similar problems could do is to adopt the sort of judicial activism that was in place in the case I mentioned at the beginning of this lecture, the Catsouras case. The situation in the US--especially in California because some of the states have different legal rulings--the situation, related to the privacy protection of the dead in California before 2010 was pretty much like the situation here in England and Wales. But in Catsouras' case, the judge, Justice Moore, decided to take a very radical look at things. You can see the quotation I've given here. He recognized the fact that, up until the case came to court, the California law did not recognize and protect the privacy of the dead, which meant that, under California law, as in English law, you were free to publish or write anything embarrassing, defamatory about the dead, you were free to use data concerning the dead. But here, the Justice said the law should take a different approach for that woman especially in view of the interests of survivors. The judge held that when you publish an embarrassing death image like the picture of the decapitated, naked body of that young woman, the judge said that it was the family that suffered most and it was the family that was harmed. And because of that the law should begin to recognize and protect the interests of the family even though the origin of that interest was the privacy of the deceased. So, from that moment the Court of Appeal in California held that if you publish the death image of a deceased person without authority, that it would be a violation of the family's privacy.

Way to go, very radical in approach, it was a case of restitution, which I would recommend for the English judiciary. But, like I already hinted, there is no uniform situation in America. You would have expected that other states in the US would follow this decision but just even a year before that case, in the New Mexico Court of Appeals case of Smith and the City of Artesia,[17] there, a similar thing happened. A woman was murdered, and the police came, took a picture of the crime scene, which showed the victim of murder: she was naked and laying on the floor. And unfortunately, the police officers investigating the case again disclosed those naked pictures of the crime scene to their friends and family members and it appeared all over the internet and social media. So, the parents of the woman sued, alleging that the family's privacy was violated, as we saw in Catsouras. But here, the judge refused to grant their request, the judge said that their privacy claim failed because privacy was a personal right, it died with a deceased.

Basically, the Court of Appeal of New Mexico was saying that, in truth, the parents were complaining not on the violation of their privacy but on the violation of their child's privacy. This is the old law, this is the tradition, this is the kind of decision that a court here would hold. But like I'm saying, the way to go should be Catsouras, and this very traditional, historic, and if you like, unhelpful approach should be abandoned, not least because of the diffusion of widespread use of modern technology including social media, which now, would mean that embarrassing information and images about the dead could be cascaded in a more diverse fashion, and could inflict more injury than in the past.

So, another way to go could be the approach suggested by the Supreme Court of Florida in the 2017 case of Weaver and Myers.[18] The court here was saying that if the privacy violation of the dead related to use of the dead's private information created or accumulated before the death of the deceased, then it will be a violation of their privacy. However, if the information used without authority was created after the death of the deceased, if, for instance, it was information related to the autopsy, which was imaged after their death, it will not be protected. If it's collected or was created before they're dead, then it will be covered by privacy. It will protect the privacy of the deceased in a considerable number of situations, but not in all situations.

And finally, because courts decide to be philosophical and take a philosophical approach to the problem, we are best to start then in the 1984 Feinberg's theory that there exists post-humous interest and autonomy.[1]

Feinberg postulated that there are certain interests that extend beyond death. In fact, after you are dead, your interests, post-humous, can be frustrated. Very interesting theories, they have attracted a lot of academic commentary. But a very big problem with this approach is a practical one.

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3. Posthumous interest underpins privacy protection?

- Feinberg's posthumous interest and autonomy - premortem person as the subject of protection?
- John Harris' 'persisting critical interests' – extensive and extending to death image?

Let us agree with Feinberg, that even after you are dead, your interests, in a way, are still alive, so that a frustration of those interests actually harms you. In the case of privacy interest, the harm here would be a privacy violation. But who is the subject of interest who can go to court and claim their vindication? Who is being protected here?

Feinberg was very much alive to this problem. He concluded that the person protected is what he called the pre-mortem. But when you look closer, the pre-mortem person is the same person as the dead person. The pre-mortem person is the person who is now dead. He is already dead. There is no practical way of translating this to action in a court. It is philosophically attractive, but the practical application is not very promising.

And then that invites a consideration of another alternative, the work propounded by philosopher John Harris of Manchester University. Philosopher Harris agrees that certain interests can outlive the dead and he called them "persistent critical interests".[2] He said that these persistent critical interests require recognition as a legal right; they require an enforcement if frustrated or violated.

But the question is whether persistent critical interest could extend to the privacy interests of the dead. When you read these works closely, you see that Harris mainly used the examples of proprietary interests as his persistent critical interests. So, for Harris, that is why it is justifiable for the law to protect the wishes you express in your will regarded the solution of your wealth after death. Okay, but beyond the proprietary lens, Harris could not find any scope for the version of his persistent critical interest. In fact, he expressly admitted that the scope is narrow. So, the persistent critical interest might not be expansive enough to extend to the protection of private information relating to the dead.

Nevertheless, a combination of these three approaches could assist, not only English and Welsh courts, but any other court in any jurisdiction mindful of giving required and legal protection to violation of the dead's privacy.

Thank you very much.

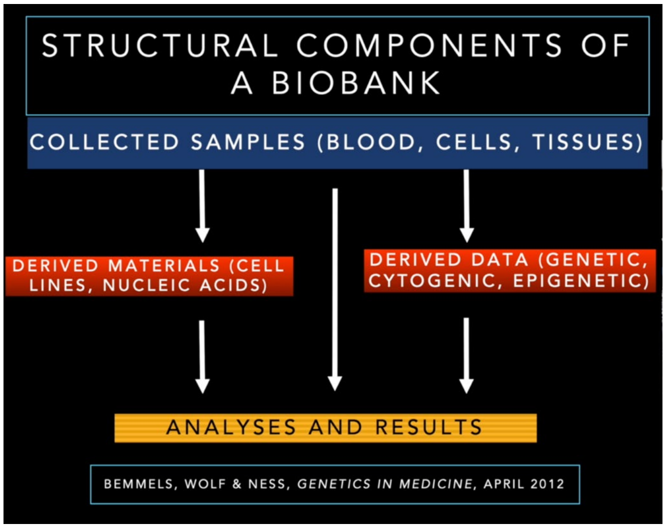
Dr Ubaka Ogbogu, Do You 'Own' Your Health Data?

Introduction by Marilène Oliver:
This morning we started off thinking more about photography of the dead and the living. Now we're going to shift thanks to Ubaka to thinking about who owns our health data. Ubaka has prepared a workshop for us, which we are looking forward to very much.

Dr. Ubaka Ogbogu is associate professor in the Faculty of Law at the University of Alberta, Pierre Elliott Trudeau Foundation Fellow. Obogu research interests include health law, public health law, science and health policy studies, law, bioethics and biomedicine, and the legal history of public health and healthcare. He's particularly interested in the points of confrontation between ethics, morality, economics, and law in relation to the governance of novel and controversial healthcare technologies.

Dr Ubaka Ogbogu:
In Dr Nwabueze's talk, he referenced the fact that privacy law and property law intersect in this area, and that there is a lack of legal clarity in many cases, with respect to that intersection. What I'm going to try and attempt to do in the time that I have with you is to explain what is going on in this intersection, focusing mainly on how property rights and property interests feature in this arena. The good news is you're going to hopefully learn something from what I'm going to tell you. The bad news is that it might leave you even more outraged or confused with respect to how the law intervenes in this area, and with respect to the many complex issues that tend to arise when we're talking about human biological materials associated with health data or data that flows from it, and the question of who owns either of those things.

I'd like to start by talking about a biobank. The reason I talk about biobank is that it will not ordinarily obtain human biological materials or any data related or derived from it on the streets. Unless you're involved in some kind of illegal operation, you will, ordinarily, in most cases, you get it from a repository where it's been stored. You're not going to cut it off someone and you're not going to go to the black market to get it. You are likely to get it from a legally established repository, which we often refer to as a biobank. I like to start by describing what you usually find it by a bank--I think that's a good starting point. Before start talking about the legal implications of that flow from the storage, and from people wanting to use it and share it, and the rights that individuals whose materials and information is stored in these repositories may have with respect to those materials and associated data, which is often health data or personal information.



STRUCTURAL COMPONENTS OF A BIOBANK

COLLECTED SAMPLES (BLOOD, CELLS, TISSUES)

DERIVED MATERIALS (CELL LINES, NUCLEIC ACIDS)

DERIVED DATA (GENETIC, CYTOGENIC, EPIGENETIC)

ANALYSES AND RESULTS

BEMMELS, WOLF & NESS, *GENETICS IN MEDICINE*, APRIL 2012

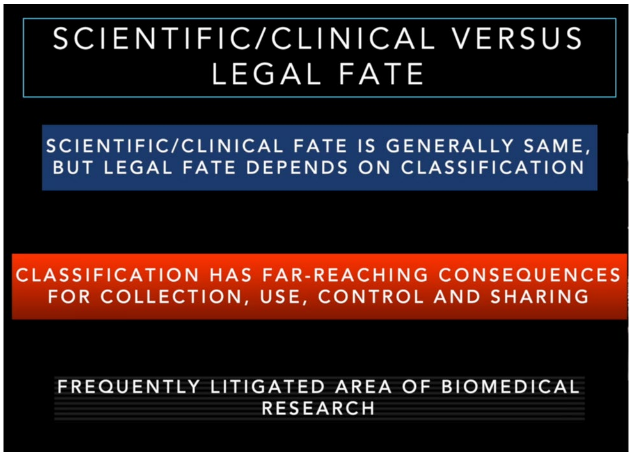
This study, published in April of 2012 by some of my colleagues at the University of Minnesota [3]--I was actually at the University of Minnesota and I was part of this work. I recommend you read it because it describes what you will find typically stored in a repository of human biological material. You will find collected samples like blood, blood cells and tissues, and then material derived from that. Usually you'll find them stored on slides, and then there are materials that are derived from that like cell lines and nucleic acids. For these materials, usually, pathologists or researchers work on those materials to derive cell lines from them, or they may derive other kinds of data from them, which is stored in a different form, usually digitally or on paper, which include genetic information, syngenetic information, or epigenetic information. Analysis is done on this in some cases, and that analysis will include all kinds of data as well, which may be anonymized, or non-anonymized. This is a fairly simple graphic that gives you an idea of the kinds of information you will find in a biobank. Of course, it gets more complex than this and in the paper there is a full graphic that shows the various types of information you will find. This study looked at the contents of an actual biobank. It's dated now, but it remains the best description of what you will find in a repository of human biological materials.

In essence, we have three main categories. We have the actual materials themselves, which have been removed from the human body. We have the materials that are derived from those samples which retain the "natural" form, if you will, and then we have the analysis done on those materials which will reveal all kinds of data and that is stored in the way that data is stored. There's a variety of uses that all of this can be put to, and different kinds of people who are interested in using and sharing all of these things that are contained in a biobank.

The question that then arises from a legal standpoint, from the standpoint of use, disclosure, and sharing, are basically two questions. The first is, who owns all of this? Because ownership implies the ability to decide what happens to it. If it's owned by the institution that has collected and processed it, a different set of legal rights and responsibilities flows from that, compared to if it is owned by the person from whom it is derived. The question of ownership comes up often. But there are also questions around what kinds of personal rights the law allows an individual to have, even if the ownership question is not settled, or even if the ownership question hasn't been answered. Dr Nwabueze addressed at length the issue of privacy. That's one of those rights that raises questions in this area, of course, even if, as an individual, this has been taken from me, and even if I don't know the answer to the ownership question. How do I protect my privacy interests in the material and the data? But also, do I have any right to control the use and disclosure of that information, or the materials? What rights essentially do I have, besides the question of ownership? My talk will focus largely on the ownership question, but I want you to think of what I describe as the various rights of control that an individual can have, even if we don't settle the ownership question. The rights of control are more settled in law, at least in Canada. They are defined, even though as Dr Nwabueze explained, the privacy implications of the privacy law is still largely unsettled, and the issues are large. But I think we have a better handle on the question of the rights of control than we have on the question of ownership. As a matter of fact, what you'll find is that the ownership question is sometimes answered, to the extent that it's been raised in courts, it is answered in a way that complicates the matter.

In terms of how we classify this material for use and disclosure, it's important to note that what I describe as the scientific or legal fate of these materials is generally the same, but the law does classify these materials based on the reasons for why they are being used. So, scientifically speaking or clinically speaking, tissue is tissue. It is classified as tissue or human biological material, the cell lines are cell lines, the data that is derived from it is data. The scientific classification and the way it is thought about, scientifically or clinically, is very clear and follows what would be the natural manifestation of the thing you're classifying.

In law, the classification is somewhat different. Classification depends a lot on the reasons for collecting it, using it, sharing it, or trying to control it. This is a frequently litigated area of biomedical research. There are tons of cases on this. What I'm going to try and do next is explain some of these cases and the reason why they add to this problem of lack of clarity around the ownership question.



SCIENTIFIC/CLINICAL VERSUS LEGAL FATE

SCIENTIFIC/CLINICAL FATE IS GENERALLY SAME, BUT LEGAL FATE DEPENDS ON CLASSIFICATION

CLASSIFICATION HAS FAR-REACHING CONSEQUENCES FOR COLLECTION, USE, CONTROL AND SHARING

FREQUENTLY LITIGATED AREA OF BIOMEDICAL RESEARCH

In law, excised human tissue is classified primarily by the original reason for removal or excision. So while clinically you might think of it as tissue or blood or cells, in law, at least in Canada, the classification depends mainly on the reasons why you remove it or excised it from the human body. That is the dominant mode of classification, from a legal perspective. It doesn't really matter whether it's tissue or it's not tissue. It is really the reason for excision that matters.

There are two reasons why you might want to legally remove tissue from the human body. The first is for diagnostic purposes. So, this is where tissue or cells or human biological material is excised from the human body as part of a clinical procedure. The second reason is excision for research purposes. [These are the] two dominant reasons for acquisition and the ways that we classify human biological tissue for purposes of legal intervention or for purpose of describing how the law intervenes in this area. The second paper that I recommend you read is this paper published in the Canadian Medical Association Journal in 2013,[4] where they describe essentially these two paths, diagnostic and research, and how the law regulates those two reasons for excision from the human body. I'm not going to spend any time on this. But all of this is to say that when you remove tissue from the human body it basically goes into two paths. There is a diagnostic path, and in that diagnostic path, there's all kinds of issues around who controls information, and also, as I'll come to shortly, the question of ownership. There is also a research path that follows a different set of rules around who can use it, who can control it, and the ownership question also comes up in this arena.

There is a secondary form of classification in law, which is based on the notion of alteration. In its original form, human biological material exists in its original form, [and] it raises questions of ownership. But you will find as I'll explain shortly, that courts have rarely dealt with this issue, and when they have, again, there's been a ton of confusion as to what exactly the legal principles are. One thing that courts have been clear on is that once you alter that tissue, once you apply what is described as human ingenuity to it, then its classification changes. It becomes something that's been altered and this alteration in effect changes its legal fate. If it's altered by application of human ingenuity, the ownership question becomes clearer. In an unaltered state, the law is very confused and in many ways still unsettled. But once it's altered, once there's human ingenuity applied to it, the question becomes clearer. I'll return to this in the workshop, but one question I am going to leave you with is, what does it actually mean to alter human biological materials? Usually in the biobank when you have a pathologist working on human biological material, they remove cells or tissues or blood from your body. With those tissues, they're going to label them, put them on a slide, and store them, put them away. That is considered unaltered. The alteration will be, say for example you have to derive a cell line from it. That cell line constitutively is still the same thing as the tissue from which it was derived. It hasn't been changed in any way, but the cell line that has been derived from it is considered a new object, something that can be classified differently because human ingenuity has been applied to it, and that has a different legal fate.


MOORE

IN ALTERED STATE, BECOMES A "PRODUCT OF HUMAN INGENUITY"

IN ESSENCE, A NEW KIND

OWNED BY THE CREATOR – ALL RIGHTS AND INTERESTS OF THE DONOR EXTINGUISHED

The first case, we're going to talk about is a case called Moore and Regents of the University of California.[19] This is a very well known case, you may have heard of this case. It is the case that is most often cited as a starting point for the discussion around the ownership question. So this was a case involving a fellow called John Moore. The case was decided in 1990 by the Supreme Court of California. John Moore visited the UCLA Medical Center in 1976 after he was diagnosed with a form of cancer called hairy cell leukemia.

So he went in for diagnostic reasons and for treatment. In the course of his treatment, a cancer researcher and doctor at the medical center called David Gold, took samples of Moore's blood, bone marrow and other bodily fluids to confirm the diagnosis, which revealed that he had a fatal infection in his spleen. And so, a splenectomy, a removal of his spleen, was recommended. Moore signed a consent form authorizing the procedure for all intents and purposes, and as far as he knew, he was receiving treatment after he had been diagnosed with hairy cell leukemia. His spleen was removed, and his blood profile returned to normal after a few days, and he was discharged. He moved to Seattle, I believe, and occasionally was asked to come back into the clinic for follow up. In the follow up visits they had to take his blood sample, his bone marrow sample, and other bodily fluids to make sure that the cancer had not returned and to make sure that he was still okay. Those materials that were basically taken from him to confirm his diagnosis, as well as to confirm that the cancer had not returned, were then stored in the UCLA Medical Center. Routinely, they will be disposed of because they are biological waste, they are not being used diagnostically, or they might be used for for research as well--there's all kinds of things that can happen to it while it's there, subject to what Moore has authorized. Now what he authorized was that they remove his spleen, and that they use his bodily materials for the diagnosis. He also signed a consent form saying you can dispose of any tissue taken from me by cremation or according to California laws. That was the extent of what he knew.

When Dr. Gold did a scan of the spleen, he discovered that Moore's blood cells were unique because they produced a protein which can help to protect the body from infection. So, he derived his cell line from it. He was intrigued and decided to derive a cell line from it, which became known as the Moore cell line. I suppose it was named after Moore, and it was then commercialized. Subsequently, Moore received the consent form saying you authorize the University of California to have rights over all your cell lines or any product that might be developed from it. And that's when he became suspicious. He said, well, I'm not going to sign this consent form, I wonder what's going on here. So when he asked, he found out that the cell line had been developed and commercialized from the samples that had been taken out of him for diagnostic purposes and for treatment purposes. He then brought this action.

His claim, essentially, was that this was conversion or theft of his biological materials. He said he had a property right in his biological materials, and in the cell line that was commercialized and that he had a right to benefit financially from its exploitation. He also brought up a number of subsidiary claims where he talked about not having authorized this so this was a breach of his consent rights. He also talked about breach of his privacy and different other legal claims, which he brought. But the main claim was, this is a violation of my property rights, because what they've done is convert my property without my authorization, and essentially they've stolen it from me, and they have expoited that commercially and I have a right to benefit from that. The court rejected that contention. And that is why, this case is so famous. The court said no, that's not correct. That excised tissue in an unaltered state is not property in the strict sense of the term 'property'. The courts kind of dodged the question on this. They refused to comment. They said we don't need to comment on this to decide the case, but we just reject the contention that posits that excess tissue in this unaltered state is property. The court reached the view that tissue, once excised from the human body, is no longer owned by the person from whom it is taken and there are different kinds of justifications offered for this that I am happy to comment on during the workshop.

So the courts said we don't need to decide the question of property rights over the tissue, but what we can say is that, once it's taken from your body, it is no longer owned by you. But that person from whom it was taken has some legally protected interests in the fate of the unaltered tissue. These interests essentially amount to what I described earlier as a right of control. You have a right to give consent to its use; you have a right to consent to the use and disclosure of the information that is derived from it; you may have some privacy interests that are protected as a result of this right of control. But the one thing you cannot say is that this is your property once it is excised from the body. Excised from your body, you no longer own it.

The court also said it is not owned by the person who has custody of it, either. But we [the courts] don't need to comment on this to decide the case. As far as we [the courts] are concerned, the ownership question, we can say it's not owned by anybody. We aren't going to actually say who owns it, we are just going to comment on that. And the court says, in the unaltered state, once you apply human ingenuity to it, once you derive cell lines from it, as has been done by Dr Gold, it becomes, in essence, a new kind. Legally, we can apply property rights to this new thing. Remember before I said a cell line is, essentially, in terms of its constitutive properties, the same as the tissue it was taken from. It will have coded for the same genetic information. It is pretty much, in many ways, constitutively, the same as the tissue. But the court says, once you have human engineering applied to that tissue, once you have derive something from it, called a cell line, that becomes, in essence, a new kind. And that we can apply property interest [to]. That is owned by the creator, and all rights and interests, as far as property go, as property rights go, of the donor are extinguished. Once altered, it becomes owned by the creators. In essence, it was owned by the Regents of the University of California, by Dr. Gold, not by Moore.

This is one case that has really commented on the question of ownership of human biological materials. You can see that the way the classification of this case revolved on altered versus unaltered. In an unaltered state the ownership question is not very clear. But in an altered state, it is much clearer. In an altered state, it is owned by the person who authored it, who created it. And there are some exceptions to the reasoning in Moore. For example there is a case called Hecht and Superior,[20] and York and Jones.[21] In Hecht, a deceased male person retained ownership over cryopreserved semen via a contract, and could be equated to a girlfriend. That's what the court decided. This was a case where contract law was used as a basis to allow someone to pass on the rights over semen to the girlfriend. And in York, the plaintiffs in York returned property rights over cryopreserved pre-zygotes for productive use, again through contract. What these cases suggest is that if you execute a contract where you transfer ownership, if you will, over human biological materials, that could be recognized by the courts. But ordinarily, if it's true diagnostic process, you may not be able to access those rights.

This is somewhat confusing. Some of the questions I have about about all of these rulings, the first is, why will the court reach these kinds of conclusions in cases involving contracts, but a different conclusion in a case involving diagnostic procedure and treatment. In the healthcare context, if Moore had signed a contract, would that have made a difference? Should persons be not accepting contracts if they want to guarantee that they are able to retain some property rights over their human biological material.

The other question I have is, where do the property rights come from for the altered tissue, or from the alteration. If there are no property rights for the tissue in the unaltered state, where do the property rights magically appear from when you've not applied human ingenuity to it. If the original thing does not have any sort of property implications, property applications, how do we then have it in the altered state? For me, the reason why that matters as a question is that, in many ways I viewed the decision with respect to how property rights are vested in the creator when it's altered, as a legal artifact, as this convention by the courts, that I don't think stands up to much philosophical analysis or logical analysis, simply because it's not clear why that would exist in the altered state, and not in the unaltered state.

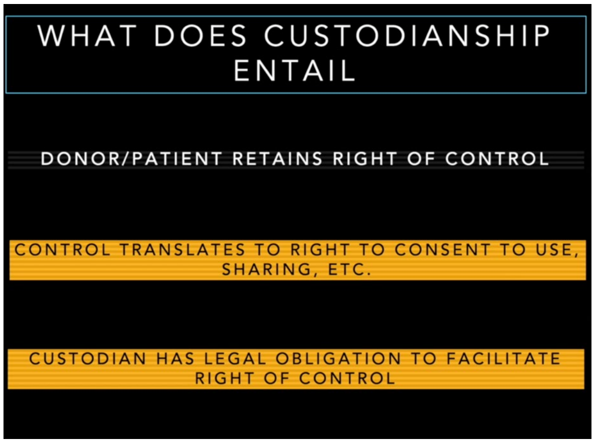
The other case I want to talk about is a case called Piljak Estate and Abraham.[22] This is a Canadian decision from the Ontario Superior Court in 2014. Prior to this case, Canadian courts had not actually commented on the ownership question. When this case was decided, there was a lot of interest in the case because it was quite radical in terms of what it decided. It was also, in my view, very wrong in terms of the decision. I don't see the case as setting any kind of precedent to follow and I don't see it as a very persuasive case. It's certainly not authoritative because it was decided in essentially the lowest court you have in Ontario. It was also decided by a judge, called a master, who is typically the kind of judge that handles procedural matters. So it wasn't a decision on the substantive merits of the case, but rather on matters of procedure surrounding the case. The judge, I think, went above his remit in answering the questions posed in this case, because it was supposed to be based purely on the matter of which rules apply and on which procedure. I should put that as a proviso, as a warning for talking about the case. It's not very authoritative, it is not clearly followed by a court that can produce binding precedent. But, it is all we have in Canada on the question of who owns human biological materials and the associated health data.

In this case, Piljak estate, the defendant, Mrs. Piljak, underwent a colonoscopy in May, 2008, which found a tumor. Mrs Piljak was diagnosed by the defendant, Dr. Abraham. A year later, she underwent another CT scan at Sunnybrook Hospital, which led to a diagnosis of advanced colorectal cancer. The first colonoscopy found a tumor, but the tumor was benign, it was diagnosed as benign. Then a year later, there was a diagnosis of advanced colorectal cancer. She died two years later, after this diagnosis. Her estate then brought a lawsuit claiming negligence for the performance of the 2008 colonoscopy.

The claim was essentially that [the] colonoscopy should have diagnosed the cancer. By diagnosing it as benign, that was negligent, because as it turns out, she actually had cancer, as early as 2008 and early detection might have altered the course of treatment, or might have led to a different fate than death. That was the negligence claim in the case. The defendant in response said look, I met the standard of care. I performed the proper diagnosis, and the conclusions that I reached [from the] 2008 test revealed that the tumor was benign. That is correct. My view is, as a defendant, is that unrelated medical conditions may have been the cause of death, not the misdiagnosis.

To resolve this, there was a motion brought to examine the pathological samples from the 2008 colonoscopy to establish or refute a possible misdiagnosis of colorectal cancer at the time of her involvement. It was a motion by the defendant to examine the samples which at the time were stored at Sunnybrook Hospital. So a defendant is saying, I did not I did not do anything wrong. You can go check the sample--I am asking for a motion to check the samples to confirm that I did not misdiagnose the tumour at the time. The deceased's estate opposed the motion on several grounds. One can think of them not wanting it to be examined because if it's examined and it's actually benign, that kind of destroys their case. But they [the courts] said, there's no law that permits the testing, she's dead now. You don't need to test the tissue for a diagnosis or treatment. In many ways, there is a related privacy argument that's going on here, which Dr. Nwabueze touched on at length. She's dead now. There's no reason under the law, for you to want to examine this, and there's no examination that would benefit the deceased, since the deceased is dead now and actually deceased. So you don't have any legal basis upon which to examine the tumor, and as [the court] resolved the question, denied the motion.

This came to this judge, who was a master, to decide. The judge had to look into a legal rule in Ontario which permits only inspection of 'real' or personal property. 'Real property' will be things like land, buildings, all that kind of stuff. The rule in Ontario that would have allowed for this to happen says, if this is considered to be personal property, then it can be examined. That was the rule that the defendant doctor was relying on. If it's personal property, then I can examine it because it's personal property, I don't need to state a reason like diagnosis or treatment, as the deceased's estate is claiming. The master had to interpret, this judge how to interpret the issue of whether a tissue sample taken from a human being for the purpose of diagnostic testing is personal property. That was what came before the master.



WHAT DOES CUSTODIANSHIP ENTAIL

DONOR/PATIENT RETAINS RIGHT OF CONTROL

CONTROL TRANSLATES TO RIGHT TO CONSENT TO USE, SHARING, ETC.

CUSTODIAN HAS LEGAL OBLIGATION TO FACILITATE RIGHT OF CONTROL

As you can see from the issue that I just stated, directly implicates the question I'm trying to answer in this talk, which is, is human biological materials and human excised human tissue or excised human biological materials, considered personal property? The judge held that all the definitions of personal property involve ownership or other legal rights with respect to an object. So if it's personal property you're going to have to talk about ownership. Property--you can't talk about personal property without thinking of it as a thing belonging to someone. So in order to decide the question of whether a tissue constitutes personal property, we have to decide the question of who owns that personal property.

The conclusion reached by the judge is that diagnostic tissue is owned by the collecting institution. In this case, Sunnybrook Hospital. And if the Sunnybrook Hospital owns it, then of course, they can decide who gets to examine it and who doesn't get to examine it. The judge held that because it is personal property, it is no longer owned by the patient. So in essence, Mrs. Piljak's rights over this are now extinguished. It is personal property because it is a medical record, in essence. Human biologic materials contain a record of someone's information. Because it's a medical record, and that Canadian courts have held previously that medical records are owned by the institutions that prepared that record. In essence, it's a medical record and so it's owned by the collecting hospital.

To be very clear about the reasoning here, the court says there's an existing Canadian decision, which I'm going to talk about shortly, that says a medical record, similar to Netcare or your medical file in your doctor's office, that physical file, or Netcare, the electronic record system is owned by the institution that built the record or bought the file. In essence, tissue is also a medical record because it holds information or data about the person. The court analogized tissue or human biological materials to a physical file, or to the electronic record system, and said, because it is owned, because those are owned by the collecting institution, the institution that built it, then the tissue is owned in the same way by the institution that collected it from the patient. That was the Piljak decision, and this is the only decision so far in Canada, that Canada has commented on. It is quite wrong in terms of the connection that it raised, and I'll tell you why it is shortly.

That's essentially what happened in Piljak. I have a description of the facts in the slides. I've already gone through that so I'm just going to skip over it and the decision as well, which I just explained to you.

One other thing that the Court said is, just because it's owned by the collecting institution doesn't mean the person from whom it is taken--in this case Mrs Piljak--does not have any rights over it. The patient, from whom it was taken, has some rights over it. But those rights are founded in privacy law, not property law. No property rights or interest whatsoever. Once it is taken from your body, all you have that remains are just some rights of control or some rights that essentially are founded in privacy law. I think both contentions are wrong. And I will tell you why in a second. But, I should note the parallels between this case and Moore. In this case, both courts have concluded that persons from whom tissues is excised, tissue or other human biological materials is excised, do not have property interests over that excised tissue. In Moore, they didn't really answer the question of who owns the tissue in the unaltered state. They dodged that question. Piljak doesn't dodge it. Piljak says it's owned by the institution that collected it. The other thing that comes out of Moore is that once altered, it is then owned by the person who perform the alteration. Piljak doesn't comment on this at all. If you combine the two cases, they state, I think, three main propositions. The first is in an unaltered state, human biological materials are, on Piljak, owned by the person who collected the human biological material from the patient. The second proposition is, once altered, on authority of Moore, it becomes the property of the person who has altered it, who has created something new--I'm putting "new" in airquotes--from it. And the third proposition is the person from whom it was taken has some remaining legal rights, but those legal rights are founded not in property law, but in other areas of law. In Moore, the courts identified things like fiduciary law, consent law, the right to control how it's used, how the health data that it contains is used and disclosed. But, in Piljak, the court also talks about the fact that it's founded in privacy rights. So that's what we have in terms of the legal landscape, at least in the cases from North America.

One other thing that I will add is, there are some exceptions in contract law, where you use contract law to pass on property rights over your human biological materials to someone else.

Now did Piljak get it right? My answer to this question is no, it didn't. The conclusion of ownership issue overstates the law and lacks legal support, in fact it's quite perverse reasoning. It doesn't make any sense. The ownership question is not settled in law, and it's not addressed in any existing ethics or policy statements. In many ways, the law has always dodged this question because courts have not found the kind of case where they needed to comment on it. As you saw in Moore, they didn't need to answer that question in order to decide the case. Why? Because we were dealing with unaltered tissue, what we're dealing with in this case is a cell line, that's what Moore is saying was stolen from him. That's what Moore brought the compensation claim for: the altered tissue, the cell line. In many ways, that's what we're going to comment on. We are not going to comment on theoretical concepts, this is a court of law, not the place where we decide theoretical matters. So the court dodged that, and that's the trend you're going to find in policy statements, and in legislation, where this is dealt with. [The courts will] say, we don't have to deal with the matter, because we don't see how it's going to come up.

It's also the case that, because we have laws in different jurisdictions in Alberta about what happens to human biological material once it leaves your body, its fate is that it either ends up in a pathology lab somewhere, or it has to be disposed as biological waste and biohazard. In many ways, the law has posed this question, because it's not often the case that cell lines are derived or something is derived from someone's tissue, or someone's tissue is commercialized directly from the tissue. But even when there's a legal dispute, this is going to be about the alteration, which is what Moore commented on.

What is really wrong with Piljak, is that Piljack misinterprets Canadian law. Piljak, in essence, analogized tissue to a medical record. This was based on the idea that a tissue is a medical record. But it's a complete misreading of the law in Canada. Where does that idea come from? It comes from a case called McInerney and MacDonald, which I will talk to you about in a second. But the gist of McInerney and MacDonald is that stewardship and custodianship is the lens through which you assess the role of the institution that collects human biological material and stores it, not ownership. The proper lens is to think of the institution as holding it as a custodian. And there are rights and obligations that are attached to the custodianship or the stewardship that these institutions perform. The ownership question doesn't come up because those rights and obligations are basically enough for what we need to do in terms of how we manage human biological materials and associated health data. From a donor rights perspective, there are protections that extend beyond privacy law, protections in law that go to consent, for example, so donors have rights to consent to the use, disclosure, and sharing of the biological materials, altered and unaltered, but also the right to control it in ways that go beyond just privacy and consent law. So what happened in McInerney and MacDonald?

This is a case that predates most if not all of the access-to-information and privacy laws in Canada today. It's a 1992 case, it is the case that triggered the enactment, in different provinces, of what we now know as health information laws across Canada. It is a very important case, it's seen as the leading case on issues relating to privacy and access to information. It's important to note that even though the courts in Piljak was relying on this decision, this was not a decision about ownership of health data, or ownership of human biological materials. This was an access to information case, fundamentally. I think that's the first mistake the court made is to take a legal principle that was created for access to health information and access to health data and apply it to the question of ownership of human biological materials. That mistake is one that, basically, to my mind, makes the Piljak decision to be one that cannot be relied on. The other thing you should know about McInerney and MacDonald was that the court was dealing with and contemplated and commented on physical records. So essentially a medical records file in a physician's office, not diagnostic tissue. That's also important.

What happened in McInerney and MacDonald? [23] The plaintiff in this case, the person who brought the complaint in this case, went to her doctor and asked for a copy of all the records in her medical file. The doctor said, I can give you two records that I prepared myself, or which I obtained myself, but I cannot, as a matter of ethics, give you the records that other physicians and other health care providers that you have see, have sent to me. That was the dispute in this case: the refusal by the physician to hand over records that were not prepared [by her], on the basis of something that the physician said was a breach of ethics.

The complainant brought this claim saying, they are my records, they contain my health information, and you should release them to me. It was fundamentally an access to information case. It's my record, they are my records, you should give them to me. The court agreed with the complainant. The court said that information in the medical record, health data, belongs to the patient. I suppose this answers very clearly the question that was posed to me, which Marilène asked me to answer for this session, which is, who owns health data?

Health data, based on McInerney, and based on provincial health information statutes which were enacted in the wake of McInerney, and which have adopted the reasoning in this case beyond a shadow of a doubt, make it very clear that the information in the medical record, or health data, belongs to the patient.

What does it mean to own health data in this context? According to the code, this means that the patient has a right to control that information however they like. The patient can refuse consent to its use, or to its disclosure, can ask for it to be changed--they have all kinds of control rights over it, which have not been enshrined in provincial health information legislation. But the court was very careful to say, it is the information we're talking about because that's what is before us. The court said [health information] has to be distinguished from the medical record itself, the physical file itself. That, the physical file, belongs to the physician, institution, or clinic that compiled it. They own the physical record.

Now why would the court say this? The court wanted to make it very clear that, even if you own the health information as a patient, you can't just walk in there and say, "Destroy the actual physical file." You can say, "There's some information in the physical file that I don't agree with. I want you to alter that." You can say, "Give me a copy of it. Give me a copy of everything in my file." That's also okay. That's a right of control. But you can't say, destroy the actual physical file. This ruling, at the time it was made, did not contemplate digitized records and digital record systems. But you can see how it is useful in thinking about record systems. It would be ridiculous, if, as a patient, you were to go to AHS, the Alberta Health Services, and say, "Destroyed netcare because it has my records in it." What you can say is, "Do not share my Netcare records," or, "I want you to change something in my Netcare records," but you couldn't say, "Destroy the entire infrastructure, because my records are in it." That was the distinction the courts were drawing.

Now, that is not the same as saying the EMR [electronic medical record] system, or the physical file is like diagnostic tissue. I actually think that, in terms of classification, those two things cannot be classified together. So one's diagnostic tissue, yes, contains health data, contains genetic information and the like, but it's not the same thing as buying a physical file from Costco or Staples. The collecting institution doesn't go to Staples and says, "Give me some diagnostic tissue so I can store it in my office," or you don't build a collection of diagnostic tissue the same way you build an electronic medical record system. Fundamentally, you're taking that out of someone's body for a particular purpose and courts have never commented on the ownership question with respect to that tissue in its unaltered state. I think Piljak, in analogizing, got it completely wrong.

What the court did say, what the court in McInerney, the Supreme Court of Canada in McInerney talks about is that the compiler of the record is a custodian, essentially. They are keeping your health information for you, in whatever form it exists in. They have custody of it. This idea of custodianship is what the provincial health information legislation actually enshrines. The notion that health information, including information contained in human bodily material, when you give it up for healthcare, it is, in essence, something that the institution has custodianship over. The ownership question, they don't talk about because they don't need to talk about it, there's no contest happening in this space. As long as it remain in an unaltered form, all you need to resolve many of the legal issues that can arise from it, is to think about this idea of custodianship. As I've explained for Moore, the question of ownership does come up when it's altered, but Moore makes it very clear that with respect to that, it is the person who has now created something new from it. And as I said we can talk about in the in the workshop about whether it's actually new or not new and what it means to have a new kind.

What does custodianship entail? I've explained before, the donor or patient retains the rights of control over that information, that held data, whether it's contained in the tissue that is stored in a pathology lab, or whether it's contained in a physical file. In whatever form the health information exists, the donor retains the rights of control. That control translates to the right to consent to its use, its sharing, its disclosure. The custodian has an obligation to facilitate direction of control. But it also captures the idea of privacy rights as well, because physicians have an obligation to protect the privacy and confidentiality of information, and this is very well settled. Provincial health information laws have a ton of rules that deal with how you safeguard and protect the privacy of this information, and to prevent its misuse or unauthorized disclosure.

On this issue of application of human ingenuity, this idea that kind is created by human ingenuity, that it belongs to the creator. One of my side interests is problems of classification in law versus science. Where someone can actually learn about classification, which I think is its own pain in the world of science--taxa and how you classify things is something that has long been an interest of scientists and people in the world of biology, whereas Law, not so much. We tend to think of classification in ways that, I think quite frankly, don't make sense most of the time. We don't classify by reference to the natural properties of the thing, or to the constituent properties of the thing, we tend to classified by reference to legal artifacts and forms of reasoning that may not cohere with the constituent properties of the thing.

This classification, where we talk about altered versus unaltered, this idea of the application of human ingenuity, is one that has always bothered me because I don't know how much manipulation you need to call it a new kind. If you derive a cell line from tissue, its constituent properties will been largely the same. It's not clear to me what makes the new kind. If you have a bird, you don't pluck off a wing from it and go, “It’s no longer a bird,” but that’s essentially what you mean here. You can pluck off just a wing from it or you can just paint it a different colour and go, “Well, look, it’s no longer a bird. It is now something else.” It’s not clear to me whether all of these types of things are new. If you derive data from it, that data describes the constitutive properties of the thing. So why is it a new kind? Why does human ingenuity change it? How about derivates like DNA and stem cells? Again, they constituent properties as the same. From a scientific standpoint, these are all the same kind in terms of constituent properties. But law [makes a] difference. And the reason that courts use, which is derived from cases that deal with patent law mostly, is that discoveries that possess markedly different characteristics from any found in nature are considered to be new kinds. But we don’t find that to be the case with respect to this. It’s not clear what the different characteristics are that these derivates possess to make them become new kinds.

I’ve talked about the fact that there are rights of control that are vested in whom human biological material that has been excised or taken from. Those rights of control include the right to consent to its use and disclosure, but also privacy protections in the form of a granted custodian to meet certain obligations with respect to safeguarding the confidentiality and privacy of that information. If you read health information laws throughout Canada, privacy protections generally depend on the idea of identifiability of the data. Generally speaking, if the data is identifiable, then the protections that are attached to it differ from when it’s non-identifiable. By non-identifiable I mean that you cannot readily ascertain the identity of the individual to whom that information relates, from the data. In fact, most privacy protection legislations in Canada do not address or apply to non-identifiable data. For all intents and purposes, not much time is spent describing the legal consequences that attach to non-identifiable data.

The rights of control I talked about generally persist and are expressed, with respect to data from which the identity of an individual can be readily ascertained, is limited or no protection, in many cases, for non-identifiable health data. One other question which I think is going to be touched on in the afternoon sessions is whether emerging reidentification technologies may force a reexamination of this binary between identifiability and non-identifiability. As we will learn in the afternoon sessions, it is becoming increasingly difficult to speak about the concept of non-identifiability because we now have technologies that are able to reestablish the identities of persons from non-identified data. So I think that’s something to keep in mind with respect to how this binary that is expressed in law right now might be challenged in future cases.

That’s all I have--it’s a wild ride!

Dr Susan Cox, Emerging Ethical Challenges in Innovative Visual Methodologies

Introduction by Marilène Oliver:
This afternoon, I am delighted to be introducing Dr Susan Cox. I first came across the ethical guidelines of Dr Susan Cox made with a number of her colleagues in Australia--I think two or three years ago, and I go back to them regularly. They are a fabulous resource for artists and we’re really honored to have you here, so thank you Susan.

Dr. Susan Cox is associate professor in the W. Maurice Young Center for Applied Ethics, at the School of Population and Public Health at the University of British Columbia in Vancouver, Canada. She is sociologist and ethicist and is director of MSc and PhD prominent programs in Population Public Health. Her current research employs art space and qualitative methods to understand and represent lived experiences of health, health and illness such as dementia, and to identify and explore challenges in graduate supervisory relationships, especially as these relate to inclusivity and diversity. Susan is also keenly interested in research ethics and brings a critical lens to identifying potentially troublesome aspects of arts-based inquiry. With colleagues in Melbourne, she has developed guidelines for ethical visual research methods, co-edited a special issue of visual methods on ethics, and collaborate on the book Ethics and Visual Research Methods, Theory, Methodology and Practice, published by Springer in 2016. She is currently collaborating on the development of ethical guideposts for research-based theatre.

Dr Susan Cox:
Thank you so much Marilène and to all of the organizers for inviting me to this fascinating day about ethics. The convergence of so many interesting technologies and health and visual arts, I'm really excited about being here.

I'd like to begin with a brief land acknowledgement. Here you see a photo of where I live in Burnaby near Vancouver, overlooking the mountains in the winter and this is the land of the Tsleil-Waututh people, the people of the inlet, and I am very grateful to live and work on this beautiful land.

I have been working at UBC in the field of ethics for quite some time, but I was thinking back over my work and the topic of this conference really made me think back to some of the early work that I did in the social and ethical impacts of genetics and genetic testing and in particular, at the time I was doing my doctoral work when the possibility of testing for adult-onset conditions such as Huntington disease was very new and very controversial.

This is an advertisement for what it meant to people in the Huntington's society, to think about predictive testing, and determining who might get this disease in adult onset, in adult years. The slogan, "I can predict my future with deadly certainty" is really very much indicative of the kind of frightening possibilities for some and powerful potentials for others that surrounded the introduction of this kind of looking at oneself and knowing about oneself.

Since then, I've spent a lot of my time thinking about research ethics and in particular in the context of the development of a great many new innovations in qualitative and other forms of arts-based research, is raising some absolutely fascinating challenges for us as researchers and for artists and for collaborative works and projects like this project that bring together scientists and health researchers and artists.

I thought this quote from Susan Sontag's book, which is classic, was as valid and important today as it was in the 70s when she wrote it. "In teaching us a new visual code, photographs alter and enlarge our notions of what is worth looking at and what we have a right to observe. They are a grammar, and even more importantly, an ethics of seeing." And this photograph, just for context, is actually the first photograph that I ever took when I got a digital camera. I was quite overjoyed to be able to use it to shoot images of these women and their beautiful dress dancing at a local folk festival and taking photos of something where people really wanted to be seen and to be enjoyed.

What I thought I would do today is touch on three areas and first starting off by just offering a little bit of an overview to the research ethics landscape in Canada, noting some particular areas of relevance, I think for this project, and then look in a little more detail at what I call ethics in practice, which is really a chance to dip into some of the work I've been doing recently in a couple of projects, and mine those project for some of the lessons learned and emerging questions. And then finally to land, I guess on the topic of future directions and in particular some thoughts around evolving ethical practices for Know Thyself. In particular, thinking about the process for doing that. We did hear some of this this morning, so I'll go a little bit more quickly over the parts that I think you're all familiar with.

System of Human Research Protection

- For all health and other research involving human participants, whether funded or not
- Operates on a rule-compliance basis
  - Canada follows TCPS2 for university research
  - Australia has National Statement on Ethical Conduct in Human Research, U.S. the Common Rule; other nations have their rules
  - International norms and conventions
- Response to a troubled history of the misuse and abuse of research participants
  - Current debates about bureaucratic overreach & delay
  - Suitability of biomedical paradigm for all research?

I did want to start by just touching on our system of human research protection in Canada. And note that, you know, all research involving human participants, whether it's funded or not, falls under the Tri-Council Policy Statements (TCPS), and that's a really important thing to bear in mind. Sometimes people think unfunded research slides under the radar and that's not just true.

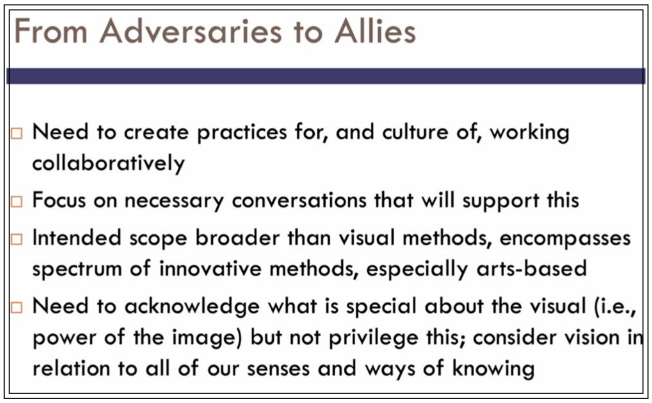
It operates on what we might call a rule-compliance basis, that is there a sort of an honor code, if you Like. We fill out these applications and commit to doing our research in a particular way, but there isn't always a lot of monitoring of follow-up. We have to report adverse effects, and sometimes there are annual check-ins to make sure that the work is unfolding as it should, but for the most part it's, it's a rule-compliance system.

Our TCPS is in many ways a response to cases in the history of medical research, which are graphic examples of the abuse of research participants and in many ways is designed to prevent and protect them from this kind of abuse. But many from the social sciences in the arts have questioned whether the paradigm for research ethics that we've ended up with is actually appropriate to all forms of research including qualitative and social science methods and creative practice which is another interesting question here. In many ways it's what we might think of as an adversarial model and most of us who have been around the block a few times with ethics applications that haven't been approved quickly, who've delayed our research, tend to see things in this way on a grumpy day anyway, so that the function of the research ethics board is often conceptualized as negative in terms of preventing unethical research and REBs in many institutions, and my own university is no exception, are increasingly oriented toward minimizing risk and avoiding institutional liabilities.

Researchers, therefore, are sometimes seen as potential offenders who are only really interested in fulfilling their own research goals. And reviewers are therefore cast as protectors and the only ones who are interested in ethical standards. Now of course this model is really a straw man and a straw person, and sets up a dynamic that's not entirely true, but there is some truth in it.

In particular, I think when we think about innovative approaches to research and creative practice, this model highlights the way that some new and innovative methods are really pushing at ethical research practice and institutionalized research ethics practices are oftentimes pushing back, so there is an inherent kind of tension.

Much of the work I've been involved in, and I have to credit here my time working on the research ethics board at Emily Carr University of Art and Design. They had a very forward-thinking research ethics board and we really tried to avoid this kind of adversarial model and think of it more as a kind of an alliance between the research ethics board and the practical, the community of researchers, and artists. So there is this need to find ways to become allies instead of backward adversaries and to focus on the kinds of conversations that will support this. AndI think this is something I really want to applaud you for undertaking in this work to see the necessity of having these conversations as part of your project and to see the importance of generating ethical guidelines as one of your outcomes that's really an important piece of this work, and something that is still somewhat unusual in my experience.



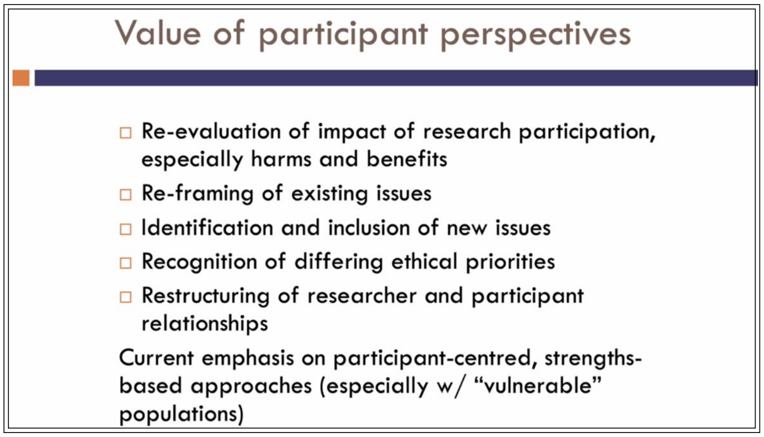
From Adversaries to Allies

- Need to create practices for, and culture of, working collaboratively
- Focus on necessary conversations that will support this
- Intended scope broader than visual methods, encompasses spectrum of innovative methods, especially arts-based
- Need to acknowledge what is special about the visual (i.e., power of the image) but not privilege this; consider vision in relation to all of our senses and ways of knowing

I wanted to also signal here that I think there are things that are special about the visual that have to do with the power of the image. But that it's important in thinking about the scope of research ethics in this field, not to perhaps privileged this, and to consider vision in relation to all of our senses and ways of knowing.

I wanted to comment very briefly here just that our TCPS is formed out of a kind of a fusion of a number of different approaches to ethics, some of which may be already familiar to you. The first is deontological, it comes from the philosopher Kant. It is very much concerned with duty and enacting what has been called the Golden Rule, do unto others as you would have them do to you, but apparently now is being replaced by the Platinum Rule where we have to think more about how people would like us to treat them and treat them as if we were first honoring their own wishes and not how we think they would like to be treated.

The second is utilitarian ethics which puts a lot more emphasis on consequences and this is where weighing costs and benefits and trying to determine what will create the greatest good is the kind of watermark of this approach.



Value of participant perspectives

- Re-evaluation of impact of research participation, especially harms and benefits
- Re-framing of existing issues
- Identification and inclusion of new issues
- Recognition of differing ethical priorities
- Restructuring of researcher and participant relationships

Current emphasis on participant-centred, strengths-based approaches (especially w/ "vulnerable" populations)

And then finally virtue-based approaches which are really concerned with how to be caring or benevolent and ethics evolves from that. I just mentioned, these ways of thinking about ethics because the four cornerstones of our Tri Council Policy Statement are really, again, a fusion of principles that are drawn from these different traditions of ethics. I'm sure most of you are very familiar with first notions of autonomy, that is respecting the agency of persons; beneficence, or the effort to do good; and non-malfeasance, the effort to avoid harm; and justice, the concern with the distribution of benefits and harms, as well as good.

It's interesting, and I think this was something Marilène noted first thing this morning that our TCPS is silent on the topic of creative practice, except for these two very brief passages which I won't reiterate because you're already familiar with them. Basically, emphasizing that creative practice is exempt from review, unless the focus is on participants and analyzing participant responses to creative practice in which case it becomes human subject research.

Some of you may be familiar with the missing chapter in the Tri Council Policy Statement which was written in 2008 by Mary Blackstone and others,[6] and was never included in subsequent revisions. I just offer one brief quote from that missing chapter that I think is probably important to hear.

The authors write, "While arts-based researchers should reflect on the moral acceptability of their approach to human subjects, it's not in the best interest of the subject if ethical review becomes a prescriptive mechanism for limiting or diminishing the impact of the arts, or for exercising prior restraint or censorship." They're worried here that the arts not be censored out of a paternalistic concern for the well-being of participants.

Now switching gears, I wanted to share very briefly a little bit of the findings from a project that ran for seven or eight years which was funded by the Canadian Institutes for Health Research called Centering the Human Subject.

In this project we were really interested in serving people who had participated in a whole range of different kinds of health research, to learn how human subjects actually experience their participation in research and how very different, in some cases, their experiences are from what we think about as researchers and how we think our research participants experience the research that we involve them in. We began by doing quite a number of interviews, some case studies and really began to try and triangulate these different perspectives and see what human participants in research thought. There's a lot I could say about that except the thing I really want to emphasize is that in valuing the stories and the perspectives of the participants in health research, there were some very important implications for how we think about ethics, how we think about the impacts for participants of being involved in projects. In some cases, leading to reframing the existing issues or concepts that are central to research ethics. Impact being a really good example of how participants instead of really talking about harms and benefits talk about the impacts of research for them. This emphasis on the participant stories really led us to advocate for a much more participant-centered and strengths-based approach to research ethics, where we foregrounded the perspectives of participants in thinking about ethics and really began pressing the research ethics boards to hear from researchers and hear from research participants about their experience.

I think in the context of innovative and arts-based methods in particular this is really important because institutional ethics, as I said already, tends to limit institutional liability and they tend to be cautious and paternalistic in many cases. Hearing from research participants that it's actually okay to go to the theater or a gallery and be a little provoked and distressed by what you've seen, that the ethics board doesn't have to worry so much about that, that's a really important piece of their experience that begins to mitigate that sometimes very paternalistic approach that the big 'E' institutional ethics will advocate.

In this slide, I'm beginning now to take us into what I call small 'e' or everyday ethics, and this comes out of some writing that one of my colleagues, Marilys Guillemin and her colleague, Lynne Gillam and did some years ago in a very widely cited paper, contrasting the way that institutional or procedural, big 'E' ethics acts in terms of helping us to think about some ethical issues in a very proactive way.[5] Overlooking in some cases, the number the myriad of messy, complex ethical issues that arise, once we actually start to do the work. And so, it emphasizes very much locating in the conduct of research, the practice of reflexivity as a response to the need to assess emergent issues as they arise, and to deal with those and to have a plan for dealing with those. And then of course the other thing we also need to bear in mind is that in many cases, artists and others have professional ethics and codes of conduct, or standards for practice that also enter the equation here.

Now I want to dig into just a few examples of what I'm going to call ethics in practice, issues that surface in the context of a few different projects that I've been working on.

The first is a kind of an interesting study called medical doodles, which is about the practice of doodling in medical education and how visual learning in particular is extremely important for many medical students.

I just want to share with you first some of the reasons why. My colleague Carol-Ann Courneya and I did a survey of medical learners, about their preferred styles of learning as a way of first understanding how it was that doodling, or drawing was as important to them as note taking. You can see here in some of the kinds of responses. Some people classify themselves as a visual learner, they talk about anatomy being inherently visual, they're really not an audio learner, etc. Others went further to say that they didn't think their understanding should be limited by the comprehension of words, and that actually engaging with the text, and adapting it into a form that is understandable through drawing, is where the real learning comes in.

Here you see an example of a rather beautiful image of the human head created by one of the, I guess more professional medical doodlers Hansen, and the site on Instagram is Hanson's Anatomy. There's some absolutely beautiful examples of the kind of work that these medical doodlers do and post on Instagram, both to represent their own learning, but also to share with the community of medical students who are learning anatomy.

Here we see another example, this one quite astonishing when you realize that this representation of the female reproductive system is entirely made of candy. It's an image that I wanted to share with you because it does raise some very interesting questions that came up when this one was posted. This is a representation of a reality that medical students have to learn, that is anatomy. And yet it's also very playful and highly aesthetic. Some of the comments were about minor inaccuracies in the way that this candy anatomy displayed the reproductive system. And this discussion emerged about the tension in this kind of work between depicting reality in a very accurate way versus the aesthetics, and the utterly delightful and whimsical playfulness of using candy in this way.

So I bring that one to your attention because I think it's actually, although it's a kind of a fun example, it's also symptomatic of a much deeper tension in many forms of arts-based inquiry where research and creative communities come together and there is a tension between this desire to have fidelity to the accuracy of what's being portrayed, yet at the same time also, the very important artistic impulse toward the aesthetic and to playfulness and to not necessarily trying to be realistic in the depiction of things.

Marilène also mentioned the guidelines for visual research [Guidelines for Ethical Visual Research Methods (2014)] which we developed--I can't believe almost 10 years ago now. My colleagues Marilys Guillemin and others in Australia. We were at the time hearing many stories about the kinds of tensions that were emerging in this work and really sought to hear from researchers who were using visual methods and understand through listening to their stories, what some of the key issues were for that. This figure really is an effort just to kind of distill into six key issues which organize those guidelines, the key themes that we heard. I'm just going to run through a few examples of these now, for you.

Beginning with a project on body mapping which I'm not sure if any of you have encountered this approach and in many ways it's probably one that will be of great interest to you given the parallels between what we do in body mapping and what you may be doing with the scanned body data that you're using.

In any case, this is a technique which focuses on embodied experience and lends itself very well to exploring sensory and psychological experience. It involves having people lie down on the floor and using a large sheet of paper where you trace around the person's body to create a life-size outline, which is then over the course of one or many sessions filled in during a creative and reflective process, using a variety of materials: it could be paints, it could be collage materials or other things. This results in this image representing aspects of that, that creators experience.

Working with my colleague Katherine Boydell in Sydney and also Marilys Guillemin from Melbourne. We became part of a project that was an event in what was called the Big Anxiety Festival which was held in Sydney in 2017.

We held a public body mapping session in the Sydney Art Gallery in which we invited people to come and spend three hours and learn about this approach and to use it to map their experiences of anxiety, and also what makes them feel better when they're anxious. We had a gathering of about fifty people in this beautiful space where people were spread out on the floor. First, talking about a little bit about their shared experience of anxiety, and then spending time in pairs creating the outline of their body maps, and then filling them in. And then finally coming back together in a larger circle to talk about what the body mapping exercise had meant to them.

There was some key concerns for us and how we offered this kind of event, clearly we wanted to be aware of the potential impact of the visual images that people were creating. And we found that the bookending was a really important piece of this in terms of enabling people to make connections with others in an opening, sharing circle and having time to debrief with others afterwards about what they created.

We also found that there were some really interesting questions that arose around how people work together to create the body maps and in particular to lie down on the floor and allow in some cases a total stranger to create a complete outline of your body. What areas were okay to draw the pen next to and which ones weren't, how was that negotiated? These were all examples of the kinds of ethics and practice issues that emerge that were in some ways quite unlikely to have arisen in a formal ethics application.

Another thing we found was that consent was clearly a process, it was never a kind of a one-off thing of giving people a form at the beginning of this activity, tell them everything that they needed to know and have them check off the right boxes and sign it and be done with it. It had to be negotiated. This example of, I guess, lying down on the floor and having a stranger make an outline is a perfect example of this. There were all these micro-decisions that had to be made as the process unfolded and required constant navigation throughout the process.

That didn't end with the completion of the body maps, either. These body maps are drawn from another project which was about early psychosis, but again, speak to the point of the importance of consent, and having the participants actively involved in deciding how the work will be exhibited, who will have access to it, and importantly in this case, what the artist statement will say alongside the work. You can see in this image there are banners with statements from the artist about the work. The key thing is that the artist, the creator has the ability to share with the viewer something about the creative activity and what it means.

It also however raises some interesting questions about what the viewer themselves needs to know. My colleague Katherine Boydell, who mounted this exhibit, was interested to share with me that many of the viewers left parting comments after seeing the exhibit, they're excited about it but they wanted to know a great deal more about the person who had created each of the body maps.

A second project that I just want to share with you a little bit about has to do with living well with dementia to the end of life. And this is a project that I initiated a few years ago now with colleagues at UBC and the Center for Applied Ethics. We wanted to elicit perspectives from people with dementia and their care partners on what it means to live well with dementia to the end of life. This is very much an effort to try and counter the predominant narrative of decline, which really doesn't enable people to live well with this disease.

We started off doing in-depth interviews but what I want to focus on here is the second phase of the work that engaged participants in art-making workshops. Fortunately, we could do four of them in person before covid, and then we moved online.

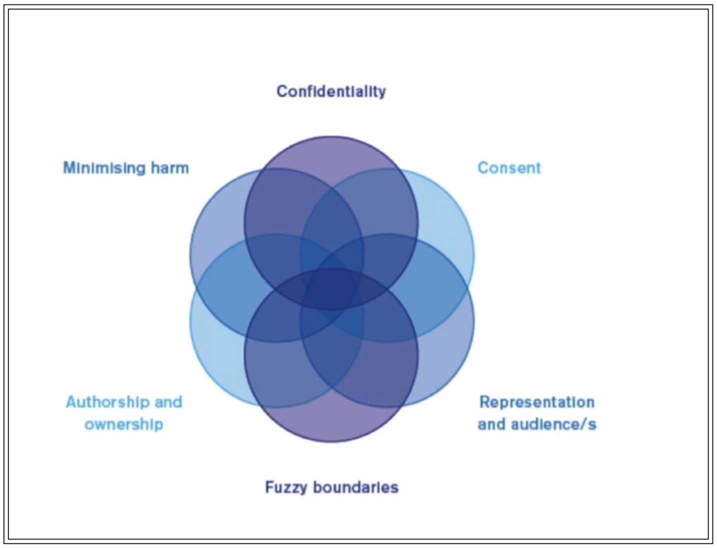
We had plans to have an in-person exhibition and a session where we would dialogue about what the work raised and how the public was responding to it, but of course that had to be put on hold and we've done that, now, in the online context.

The exhibit called In There Out Here: Art Making Space to Live Well with Dementia, features the works of the participants in these four workshops. There was a great variety of materials that we used, and in some cases, after we had to move online, we delivered art-making supplies to people's homes so that they could do this work, and then meet together online to do it.

One of the first issues that we had to deal with and moving from that kind of workshopping and data collection and talking about the work into creating an exhibition was a question of whether or not people wanted to be named by first or first and last name, and whether they wanted to be identified as a person with dementia, a carer, or not identified at all. That was a very challenging conversation, in some ways, and I use the mask here to depict this; masks was one of many things that we created.

In the end we came up with a rather interesting solution I think in that as a collective we decided, both as researchers and as carers for people with dementia, and people living with dementia, that we would all use our first name, but that we would not identify who had dementia, and who was a carer, and who was a researcher. And so that was a kind of an interesting solution for wanting, in some cases people wanted to have your name attached to their work, they wanted to share their story, but they didn't want to do it in a, in a way that necessarily revealed who they were outside of the community that made them.

This is also an example of what we might call fuzzy boundaries which is, as you know, one of the other themes that came out of the guidelines for visual research. For us we really experienced this as a kind of inversion of expertise in which our participants became the experts in determining how our website should be designed, both in terms of things like maximizing ease of access for people with dementia, but also when it came to determining what the viewers needed to know about the works that they were seeing.



Authorship and ownership is another crucial issue, which came up in many interesting ways this morning. I share with you here an image of a Mandela which is made completely of natural materials, and this is typical of the kind of process that we used in the workshop. We would try to have some collective art making activity where we brought everyone in the workshop together to create something together, both to generate social interaction, also to kind of get past a sense of isolation or for some people a concerned about not being able to do art or make art or that they're not creative.

This is one of the collective projects that we did. And this piece on much like some of the others, raised the question of authorship and ownership. Who do we credit for the work, how do we represent it when it goes public? How do we learn from this activity of creating these group pieces? Something about the ethics of how we as a community, together, want to present the work to the larger world.

So back to reflectivity as an ethical practice which is, as I mentioned earlier, the kind of cornerstone of the work that Guillemin and Gillam did looking at big and small 'e' ethics and this kind of ethics of practice is developing this sensitivity toward what they call ethically important moments, that kind of gut instinct that feeling that something isn't quite right, or there is a solution, but we haven't quite found it. And it is being able to recognize that and have a means of addressing and responding to ethical concerns that arise in doing the research. That is really one of the key features in finding the way forward in these kinds of sticky situations.

Just by way of brief summary of some of the kind of takeaway messages from the work on ethical guidelines in the work in these projects is that sometimes there's a tendency to think that just because something is creative or artful that it's necessarily good or beneficial. I think we have to clearly proceed with caution, that there are a number of ways in which this work can provoke and unsettle and be distressing.

We need as I've already said to hear stories from research participants or from viewers of exhibitions that help us understand their experience of what it is we're creating, and not rest on assumptions about what we think that they're experiencing.

It's important that we share stories about doing this kind of work in conference formats like this but also in scholarly and other publications. It's also important that given the opportunity, we participate in institutional ethics review and help to ensure that the right kinds of expertise are present there on the Review Board.

These are some of the resources we've created around ethics and visual methods, [24] and now you are embarking on doing this exercise of creating ethical guidelines for how to do this project, Know Thyself in Virtual Reality. There's just a couple things I wanted to suggest in terms of a process.

Many kinds of ethical guidelines are derived in a kind of traditional top-down approach, where there are philosophical principles, and they're argued through strenuous scholarship. I'm not saying it's not, but there's sometimes a dysfunction between that and what the people who are actually using these innovative kinds of methods are experiencing in the field. And so it's important, and I think we did this, it was largely the backbone of how we approached creating the guidelines for visual research, was that we got hold of artists and visual researchers from around the world and ask them to respond to several questions around what kinds of challenges they've confronted in their own work, what questions they still feel are unresolved, and what solutions they might propose. These were identified in short position papers and workshops and then we analyze them as a data set, thematically to come up with the kind of six core issues that we saw in that figure.

And these, these things, you know, as we might expect reflected traditional ethical concerns but also some new things that we had not so much anticipated.

On that note I think I'll just share with you the list of resources. There are others I can steer you to if you're looking to things, and I would welcome any comments and questions.

Fahim Hassan and Katrina Ingram, Navigating Data Dilemmas Workshop

Introduction by Marilène Oliver:
We are going to move on now to our "Navigating Data Dilemmas" workshop It is going to be run by Fahim Hassan and Katrina Ingram.

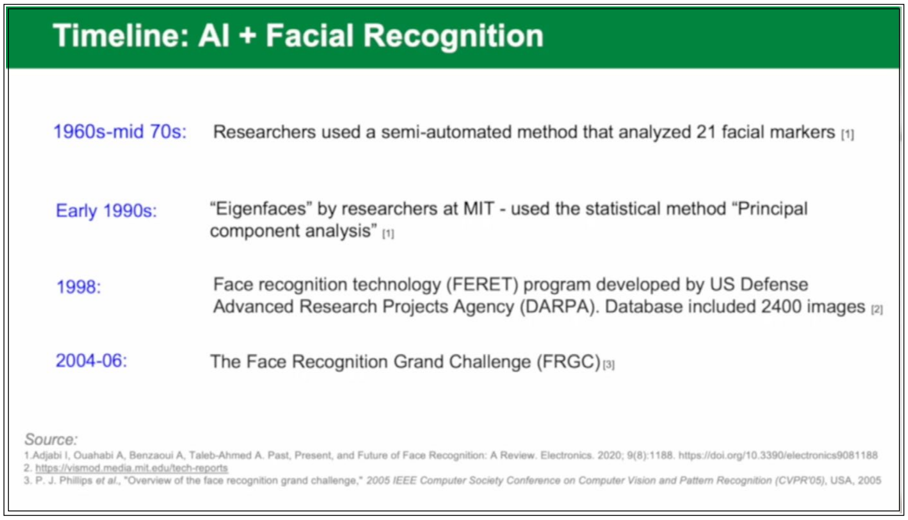
I will start by introducing Fahim. Fahim is a PhD student at the School of Public Health at the University of Alberta. His research interest is to study the application of machine learning and public health surveillance with communication and health promotion. He is currently working in the Ministry at Advanced Education, the Government of Alberta, as a civil servant who has contributed to various government initiatives on open data, social determinants of health and health informatics. In addition, he is vice-chair and advisory council member for Alberta Health Services in the greater Edmonton area. As council member he works with local communities on health promotion activities and shares their voices to healthcare service providers.

Katrina Ingram recently completed her Master of Arts at the University of Alberta, with a focus on communications and technology. Her research is in the area of artificial intelligence, ethics and healthcare. Since completing her degree, Katrina has founded a company called Ethically Aligned AI which is an extension of her graduate research and aims to help companies build better AI. Katrina has previously held senior management roles in media, technology, and the cannabis sector. Thank you, and I will pass it over to you two to start on our Navigating Data Dilemmas workshop.

Fahim Hassan: AI and Facial Recognition Technology: The Path Forward

This presentation is basically something I deeply care about. It's not part of my PhD research, but something I learned along my way. When I was thinking about a good research topic for my PhD, and with the recent focus and discussion on AI technology and facial recognition, I had brainstormed with Katrina and thought that it would be great for today's event to just share a brief overview of how AI and facial recognition technology evolved over time. Some of the issues, biases, and what can we do as researchers and as well as active and concerned citizens.

AI and facial recognition technology--they're both hot topics right now, trending in media, social media, everywhere, but they both have a relatively long history. Around 1960s and mid-70s, researchers used a semi-automated method looking into some of the key facial indicators such as the color of the eye, hair, the distance between eye and nose, to try to develop a computer-generated system that automatically or semi-automatically detects different faces.



Timeline: AI + Facial Recognition

1960s-mid 70s: Researchers used a semi-automated method that analyzed 21 facial markers [1]

Early 1990s: "Eigenfaces" by researchers at MIT - used the statistical method "Principal component analysis" [1]

1998: Face recognition technology (FERET) program developed by US Defense Advanced Research Projects Agency (DARPA). Database included 2400 images [2]

2004-06: The Face Recognition Grand Challenge (FRGC) [3]

Source:

1. Adjabi I, Ouahabi A, Benzaoui A, Taleb-Ahmed A. Past, Present, and Future of Face Recognition: A Review. Electronics. 2020; 9(8):1188. https://doi.org/10.3390/electronics9081188
2. https://vismod.media.mit.edu/tech-reports
3. P. J. Phillips *et al.*, "Overview of the face recognition grand challenge," *2005 IEEE Computer Society Conference on Computer Vision and Pattern Recognition (CVPR'05)*, USA, 2005

Since then, different research groups have tried different methods, including a group of researchers from MIT who used more sophisticated technique to normalize our use of the dimensions of the data, also known as a statistical method principal component analysis, and similar kinds of automated detection of different faces.

Later in the 90s, it became a major research topic for federal agencies, especially in the US: the face recognition technology program developed by Defense Advanced Research Projects Agency, or DARPA, and the National Institute of Standards and Technology, NIST. They did extensive research on improving these novel algorithms and computer systems that use large datasets on images and try to detect faces and recognize people in an automated fashion. What's interesting, around 2004 to 2006 is they opened the whole platform and invited researchers and companies to look into some of these data sets and try to develop or push the envelope on this automatic detection of faces.

I think the key important take away, for me when I was looking into the history of how these facial recognition technologies evolved over time, is that the datasets became larger, the algorithms or the computational techniques became more complex and difficult to interpret, as well as the ethical boundaries, the issues on privacy and consent--they got really messy. It was particularly pronounced when Facebook published their own research based on their user data on faces. They call it DeepFace. Without any active consent from their users, they used almost 4 million images, and the model included more than 120 million parameters. So quite a leap from some of the earlier research that we have noticed before.

After Facebook, a lot of other commercial companies, they also announced and showcased their advancement in facial recognition technology. For example, the iPhone 10 or iPhone X, they featured face ID as an unlocking mechanism, one of the very first commercially accessible features for their own users. Then fast forward to 2021, there was a lot of media attention on a company named Clearview AI. What this company did was create social media and other web portals where people uploaded their photos without their consent, (Clearview AI) collected all those images to use and develop a facial recognition technology, and sold it to law enforcement organizations, including the Canadian RCMP. Around July 2021, the federal government, in collaboration with their provincial partners, they launched an investigation against Clearview AI to see whether it violated federal and provincial laws. Recently they have announced--and also they had several testimonies, it's all available in the Privy Council website--that Clearview AI clearly violated these privacy laws, and the Privacy Commissioner of Canada is now calling for stricter legislation and regulations on this topic.

There are various other applications of facial recognition technology I mentioned about cell phone companies using it for commercial purposes to unlock cell phones; law enforcement agencies, they use surveillance systems; some commercial companies, they also use anti-theft systems, like all the CCTVs we see in commercial real estate properties, in our shopping malls, and other various business buildings and commercial buildings. My favorite pick is how different animation studios like Pixar or Disney are using facial recognition technology to analyze the different kinds of facial expressions and made their cartoons and animations more lively. The point I wanted to make is, there is a large spectrum of facial recognition technology, including some of those questionable ethical practices by commercial companies, but also some other organizations where the intent is quite different.

Now recently, AI and facial recognition technology have been trending in the media. In fact, over this weekend, a popular news channel did a segment on how facial recognition technology has concerns in terms of bias and inaccuracy. I wanted to share two research papers--one research paper and one research report on this particular topic. The first one is a Gender Shades project led by a computer scientist, Joy Buolamwini from MIT and Timnit Gebru, who used to work for Google, but mainly PhD computer scientist a PC graduate from Stanford University. They did similar research, evaluating three

Gender & Racial Discrimination

- Gender shade project
    - Buolamwini, Joy, and Timnit Gebru. "Gender shades: Intersectional accuracy disparities in commercial gender classification." *Conference on fairness, accountability and transparency*. PMLR, 2018.
- Misidentifying people of color
    - West, S.M., Whittaker, M. and Crawford, K. (2019). Discriminating Systems: Gender, Race and Power in AI. AI Now Institute. Retrieved from: https://ainowinstitute.org/discriminatingsystems.html.

commercial gender classification systems, including the ones developed by IBM, Microsoft, and a company named face++. What they realized is, the three different classifiers to automatically detect faces had better performance on male faces, compared to female faces. They also found that all three classifiers had better performance on lighter faces, compared to darker faces. Probably not too surprisingly, the most misclassified group of images actually belonged to darker skinned females. Since then, this duo teamed up, they're doing a lot of advocacy, their research got a lot of traction. It has been a widely cited research paper. There are other research groups who are exploring studying similar concepts and doing extensive research on this project.

Legislations & Regulations

- European Union's General Data Protection Regulation (GDPR)
- Algorithmic Accountability Act, USA, 2019
    - Regulating companies + evaluating algorithmic accuracy, and data privacy.
- Canadian Federal privacy laws:
    - *Privacy Act* – Government
    - *Personal Information Protection and Electronic Documents Act* (PIPEDA) – Business
- Others:
    - Pan-Canadian AI Strategy by Canadian Institute for Advanced Research (CIFAR)
    - Government of Alberta AI Strategy (in progress)

The other research report that I wanted to share, or highlight, is published by an organization named AI Now, and the researchers are Sarah Myers West, Meredith Whittaker, and Kate Crawford. It's easy to read in lay language.

They came up with a set of observations, not only in terms of the lay-of-the-land in computer vision literature, but also the background of the researchers and pointed out that there is a major diversity crisis when it comes to AI or computer vision research. One of their key findings found that the use of AI systems for classification detection and prediction of race and gender is in ardent need of re-evaluation. It summarizes all the major issues with training data sets, how there are inaccuracies in labeling, as well as severe equity and major issues in the algorithms that are used by these commercial companies and big tech in developing facial recognition technologies.

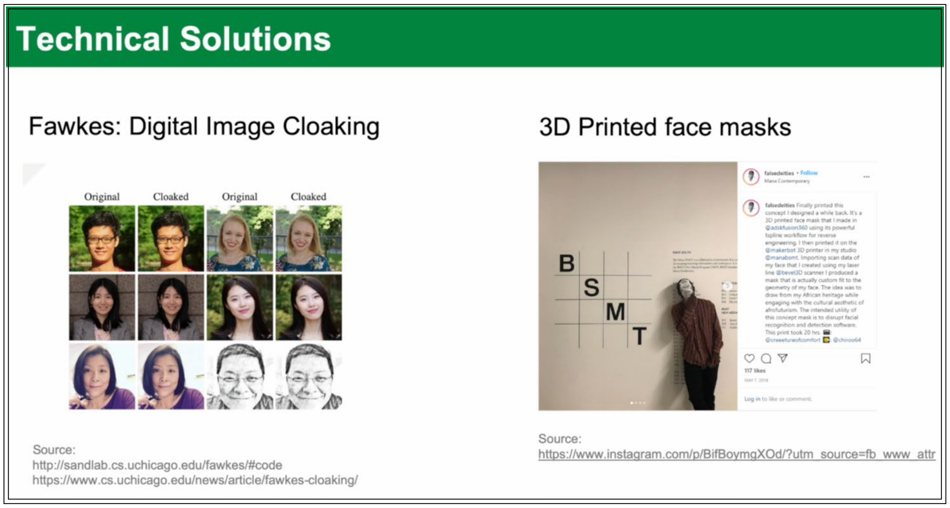
I wanted to share a couple of examples of bias and harm. There are some major examples that have been covered extensively by the media. One is how the Amazon facial recognition technology actually misclassified Oprah and showed that there is a very high chance for a photo of Oprah to appear as a male. The other case that has been covered extensively by media and went viral on Twitter and other social media, was a Google photo app that tagged a person of color as a gorilla. It showed how the training data set and labels that were used to develop these kinds of technologies or applications were deeply flawed.

The bias and harm were not limited to these kinds of misclassification. There are actual real life cases where people from the black community have been wrongfully convicted by law enforcement agency just for being black. This is an example The New York Times covered on the case of Robert Williams, a Michigan citizen who was arrested by the police and spend time in jail because the facial recognition technology that was used incorrectly identified him for a theft. The question is, what can we do about it?

There are several advocacy groups and researchers that are doing fantastic research. I'll just quickly highlight one of my personal favorite examples, as some of the technical or technology-based solutions that can show some light at the end of the tunnel.

A group of University of Chicago researchers came up with the technology named Fawkes. It's a way they call digital image cloaking. The way it works is actually fascinating. It means very tiny pixel-level changes to a photo that are invisible to the naked eye. When these photos are shared to social media and companies such as Clearview, or any other commercial company has scraped this image and try to train an algorithm or develop facial recognition technology, this photo actually poisons the dataset. The way it was supposed to work, it [the facial recognition technology] actually doesn't work and fails to recognize those individuals from those images or datasets scraped from online.

The other example I wanted to share is, we noticed that there are several movements and political activisms that are going on right now or happened recently. There has been a growing tendency for these activists to use a different kind of face mask, including 3D printed face masks, to avoid state sponsored surveillance.



Technical Solutions

Fawkes: Digital Image Cloaking

Source:
http://sandlab.cs.uchicago.edu/fawkes/#code
https://www.cs.uchicago.edu/news/article/fawkes-cloaking/

3D Printed face masks

Source:
https://www.instagram.com/p/BifBoymgXOd/?utm_source=fb_www_attr

There are also different kinds of legislations and regulations that are in place. Quite a few of my previous speakers covered the GDPR, and different legislations in the US. Quickly point out that there are also Canadian privacy laws, including the Privacy Act, as well as the Personal Information Protection and Electronic Documents Act, which mainly applies to businesses, whereas the Privacy Act is mainly applicable for government agencies. There are other Canadian strategies, or even provincial strategies--working for the Government of Alberta I can share a bit. That GRA is also looking into artificial intelligence strategy where the ethical application of different kinds of AI systems and technology, including the facial recognition technology, is one of the key pillars. My key observation in this case is, there is a huge knowledge gap between the policymakers and the developers of AI and facial recognition technologies.

Legislations and regulations are struggling to keep up. At the same time, it is very difficult to enforce these legislations and regulations. But I hope that with the recent case of Clearview AI, and there is also a company named Cadillac Fairview, with these recent cases which the Privacy Commissioner of Canada is paying more attention on tailoring, tweaking, improving, or even introducing new legislations and regulations that address some of the challenges that we are observing in this space.

There are growing advocacies by Civil Liberties Union, there are civic technology groups, researchers establishing organizations such as the Algorithmic Justice League. So, remember the computer scientists from MIT, Joy [Buolamwini], who was one of the co-leaders of the Gender Shade Project, she's a vocal advocate, calling for a ban on facial recognition technology and asking governments to pay more attention, to establish this Algorithmic Justice League [who are] doing fantastic work.

I will also do a quick shout out to our own UofA communities; there are multiple signature areas, including AI for Society, and there are also different reading groups, informal groups such as the AI Arts and Culture Salon where researchers, enthusiasts, curious minds are coming together and discussing some of the recent advances in technology, some of the new discoveries in this field [that media uncovered]. Given that legislations and regulations are still struggling to keep up with this kind of civic activism, the discussions that we are having today will ultimately get more traction and bring more focus and raise awareness. It is very important to pay attention to what kind of technology we are using. Some of the cell phone applications such as photo swap or face swap, TikTok videos, they're becoming part of our everyday experience in virtual experiences; people are creating great art with these applications but behind the scenes, these companies are actually taking our images and using it for purposes that do not require active consent from the user. And obviously there are some questionable applications of these technologies. So, the more we discuss these issues beyond the academic boundaries, I think it will help us to navigate, take the next steps on developing ethical guidelines that actually meet today's standards and needs.

Wrapping up, I'll share this quote, one of my personal favorites. [Don't ask if AI is good or fair, ask how it shifts power."] There are several frameworks, data ethics guidelines, and best practices that looks into whether or not a particular technology is fair, whether it's trustworthy, whether it's good. These definitions are inherently abstract and difficult to grapple [with]. There was a Nature article last year,[9] [the author, Pratyusha Kalluri, building upon the work of one of the pioneers in this space, cites] Ruha Benjamin, encourages us to ask the question whether or not, or how, artificial intelligence, or facial recognition technology, or other kinds of technology, is shifting power. There is a major imbalance in power and academics from critical race theory, sociology, the humanities, they all need to come together to ask these kinds of meaningful questions and put our brains together and look into to these issues from different perspectives. Katrina and I, we discussed how to make this discussion more engaging, more fun and more interactive. Katrina developed a case study that will help us to have these kinds of discussions. So with that being said, I will wrap up, and I am happy to answer any questions or comments.

Thank you.

KATRINA INGRAM: THE CIRCLE OF HEALTHCARE DATA

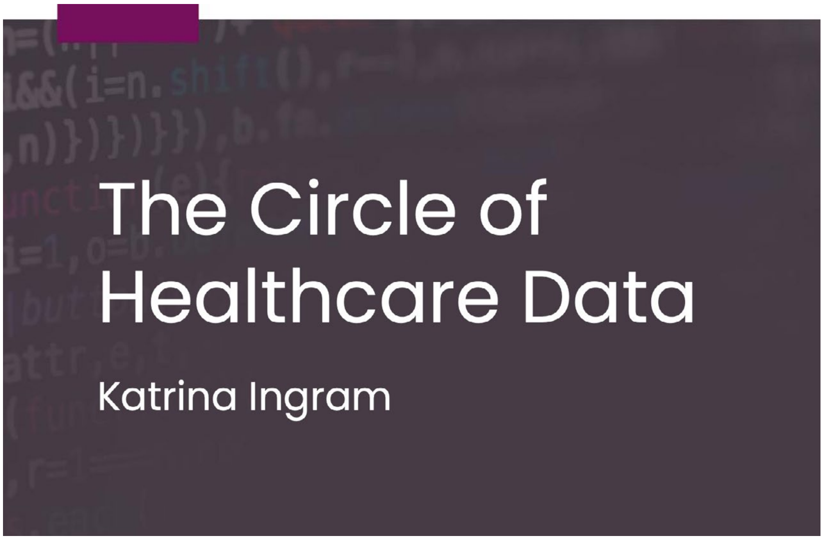
So, I'm going to set up our case by sharing two short videos. The first is from a Hollywood movie called The Circle. We were talking about what kind of a case we want to do. And Marilène brought up this movie. She said, "You know, this movie, The Circle, which is based on a book by David Eggers, this will be a perfect segue into talking about what might happen if one company had control of all of our data." I'm going to share with you a little clip from that movie; this is a scene where the CEO Tom Hanks is explaining to the staff of the circle, this brand-new technology that they're bringing to market. We're going to take a look at that, and then we're going to take a look at a real-life scenario.

Tom Hanks in *The Circle*, (2017): [25]
"Do you see any cameras here? No. We have one hundred and forty-four cameras in place here. And it took us just a day to do it and they're virtually invisible, they come in every color. So camouflaging is essential. This is my favorite. Now, the entire world is watching. You know, I agree with the human rights activists all over. There needs to be accountability. Tyrants and terrorists can no longer hide. We will see them. We will hear them. We will hear and see everything if it happens. We'll know. We're calling it See Change. We will see it all. Because knowing is good. But knowing everything is better.

Sundar Pichai on Google Health: [26]
AI is going to impact many, many fields. I want to give you a couple of examples today. Healthcare is one of the most important fields [that] AI is going to transform. Last year, we announced our work on diabetic retinopathy. This is the leading cause of blindness, and we use deep learning to help doctors diagnose it earlier. We've been running field trials since then, at Aravind and Sankara hospitals in India, and the field trials are going really well. We are bringing expert diagnosis to places where trained doctors are scarce. It turned out, using the same retinal scans, there were things which humans quite didn't know to look for. But our AI systems offered more insights. Your same eyes scan, turns out, holds information with which we can predict the five-year risk of you having an adverse cardiovascular event, heart attack, or stroke. So to me, the interesting thing is that you know more than what doctors could find in these eye scans. The machine learning systems offer newer insights. This could be the basis for a new, non-invasive way to detect cardiovascular risks, and we are working--we just published the research-- and we are going to be working to bring this to field trials with our partners.

Another area where AI can help is to actually help doctors predict medical events. Turns out, doctors have a lot of difficult decisions to make. And for them, getting advanced notice, say, 24 to 48 hours before a patient is likely to get very sick, has a tremendous difference in the outcome. And so, we put our machine learning systems to work. We've been working with our partners, using de-identified medical records, and it turns out, if you go and analyze over 100,000 data points per patient--more than any single doctor could analyze--we can actually quantitatively predict the chance of readmission 24 to 48 hours before, earlier than traditional methods. It gives doctors more time to act. We are publishing our paper on this later today, and we are looking forward to partnering with hospitals and medical institutions.

Katrina Ingram:
I'm going to share with you just a bit of the backstory on Google Health [that] Sundar Pichai was sharing a little bit about in that last video. Google Health has kind of an interesting story. It actually started many years ago, way back in 2006. Just before the iPhone launched in 2007, Google had this notion that they wanted to be the de facto place where patients would go to access their healthcare records. And so, they came into the market with



The Circle of Healthcare Data

Katrina Ingram

Google Health with that objective. But things weren't quite ready, from a market perspective, for Google to take on that role. And by 2012, from a marketing standpoint, Google Health was a bit of a disaster. It just didn't get any market traction. Nobody seemed to be interested in it, and so they folded it up in 2012. 2012 is an interesting year because 2012 is the year where it's been noted that GPUs were starting to come online. We were just starting to get to that point where we were seeing the beginnings of this AI Renaissance--so this happened recently. And so, that was happening in 2012 as well. Google actually decided to take another run at Google Health in 2018, but in the years between 2012 and 2018, it was laying the foundational groundwork for Google Health to re-emerge again. Part of that foundational groundwork was acquiring a company called Deep Mind.

Deep Mind--some of you may know has some interesting Edmonton connections. We have, I believe, the only office outside of the UK, right here in Edmonton. We have a group of about 30 or 40 researchers that work for DeepMind. DeepMind is a company that was known for its advances in game technology, in reinforcement learning. Some of you may have seen the AlphaGo movie, but it also had a division called Deep Mind Health. Deep Mind Health was an interesting organization. It had all kinds of partnerships in the UK with the National Health Services, and it had access to all of this data, millions and millions of records of patient data, through these partnerships that it had in the UK. In doing my research, I also learned that it has developed a lot of that retinal scan technology that we just saw in the last video. Google found a way to acquire Deep Mind and as part of that, it acquires Deep Mind Health. It folds up that brand and folds it into Google Health. That's part of this relaunched Google Health and emerges in 2018.

But that's not the only play that Google was making in the healthcare space. Through its parent company Alphabet, Google has also invested across the health and wellness spectrum. I've named some of the more popular companies that you might recognize that are part of this. 23andme, this is the company that it started out with and kind of the genealogy area, helping you with ancestry that sort of shifted into genetic data. It has a company called Oscar which is all about health care insurance. There is Fitbit, many of us have Fitbits, that track our health and wellness data. Nest is another Google-backed company. Nest is best known for its smart thermostats, but it's also moving into this area where your home becomes a site of data collection, and there's interesting applications that are connected to health as a result of having technology in your home to collect data. Doctor On Demand is another popular Google company in the US, it's actually built on top of the Google Maps platform, and it helps you to connect to doctors through virtual care. That's just the tip of the iceberg. There are many, many more other companies doing research and other things in health. Basically, Google has a large landscape when it comes to health. And so that's a little bit of the backstory of Google Health.

Moving along to a specific project called Project Nightingale. This was also referenced in the video that we just watched. This is a partnership between Google and primarily universities but also a healthcare body called Ascension in the States. This gives Google access to actual patient healthcare data. A lot of the other data that Google has access to I would say is more along the lines of consumer-focused, quasi-health data, but not actual patient data. These partnerships give Google access to patient data. Project Nightingale was run as a secret project. In 2019, The Wall Street Journal broke the story, and it raised all kinds of privacy questions about whether Google should be partnering with these universities, what did this mean, how was HIPAA being applied or not applied in this case, and a couple of lawsuits were launched. Ultimately it was found that Google was not offside in any of these partnerships and in fact, they've advanced these partnerships further since 2019.

What you’re seeing on the screen right now is a new product, Care Studio. What Care Studio does is it aggregates electronic health records across various sites into one view so that physicians can have an aggregated view of data. Electronic health records, Ubaka mentioned this in his presentation earlier, they are used more and more frequently. Here in Alberta, we have Connect Care, which is really quite well known. It is the electronic health record for Alberta Health Services. However, every primary care doctor can choose whatever technology they wish to create an electronic healthcare record. This idea of aggregating data becomes important because there was not necessarily operability between these different kinds of electronic health care records. Essentially, Google centered itself as the interface between the physician and the healthcare system through this particular project.

On the patient side, Google is somewhat coming full circle from where it started way back in 2006. As of a month ago, it’s back in the patient portal business, and it’s now feeling like the market is ready for [Google] to be the patient-facing portal for all of us to access our healthcare records. This is obviously primarily happening in the US right now, given how their healthcare system is set up, but it could happen in other markets as well. This is what’s been going on just in the last several months at Google with respect to various aspects of its health and wellness companies.

A billion-dollar IPO for Oscar, this is the Google-backed health insurance company. The launch of Care studio, that’s the physician tool that I just mentioned. There is a new contactless sleep-tracking app that’s part of Nest. This was built off another Google product, a sensor called Soli. This integrates with your Fitbit; it monitors your sleep. Sleep is noted as an early warning sign for adverse health events, like a heart attack. That could be really interesting information for Oscar, the health insurance company, to know, for example. You can see how all of these things stack onto each other from a business strategy perspective. In April, when the launch of the patient-facing portal re-emerged, and Google used its dominance in the Android platforms to kind of recruit people to be part of this beta. So, it’s again taking different aspects of its business and linking them together. Recently, as of even a couple of weeks ago, 23andme is set to go public, in partnership with Richard Branson. This is, again, raising new concerns over data privacy. 23andme has had other controversial partnerships. A couple of years ago it partnered with GlaxoSmithKline, a drug company. They were making drugs that were specifically tailored to some of the genetic data that 23andme was supplying. All of this, again, has happened recently at Google. It seems like Google is making an aggressive move into the healthcare space.

I was also really curious about Google and privacy because those of you who know a little bit about Google may know that it is a very secretive place. When it comes to knowing things about Google, Google doesn’t want us necessarily to know things. Projects like Project Nightingale were done in secret, and it was only until a media investigative report brought everything to light that they had to go public with that project. It’s interesting to see how a company that wants to know everything about you, wants you to know very little about it.

When I was taking a look at Google’s privacy policy and building this case, I was looking at Google Health specifically. I was clicking on the privacy policy and it kept taking me back to this main Google Privacy Policy. I thought that was really interesting. I thought at first I was missing where the policy that specifically covers healthcare data is. But the way Google looks at privacy is, it seems to look at it as one big thing, like data is data is data, so whether it’s your YouTube account or your Google Health account, it’s all one big privacy policy. It’s all covered in the same thing. I thought that was an interesting commentary about the culture of how Google approaches the idea of data and the idea of privacy.

There was recently a story about the Android phone Covid app. This was the partnership that Google and Apple had, basically saying that we were going to be able to process data locally on your phone, so your Covid-state data stays safe. It was found that there was a privacy vulnerability with certain other pre-loaded apps on the Android phone that would compromise your data. This came out after the fact, and only came to light because of an investigative journalism story.

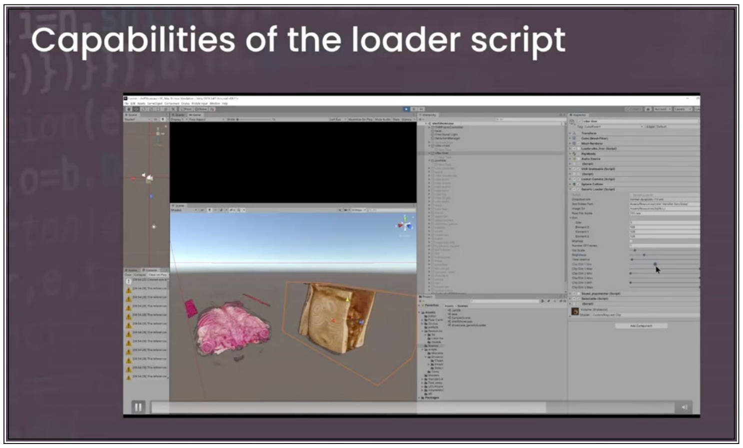
I want to touch briefly on this idea of what happens after you die or if you have a loved one pass away, what happens to all of that data? Google has this thing called "inactive accounts". Some people have called it the Google death manager. Essentially, it's a way to put an expiration date on your data. They say they're going to delete it, but in reading the policy it isn't necessarily clear to me if it gets deleted completely or what exactly that means. And again, it raises some questions as to how does Google treat privacy overall.

We're going to get into four groups. Group one is going to take a look at medical scan data and will be led by alissa; group two will look at data and patient rights and will be led by Fahim; group three will cover privacy and consent and be led by Walter; and group four will look at private versus public interests and be led by Chelsea. There are a number of thought-starter questions that were sent out along with the case; those are jumping-off points for everyone. I invite everybody to bring their own perspectives to these questions and, really, it's just an opportunity to unpack everything that we've been talking about today from the morning sessions on the legal implications surrounding data, to the ethical guidelines, to new technologies like facial recognition. What does this all mean in the context of a company that might be able to know everything about all of us?

Student Short: Walter Ostrander, Loading Medical Scan Data into Unity

My name is Walter, I'm a student here at U of A. I've been hired on as part of a co-op with the Know Thyself as a Virtual Reality project, to christen new unity scripts and tools. These will all be shared later on in the fall as part of the entire Know Thyself project.

I'm going to give an overview of some of the progress made adding extra functionality to the 3d medical image loader script created on previous projects with help of Kumar. This is special script that loads the image data into Unity, using its native renderer. One thing to note is that a lot of this functionality is already in other VR projects such as the Body VR, Medical Holodeck, as well as being inside the application 3d Slicer. If you want to read more, we have a literature review on our website.



Capabilities of the loader script

All that being said, we wanted to create an open source and functionality in Unity, as it allows for easy interactivity and integration with images and word clouds, among other things.

The first script I'm going to showcase is the previous capabilities of the loader script itself. As you can see in this demo video, before you load in a data set , you can specify a given colour transfer function. Colour transfer function just denotes what colour any given region is going to be based on its intensity. Once you load it in, you can select a data set, resize it, and change the brightness of the texture. You are also able to clip away in any of the clipping plane dimensions, so left, right, up, down, front, back.

With the previous LotusScript, you were not able to do a couple of different things. Being able to change the color transfer functions was a crucial thing that we wanted to have with our LotusScript; being able to resize datasets in virtual reality, modify the clipping planes--everything that you're allowed to do here in the inspector, we weren't capable of doing in virtual reality at the time. The first modification we made was being able to change the color transfer functions on the fly. We added a custom property drawer to the inspector window on the loader script. So, once the scene is playing, once your data sets are loaded in, you can pick and choose between all of the color transforms within a given folder, and once you click one, it reloads the entire texture with a different color transfer function applied to it.

Next was being able to manipulate the data in virtual reality. We made it possible for you to select the dataset--as you can see, this one starts to shimmer when it's selected. You can increase size, and decrease size, and resize them. We also made it possible for you to select an object and reload the entire texture with a different color transfer function. Like I mentioned earlier, you can change the color transfer function. If the datasets are a bit larger, they take another minute to load in.

The next thing we made possible is being able to modify the clipping planes in virtual reality. We mapped the direction that your palm is facing to its corresponding clipping plane so that I can cut away parts of the body in whatever direction my palm is facing. You can use both hands, it works with both hands. You can also bring the clipping planes back to reconstruct the whole body.

Once we were done with a couple of the shortcomings of LotusScript, we then added on a couple extensions of our own. This extension lets you wave a wand around inside of a body, and if you have a sound playing in the scene, you can attach a sound to this extension. Once you wave a wand inside the data set that you have loaded, it will modify the pitch of the sound. Once it is in a higher intensity area, it will increase the pitch relative to that intensity. Once you move it to a lower intensity area, it will modify the pitch to a lower pitch. I won't go into too much detail--I don't have any sampling on this one because Scott is doing a piece using this. I wanted to go over the technical side of it.

The last thing I'm going to showcase is an extension we made to Google's Tilt Brush. We incorporated our DICOM loader with Tilt Brush--for those of you don't know, Tilt Brush is a virtual reality free painting app where you start with an empty 3d canvas and you can paint whatever you'd like. For example, this is a 2d image of a 3d piece created by one of Google's artists and residents, Peter Chan. As you can see, you can do amazing artworks with it. I have here an example of incorporating our DICOM loader script with Tilt Brush. As you can see, it's loaded in here, and then you can do whatever you like--paint over it however you like. I created a little guy here on top of our DICOM

of a skeleton. Previously with Tilt Brush you could load in surface meshes, so you can load in any surface you want into Tilt Brush, but you couldn't render 3d volumes, if that makes any sense. That's our goal with this.

STUDENT SHORT: ALISSA ROSSI, PRIVACY AND CONSENT ACROSS JURISDICTIONS

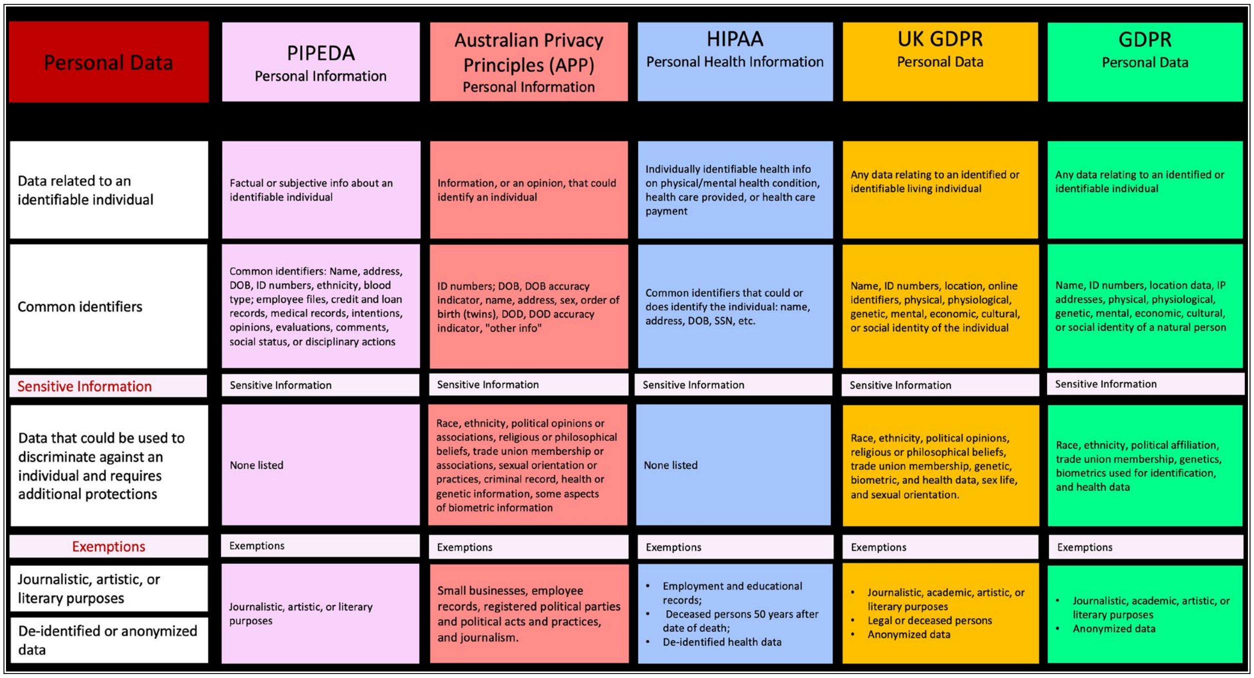
Good afternoon. I'm going to be doing a short presentation on data privacy laws in the European Union, the United Kingdom, Canada, the USA, and Australia. I will look at the differences and consistencies of legislation in defining personal data and consent and where that legislation does and does not apply.

I focus on the EU, the UK, Canada, the USA, and Australia for a number of reasons, one being an ease of language but also a consistency in cultural approaches to privacy. These five jurisdictions have a common individualistic approach to social values and ideas about privacy and individual rights and therefor makes it easier to compare the legislation. In countries with communal rather than individualistic approaches to society, there is a significantly different in understanding of privacy and personal data which makes the comparison much more complex.

I will be identifying consistent components within personal data and consent legislation and identifying significant differences in that legislation.

This is a very basic summary of how personal data is defined by the five legislations. For a quick introduction: PIPEDA is Canadian; Australian privacy act is Australia; HIPAA is American; UK GDPR is British; and the GDPR is the European Union.

Personal data is protected under various privacy charters. What are the consistent components of personal data across legislation? First, personal data is consistently defined across the legislation as data related to an identifiable individual. This is data that could be used to identify the individual. The data is consistently described as common identifiers, so data points such as name, address, date of birth,



Personal Data	PIPEDA Personal Information	Australian Privacy Principles (APP) Personal Information	HIPAA Personal Health Information	UK GDPR Personal Data	GDPR Personal Data
Data related to an identifiable individual	Factual or subjective info about an identifiable individual	Information, or an opinion, that could identify an individual	Individually identifiable health info on physical/mental health condition, health care provided, or health care payment	Any data relating to an identified or identifiable living individual	Any data relating to an identified or identifiable individual
Common identifiers	Common identifiers: Name, address, DOB, ID numbers, ethnicity, blood type; employee files, credit and loan records, medical records, intentions, opinions, evaluations, comments, social status, or disciplinary actions	ID numbers; DOB, DOB accuracy indicator, name, address, sex, order of birth (twins), DOD, DOD accuracy indicator, "other info"	Common identifiers that could or does identify the individual: name, address, DOB, SSN, etc.	Name, ID numbers, location, online identifiers, physical, physiological, genetic, mental, economic, cultural, or social identity of the individual	Name, ID numbers, location data, IP addresses, physical, physiological, genetic, mental, economic, cultural, or social identity of a natural person
Sensitive Information	Sensitive Information	Sensitive Information	Sensitive Information	Sensitive Information	Sensitive Information
Data that could be used to discriminate against an individual and requires additional protections	None listed	Race, ethnicity, political opinions or associations, religious or philosophical beliefs, trade union membership or associations, sexual orientation or practices, criminal record, health or genetic information, some aspects of biometric information	None listed	Race, ethnicity, political opinions, religious or philosophical beliefs, trade union membership, genetic, biometric, and health data, sex life, and sexual orientation.	Race, ethnicity, political affiliation, trade union membership, genetics, biometrics used for identification, and health data
Exemptions	Exemptions	Exemptions	Exemptions	Exemptions	Exemptions
Journalistic, artistic, or literary purposes De-identified or anonymized data	Journalistic, artistic, or literary purposes	Small businesses, employee records, registered political parties and political acts and practices, and journalism.	• Employment and educational records; • Deceased persons 50 years after date of death; • De-identified health data	• Journalistic, academic, artistic, or literary purposes • Legal or deceased persons • Anonymized data	• Journalistic, academic, artistic, or literary purposes • Anonymized data

identification numbers, etc. Within personal data there are categories that are considered sensitive information that need extra protections. This is data that could be used to discriminate against an individual. Data points that fall into this category are race, ethnicity, political opinions, religious affiliation, etc.

There are exemptions from privacy legislation. One exemption is when data is used for journalistic artistic academic or literary purposes. These "special" purposes do not require consent. Data that has been deidentified or anonymized is also exempt from privacy laws. Consent is not required for use of anonymized data sets since personal information has either been removed or obscured in a way that re-identification is difficult.

Now that we have a rough idea of the commonalities between legislation defining personal data, what are some of the differences? Just as a reminder: HIPAA is only about health information and does not apply beyond a health context.

The UK GDPR specifies that privacy legislation is only applicable to a living individual. PIPEDA and the two GDPR charters have broader definitions of what common identifiers are; PIPEDA includes things like intentions, opinions and comments, evaluations and disciplinary actions, and social status, whereas both the EU and UK GDPRs include categories of genetic, mental, economic, cultural, and social identity of the individual, which tends to be more broad.
Both HIPAA and the UK GDPR have exemptions for deceased persons. While the GDPR does not indicate when the termination of privacy happens with the death of an individual, HIPAA specifies that it occurs 50 years after the date of death. Under UK GDPR, legal persons are not covered by the privacy act.

Under HIPAA one of the exemptions is employment and educational records. Both of those sets of records are maintained by either the employer or the educational Institution. n the case of employment records, HIPAA says,

> The Privacy Rule does not protect your employment records, even if the information in those records is health-related. In most cases, the Privacy Rule does not apply to the actions of an employer.

And that,

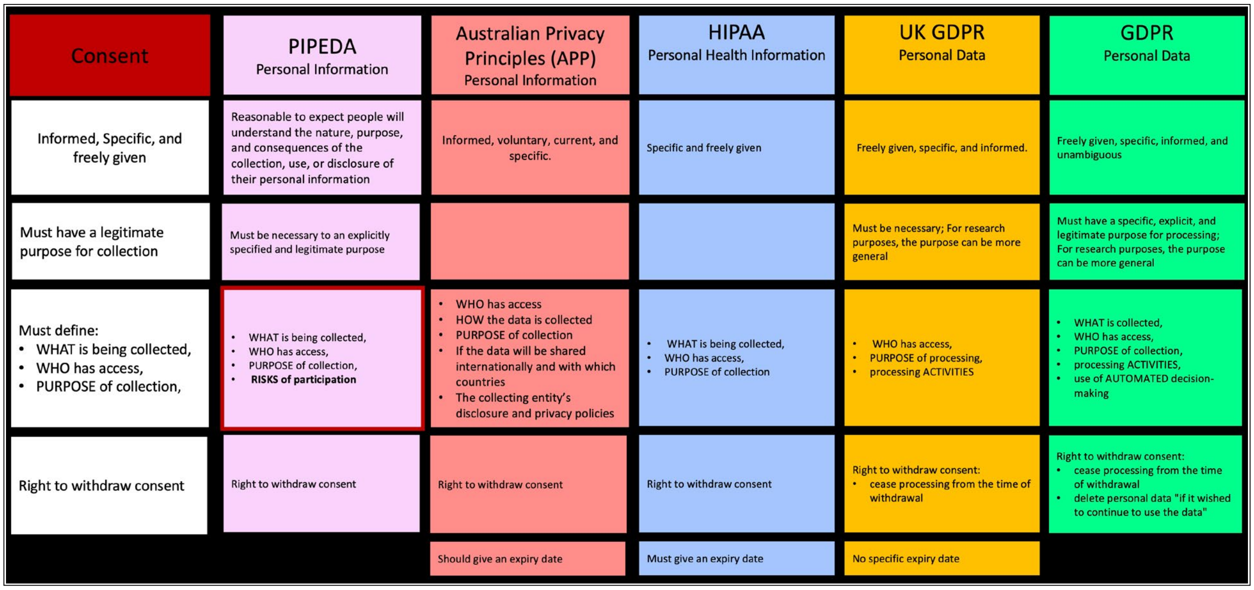
> If your employer asks your health care provider directly for information about you, your provider cannot give your employer the information without your authorization unless other laws require them to do so.

Finally, the Australian privacy act and the two GDPR's all include in their sensitive information health, genetic, and biometric information.

Consent must be obtained from data subjects before personal data can be collected. What are the consistent components of consent across the data legislation?

From my summary of the principles of consent, consistent across the five charters, consent needs to be informed specific and freely given; the purpose for collection needs to be legitimate and necessary; what is being collected, who is collecting/who has access to the data, and the purpose of collection all need to be communicated to the data subject; and, consistently across all of the legislation, data subjects have the right to withdraw consent at anytime.

Now that we have the consistency amongst these five data legislations what are some of the differences between them?



Consent	PIPEDA Personal Information	Australian Privacy Principles (APP) Personal Information	HIPAA Personal Health Information	UK GDPR Personal Data	GDPR Personal Data
Informed, Specific, and freely given	Reasonable to expect people will understand the nature, purpose, and consequences of the collection, use, or disclosure of their personal information	Informed, voluntary, current, and specific.	Specific and freely given	Freely given, specific, and informed.	Freely given, specific, informed, and unambiguous
Must have a legitimate purpose for collection	Must be necessary to an explicitly specified and legitimate purpose			Must be necessary; For research purposes, the purpose can be more general	Must have a specific, explicit, and legitimate purpose for processing; For research purposes, the purpose can be more general
Must define: • WHAT is being collected, • WHO has access, • PURPOSE of collection,	• WHAT is being collected, • WHO has access, • PURPOSE of collection, • **RISKS of participation**	• WHO has access • HOW the data is collected • PURPOSE of collection • If the data will be shared internationally and with which countries • The collecting entity's disclosure and privacy policies	• WHAT is being collected, • WHO has access, • PURPOSE of collection	• WHO has access, • PURPOSE of processing, • processing ACTIVITIES	• WHAT is collected, • WHO has access, • PURPOSE of collection, • processing ACTIVITIES, • use of AUTOMATED decision-making
Right to withdraw consent	Right to withdraw consent	Right to withdraw consent	Right to withdraw consent	Right to withdraw consent: • cease processing from the time of withdrawal	Right to withdraw consent: • cease processing from the time of withdrawal • delete personal data "if it wished to continue to use the data"
		Should give an expiry date	Must give an expiry date	No specific expiry date	

The Australian and American charters do not include caveats that the collection of personal information needs to be necessary or legitimate –I assume that this is up to the discretion to the data subject when they are giving consent. Expiry dates are not consistent among any of them. HIPAA indicates that you must give an expiry date [limiting how long the consent is valid for], but that expiry date can be vague. It can be articulated as "at the conclusion of the study". UK GPR does not require a specific expiry date and the Australian privacy principles indicates that you should give an expiry date, but it is not a requirement.

The Australian legislation is the only one to require the data subject be informed on whether their data will be shared outside of Australia, and it is required that the consent indicate with which countries the data will be shared. This is important because data is controlled by the legislation of the location from which it is being accessed. So, if data is created in Canada, it falls under PIPEDA legislation. But if it is accessed in the US, the data then falls under HIPAA and not PIPEDA. This is articulated in a consent form out of British Columbia. The BC Cancer Research Institute specifies that if your data were to leave Canada it is no longer protected under Canadian legislation.

In both GDPRs, how the data is going to be processed needs to be articulated, and in the EU it must be communicated if there is any use of automated decision making. They also include what actions are required once consent is withdrawn. For both of them, as soon as consent is withdrawn data processing must immediately cease. The EU GDPR further specifies that personal data needs to be deleted if the entity wants to continue to use the data. This is interesting because this suggests that even though a person has withdrawn their consent, their consent is only around personal data. So data that is not personal does not need to be deleted and can continue to be used. I assume that the deletion of personal data essentially renders the data anonymous, and therefore falls outside of GDPR privacy legislation.

Finally, PIPEDA indicates that consent must include the risks of participation.

Going back to the consent form from the BC Cancer Research Institute, they articulate that, "the possibility of someone identifying you can never be completely eliminated," and that data could be compromised accidentally or on purpose. As well, they acknowledge that "the risk of someone identifying you may increase in the future as people find new ways of tracing information." This acknowledges that anonymity cannot be guaranteed, and that information can be compromised by human action, or through future changes in technology and digital behaviours that cannot be accounted for in the present moment.

It is this element of future risk that is potentially the most important in creative practice because, when artists use anonymized data sets or deidentified, content-rich information such as medical scans, there is a potential for re-identifying data subjects and thereby unintentionally disclosing their personal data. It is important that researchers understand the risks their work may pose to their data subjects in order to inform the subjects of the possible implications of participation.

Student Short: alissa rossi, Our Digital Lives

Anonymized and de-identified data sets are not protected under privacy laws because it is thought to be relatively difficult to re-identify the data subjects included in the data set. HIPAA and both the UK and European GDPR exempt anonymized data from privacy regulation. In Canada, the Tri-Council Policy Statement states that research does not fall under privacy laws if the data used is anonymous or non-identifiable, and if there is no linkage of two or more anonymous data sets.[27] Considering the changes in technology and the rapid development of our digital lives and the subsequent digital footprints, are there increased risks of re-identifying data subjects in anonymized data?

A 2019 study found that subjects in anonymous data sets with 15 or more data points could be re-identified. The researchers noted that,

> Using our model, we find that 99.98% of Americans would be correctly re-identified in any dataset using 15 demographic attributes. Our results suggest that even heavily sampled anonymized datasets are unlikely to satisfy the modern standards for anonymization set forth by GDPR and seriously challenge the technical and legal adequacy of the de-identification release-and-forget model.[28]

Beyond conventional data sets, we are now generating incredible amounts of data about ourselves through our smartphones and our online behaviors. In a 2017 infographic produced by Domo [29] and sighting a range of sources, they gave an estimation of how much data is produced in a single minute. Being four years out of date, it is reasonable to assume that our data production has gone up. Many of us in the early months of the pandemic were shocked when we discovered our average daily screen time had increased by three to four hours. That increase in screen time most likely translates into more data for the companies that track us.

As a study from December 2020 discovered, companies that collect our data can make inferences about us just from our location data. The study said,

> Data gathered from smartphones enables service providers to infer a wide range of personal

> information about their users, such as their traits, their personality, and their demographics. This personal information can be made available to third parties, such as advertisers, sometimes unbeknownst to the users. … Understanding the types of information that can be extracted from location data and implications in terms of user privacy is of critical importance.[30]

The New York Times produce The Privacy project in December of 2019. In it they visualize cellular location data leaked to them from a data location company. They showed one individual cell phone and tracked it over a period of time throughout New York City. Because the visualization gives a satellite view, the granularity of the movement is lost. However, the data collected would have given information such as where the person lived and worked, who they visited, who they sat next to on the subway, where they got lunch, or did their grocery shopping, whether they visit a doctor's office or hospital and a multitude of other location data. From just the location data, inferences can be made about the kind of person that this data belongs to.

If such rich data sets are being produced daily, what kinds of reassurances are there that anonymize data will remain anonymous? As artists, what are the ethical implications of using data-rich information, such as medical scans, if we do not know that we can protect the anonymity of the data subject? Is it enough to acknowledge through consent forms that anonymity is the goal, but that it is not a guarantee? And if we generate so much personal information on a daily basis. Is it really the artists responsibility to protect data when data itself seems to have become a public commodity.

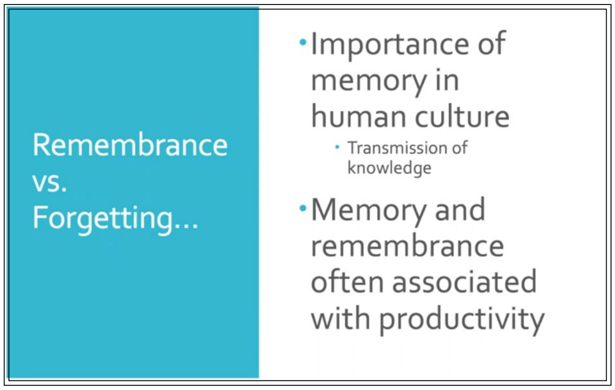
Student Short: Erin Ratelle, Art of Forgetting

Hi everyone, my name is Erin Ratelle and I'm a PhD student at the University of Alberta in the Faculty of Kinesiology, Sport, and Recreation. Today I'll be discussing an assignment that was written for Dr. Geoffrey Rockwell's Information Ethics course from this past term which also happens to be my last course in post-secondary education.

I would first like to acknowledge that I am on Robertson Huron treaty 61 territory. The traditional territory of the Anishinaabe peoples. Beyond an acknowledgement statement, I welcome accountability and meaningful dialogue applied through my work, words, and actions. In general, I see a lot of the work we do in academia as a dialogue and so my hope for this piece is to encourage some thought and discussion around the ethics of data management and storage practices.

It's funny how we think of memory--a dichotomy between remembrance and forgetting, where forgetting is rarely pictured as an admirable trait. To forget is often associated with decay and damage, the passive loss of information over time, that occurs with age or the traumatic loss of information from physical or psychological injury. To forget is to lose something, and it's unsurprising that memory and remembrance is prized over forgetting.

Memory has had a long-standing importance in human culture. In oral cultures, memory was needed for the very transmission of knowledge. Plants, too, remember. For example, a venus flytrap needs to remember that two of the hairs on its leaves have been touched by an insect in order for it to shut. And in order to do this, it needs to remember that the first one has been touched. Wheat seedlings remember that they've gone through a winter before they start to flower and make seeds; people with photographic memories are praised for their excellent recall; and, online applications such as luminosity offer daily brain workouts, aimed at helping users improve their memory.



Remembrance vs. Forgetting…

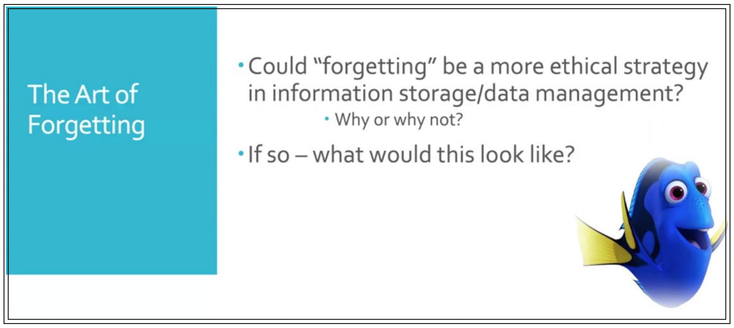
- Importance of memory in human culture
  - Transmission of knowledge
- Memory and remembrance often associated with productivity

What is seen here is that to remember is productive. It helps plants to flower at the correct time, it helps us to learn and make decisions in our everyday lives. In other words, it helps us do things. At the crux of memory is the storage of information. To remember is to be able to retrieve and access the information from past events stored in our minds. But we know that this stored system is fickle. Memories fade, and so we turn to other methods for storing and retrieving information. Today, cloud and other computer-based technologies are popular strategies for storing information with seemingly limitless capacities. Yet, researchers predict that in about 180 years or so, we'll run out of space to store information digitally. The panic that surrounds this predicted information storage issue, it's resulted in research and development that focuses on expanding our capacity to store information. And in fact, some researchers at MIT right now are looking to see how they can store information on DNA.

It's no wonder that more is the primary focus of data management--the world of big data is a lucrative market wherein corporations such as Facebook and Google, they profit greatly off of the information that they gather from their users. But what strikes me about this information storage issue is that our antidote to this running-out-of-space is focused on how we can store more information rather than considering strategies to downsize information. Instead of expanding information storage capacities, what might it look like to incorporate forgetting as a strategy in information storage. To an extent this already does happen, but it's typically an unwelcomed practice, a result of hardware limitations. What would our information storage practices look like if forgetting was seen as a strength, rather than a weakness?

Some neuroscientists contend that forgetting serves a functional purpose. Recent research suggests that the brain may actively erase memories in order to be more efficient. If we revisit the venus flytrap, the plant will only remember that one of the hairs has been touched for about 20 seconds, and then it forgets. Here, the Venus flytrap's ability forget serves a purpose and allows the plant to conserve energy.

Drawing from these scenarios where forgetting is framed as productive, I wrote a short story called The Art of Forgetting. It's centered around the storage of big data and asks readers to consider the ways in which forgetting could be useful in an information ecosystem. Instead of this continual search for more storage capacity, could forgeting potentially be a more ethical strategy in Data Management.



The Art of Forgetting

- Could "forgetting" be a more ethical strategy in information storage/data management?
  - Why or why not?
- If so – what would this look like?

So the story is set in the not-so-distant-future, and begins with a woman learning she'll become a mother. However, in a world facing overpopulation issues, motherhood for most does not mean a physical child but a digital one. These digital children are born in part from their parents self-tracking data, social media profiles, and other online habits. The story follows this new mother and her AI child in their experiences. In this story, we see that much like testing data that is used to improve the function of an AI, the more data, the child is given, the more it flourishes. But at a certain point, something is wrong and the child is unhappy, it's unclear why. Later, the company that runs this digital child service is sold to new owners, Disney, who take over and break up the company. As a result, there's less space available to host all of the data that make up these digital children. This results in the need for them to forget some information. At first this information loss is seen as a detriment to these digital children. But later, the reader realizes that the AI children are experiencing information fatigue.

The exhaustion of information overload is perhaps best captured by David Foster Wallace's *Total Noise*. For Wallace, total noise is the tsunami of available fact, context, and perspective, and it can be likened to a sensation of drowning, combined with a loss of autonomy and the looming personal responsibility of being informed. My story ends where the child is happier now that they can forget. And in the story, the name of the protocol that's used to decide which information the child keeps or loses is called the Dory protocol. It's named after the forgetful but very happy fish from Disney Pixar's 2003 animated film Finding Nemo, whose catchphrase is to just keep swimming.

My overall goal for the story was to get people to consider different ways in data management and storage practices. I leave you with this question: could forgetting, in a sense, be a more ethical practice in data storage? Why or why not? If so, what might that look like? Thank you.

Workshop Case and Report: The Circle of Healthcare Data

The Case

> Rising up from her working class roots, Mae Holland lands a job at The Circle, the hottest technology company in a world that represents the near future. Mae's new job is not only a fantastic career opportunity, it's also the ticket to an improved healthcare plan for her ailing father who is suffering from Multiple Sclerosis. There's only one condition - Mae and her family need to agree to an "always on" data monitoring system. For Mae, this means going fully "transparent", handing over every waking moment of her life's data to be owned by her employer and consumed in real-time by millions of followers as entertainment. - adapted from The Circle by David Eggers.[31]

The Google Health Story

- Launched in 2006, folded in 2012, relaunched in 2018
- Acquired DeepMind Health which has access to millions of UK NHS patient data (retinal scan tech)
- Alphabet is invested across the health and wellness spectrum - 23andme, Oscar, Fitbit, Nest, Doctor on Demand etc.

Knowing is good, knowing everything is better.

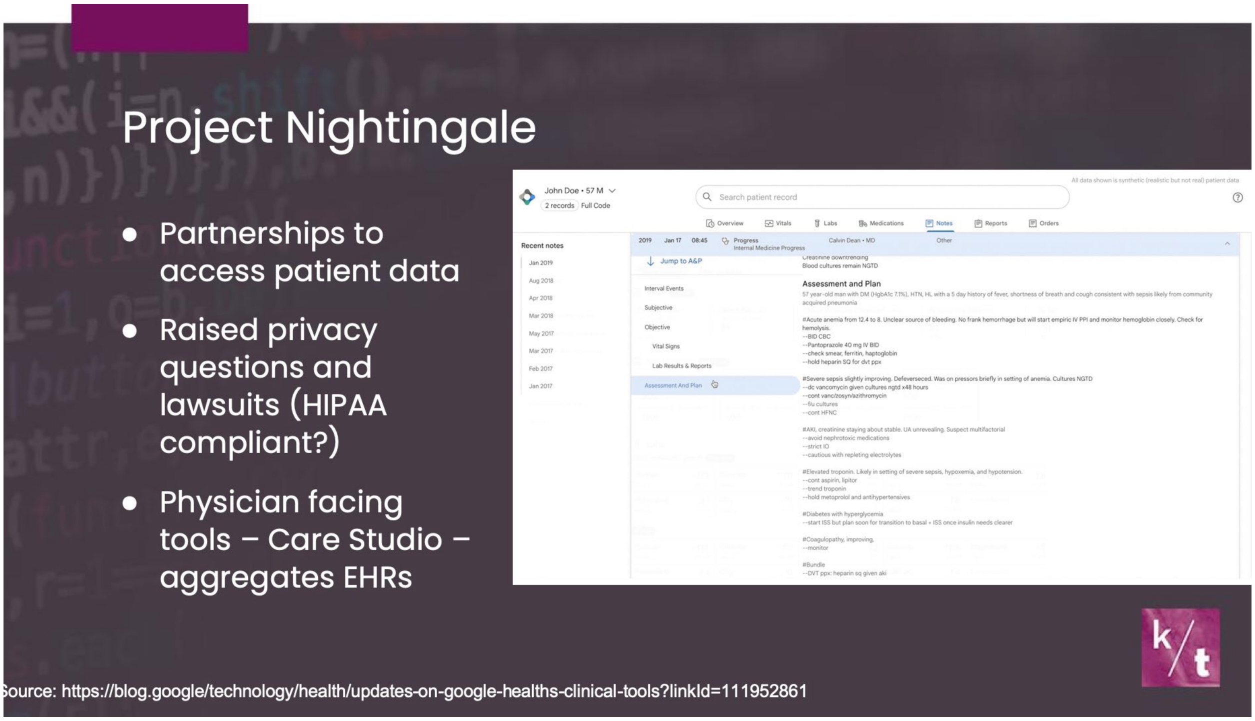
Google has the majority of the search market and has direct or indirect investments in a range of consumer and business to business companies, giving it a very wide scope of access to data that crosses virtually all industries. At the fictitious company, The Circle, where knowing is good, but knowing everything is better, a similar dynamic was at play as the organization leveraged it's digital dominance into new spheres, including health care.

In 2006, Google embarked on it's first foray into the healthcare market with Google Health headed by Dr. Roni Zeiger. A lack of market uptake resulted in Google shuttering it's health aspirations by 2012. In 2018, it was ready to try again. It had since acquired DeepMind, which had a robust healthcare division. DeepMind Health, a company which faced its own issues around patient privacy and data sharing in the UK, was absorbed into the new Google Health division in 2019.[32] As part of this acquisition, Google disbanded the independent ethics review boards that DeepMind Health had established.[32]

Through its parent company, Alphabet, Google has investments in 23andMe (DNA testing), Oscar Health (insurance), Doctor on Demand (virtual care), Verily (bio research), Calico (anti-aging research) and many other health related companies.[33] Google's consumer-facing Nest, best known for its smart thermostats, is broadening it's reach through the development of consumer health monitoring technologies following its purchase of Senosis Health in 2018.[34] Google also acquired Fitbit in 2019. [35]

Project Nightingale or privacy nightmare?

In late 2019, The Wall Street Journal broke the story that Google's Cloud division had entered into a secret partnership called "Project Nightingale" with Ascension, a private US healthcare provider. [36] Patient data in the United States is protected under HIPAA, the health information portability and accountability act, which contains specific provisions for sharing information in order to provide care or improve the quality of care. This seems to be the basis under which this data sharing arrangement was permitted. "The data involved in the initiative encompasses lab results, doctor diagnoses and



Project Nightingale

- Partnerships to access patient data
- Raised privacy questions and lawsuits (HIPAA compliant?)
- Physician facing tools – Care Studio – aggregates EHRs

Creatinine downtrending
Blood cultures remain NGTD

Assessment and Plan

57 year-old man with DM (HgbA1c 7.1%), HTN, HL with a 5 day history of fever, shortness of breath and cough consistent with sepsis likely from community acquired pneumonia

#Acute anemia from 12.4 to 8. Unclear source of bleeding. No frank hemorrhage but will start empiric IV PPI and monitor hemoglobin closely. Check for hemolysis.
--BID CBC
--Pantoprazole 40 mg IV BID
--check smear, ferritin, haptoglobin
--hold heparin SQ for dvt ppx

#Severe sepsis slightly improving. Defeverseced. Was on pressors briefly in setting of anemia. Cultures NGTD
--dc vancomycin given cultures ngtd x48 hours
--cont vanc/zosyn/azithromycin
--f/u cultures
--cont HFNC

#AKI, creatinine staying about stable. UA unrevealing. Suspect multifactorial
--avoid nephrotoxic medications
--strict IO
--cautious with repleting electrolytes

#Elevated troponin. Likely in setting of severe sepsis, hypoxemia, and hypotension.
--cont aspirin, lipitor
--trend troponin
--hold metoprolol and antihypertensives

#Diabetes with hyperglycemia
--start ISS but plan soon for transition to basal + ISS once insulin needs clearer

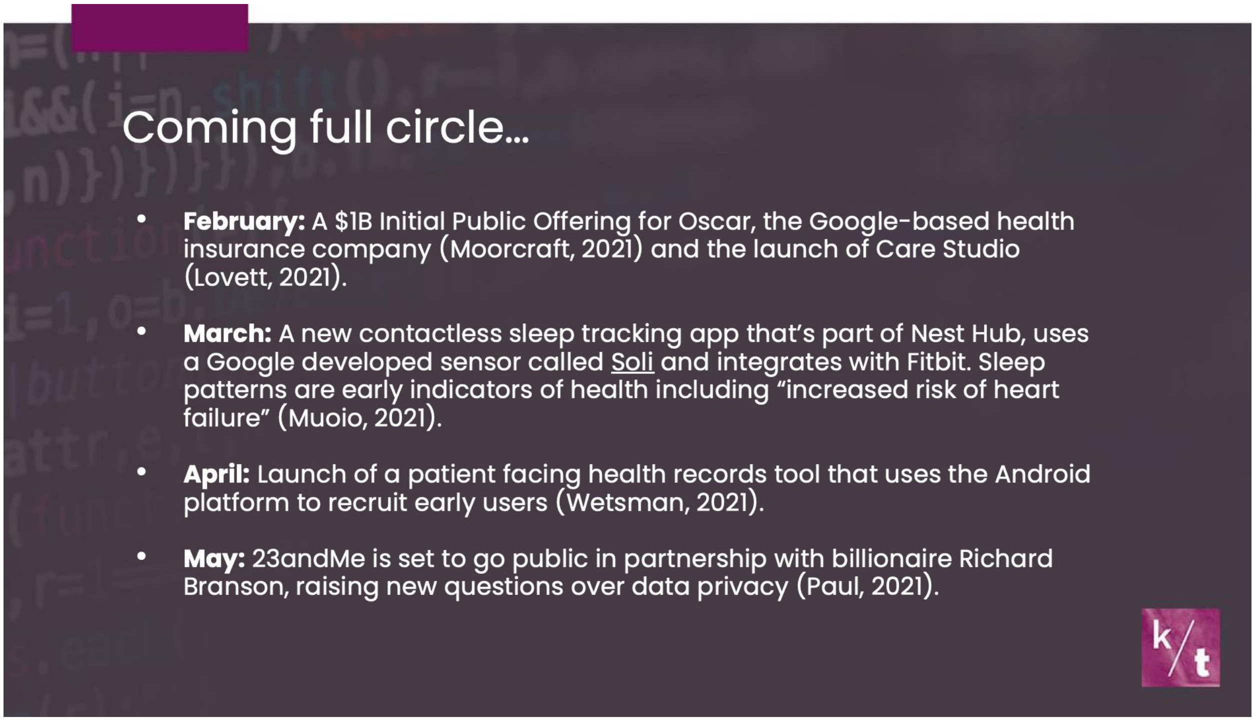
#Coagulopathy, improving,
--monitor

#Bundle
--DVT ppx: heparin sq given aki

ource: https://blog.google/technology/health/updates-on-google-healths-clinical-tools?linkId=111952861 hospitalization records, among other categories, and amounts to a complete health history, including patient names and dates of birth."[36] A Google executive publicly pledged that the patient data would not be combined with consumer data,[37] yet critics have speculated as to why specific identifiers like names and dates of birth were included.[38]

In a similar case, Google and the University of Chicago successfully defended their data sharing rights after a judge tossed out a lawsuit filed by a UChicago patient over improper data sharing practices.[39] Google has struck similar patient data partnerships with Stanford and the University of California San Francisco, which are legal per current regulations.[39, 40]

One outcome from Project Nightingale is Care Studio which launched as a pilot in February 2021. Care Studio is a tool for clinicians that harmonizes data from disparate electronic health records into a single dashboard.[41] Through this work, Google has centered itself in the healthcare system as an interface between physicians and patients. A patent filing indicates these systems could be used to predict future health events.[42]



Coming full circle…

- **February:** A $1B Initial Public Offering for Oscar, the Google-based health insurance company (Moorcraft, 2021) and the launch of Care Studio (Lovett, 2021).
- **March:** A new contactless sleep tracking app that's part of Nest Hub, uses a Google developed sensor called Soli and integrates with Fitbit. Sleep patterns are early indicators of health including "increased risk of heart failure" (Muoio, 2021).
- **April:** Launch of a patient facing health records tool that uses the Android platform to recruit early users (Wetsman, 2021).
- **May:** 23andMe is set to go public in partnership with billionaire Richard Branson, raising new questions over data privacy (Paul, 2021).

Coming Full Circle

Perhaps now, in the wake of the COVID-19 pandemic, the time is right to come full circle and aggressively advance Google Health. Google and its health related subsidiaries made several major announcements in 2021:

- **February**: A $1B Initial Public Offering (IPO) for Oscar, the Google-based health insurance company [43] and the launch of Care Studio.[41]
- **March**: A new contactless sleep tracking app that's part of Nest Hub, uses a Google developed sensor called Soli and integrates with Fitbit.[44] Sleep patterns are early indicators of health including "increased risk of heart failure".[45]
- **April**: Launch of a patient facing health records tool that uses the Android platform to recruit early users.[46]

- **May**: 23andMe is set to go public in partnership with billionaire Richard Branson, raising new questions over data privacy.[47] In 2018, 23andme's controversial partnership with pharmaceutical giant GlaxoSmithKline to facilitate genetic drug research was ultimately determined as "following best practices" by the Federal Trade Commission.[47]

It isn't a big stretch to see how all of these product and service offeringsform a fully integrated health technology stack.

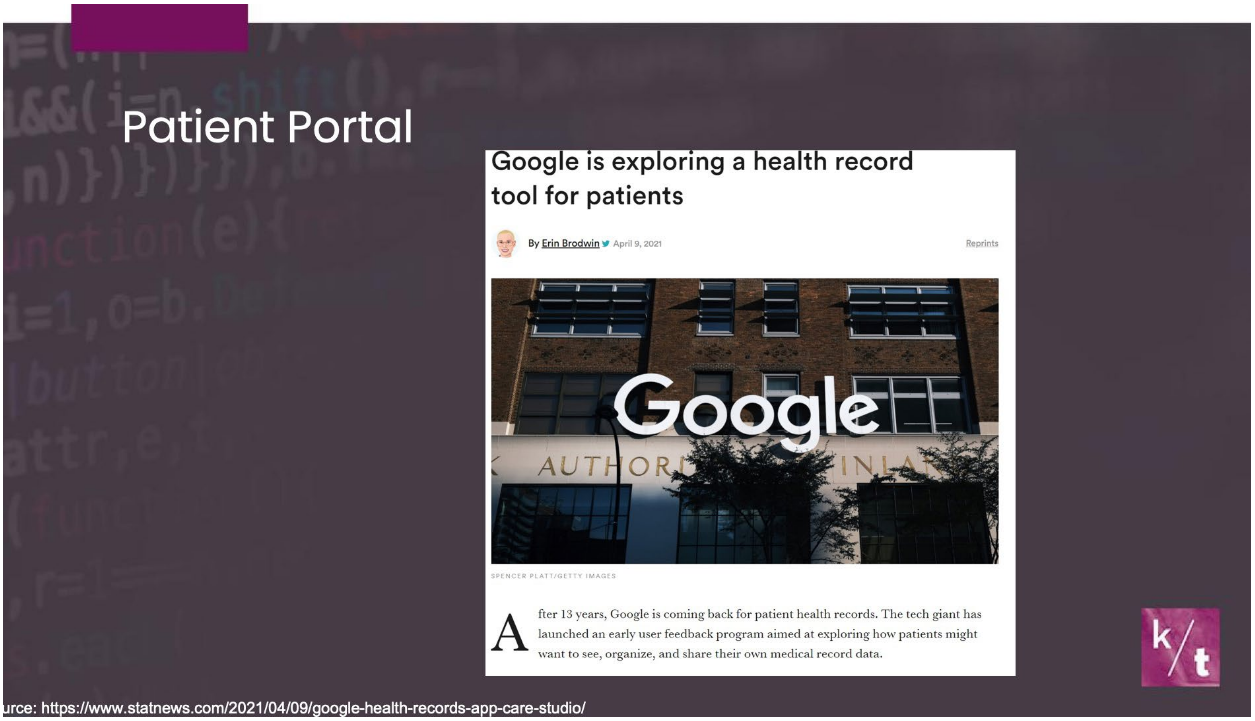
Concerns have also been raised about Google's Android phone COVID-19 contact tracing app.Despite assurances that the data would remain local to the device, a recent investigation has found the potential for privacy breaches due to the interaction of data with pre-loaded apps.[48]

It's interesting to note that there is no separate Google Health privacy policy. The same policy that governs the use of other Google platforms, such as YouTube accounts, also applies to Google Health. This one-size-fits-everything approach is telling. Google does not distinguish between different types of data.

Finally, the legacy of Dr. Roni Zeiger, who helped launch Google Health in 2006, is igrating to other companies. Dr. Zieger was offered a self-described "opportunity I can't resist"[49] and is now the head of Facebook's health strategy.[50]

Report

The case was sent to attendees three days prior to the event along with proposed questions and instructions about the breakout sessions. The hope was that attendees might read the case and come prepared for a discussion. However, it was not assumed that everyone had done the advance prep work, so the case was also present at the session.



Patient Portal

Google is exploring a health record tool for patients

By Erin Brodwin April 9, 2021

Reprints

SPENCER PLATT/GETTY IMAGES

After 13 years, Google is coming back for patient health records. The tech giant has launched an early user feedback program aimed at exploring how patients might want to see, organize, and share their own medical record data.

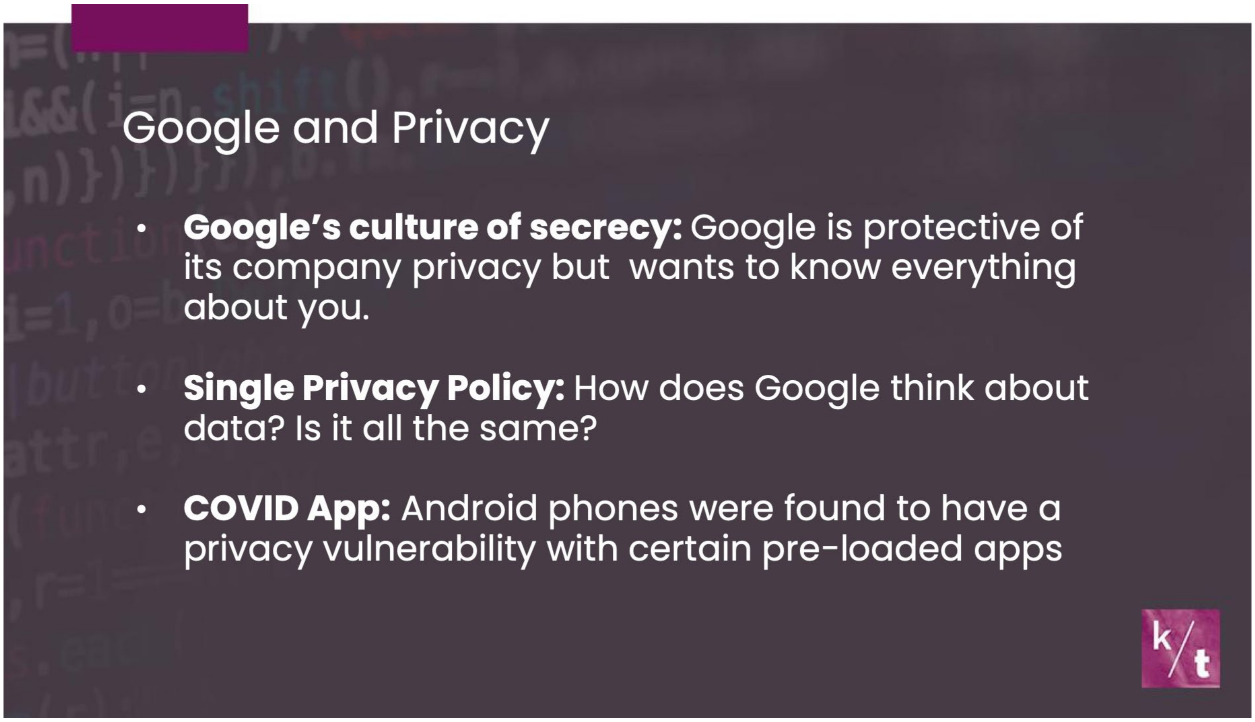
urce: https://www.statnews.com/2021/04/09/google-health-records-app-care-studio/

In order to complement the material, two videos were selected to set the context of a company whose business model is centered on "knowing everything". The fictitious company, The Circle, was used as a set up for the real focus of the case, Google Health. Parallels were drawn between the two companies, illustrating the highly invasive practices of the fictional company as a way in to exploring issues around surveillance, privacy, consent, data aggregation, data ownership, extractive business models and the ethical questions raised by all of these practices.

The remainder of the case presentation focused on Google's healthcare division, starting with the story of how Google entered the healthcare industry, exited it and then recently reentered the space. Google may have initially been too early to the space as there was not enough market demand for patient access to data records in 2006.

However, Google has now "doubled down" on a range of investments, acquisitions and expansions into the healthcare space, pushing the boundaries of what constitutes healthcare data. This has accelerated in 2021, with a number of new projects.

Yet, all of this is not without controversy. Should a private company whose reach is so vast in terms of consumer goods and business to business infrastructure, also be working within the healthcare system? Google is trying to position itself as both a portal for physicians by aggregating electronic healthcare records, as well as it's original ambition of being the "go to" portal for patient data.



Google and Privacy

- **Google's culture of secrecy:** Google is protective of its company privacy but wants to know everything about you.
- **Single Privacy Policy:** How does Google think about data? Is it all the same?
- **COVID App:** Android phones were found to have a privacy vulnerability with certain pre-loaded apps

Finally, Google itself is shrouded in a veil of secrecy, even as it advances its data collection practices into virtually every realm. It's interesting to consider how Google's culture informs its views on privacy, data protection and data ownership. Themes that were touched on throughout the day were brought forward as part of the questions that each breakout group was asked to explore.

Following the delivery of the case, our facilitators hosted three breakout sessions. The notes from these sessions. The whole group was then brought together for the final closing session to share major takeaways.

QUESTIONS

Medical Scan Data

- Is scan data different from other data? If so, how is it different? Does it deserve different protections or to be treated differently?
- What is the role of context when it comes to the use of medical scan data?
- Should there be different guidelines for creators to use this data?
- It is possible to make powerful VR experiences and print 3D models with our own data and the data of loved ones - should we not be allowed to do that with our own image data?

Data and Patient Rights

- GPR advocates that patients have access to their data - would this mean they could manage their health record?
- Does health data belong to the patient, to the health care system or entity that generates and stores the record?
- Who should control health care data?
- Should it be a human right to be allowed to delete data?
- Circling back to our first presentation by Dr Dr. Remigius Nwabueze this morning, what should happen to all this data when we, or our loved ones die?

Privacy and Consent

- Is getting better healthcare a reasonable tradeoff to give up privacy?
- Does getting better healthcare have to come with a tradeoff of privacy?
- Even though Project Nightingale is legally acceptable given current regulation, is there an issue with it from a patient data perspective given Google's involvement? How might it be a problem? How might it be a benefit?
- What does meaningful consent look like?
- Who decides what kind of information is shared? I
- s there a duty to explain potential harm to patients when they are given data?
- Should this be part of our school curricula? To teach children about all the kinds of data they generate and how they can be responsible for it?

Private vs Public Interests in Healthcare

- What are the implications of having a private company like Google Health control health care data?
- Thinking about a Canadian context - what aspects of this scenario may or may not be applicable? Would our inter-provincial public healthcare system protect us from this type of scenario or not?
- Has the introduction of virtual care changed how we think about health care delivery and data in Canada?
- Has virtual care opened the door to more private health care delivery?

SUMMARY OF GROUP DISCUSSIONS

Privacy and Consent (Facilitated and reported by Chelsey Campbell)

- Is getting better healthcare a reasonable tradeoff to give up privacy?
- Even though Project Nightingale is legally acceptable given current regulation, is there an issue with it from a patient data perspective given Google's involvement? How might it be a problem? How might it be a benefit?
- What does meaningful consent look like? Who decides what kind of information is shared? Is there a duty to explain potential harm to patients when they are given data? Should this be part of our school curricula? To teach children about all the kinds of data they generate and how they can be responsible for it?
- One possible benefit with Project Nightingale and creation of a public health record is that it could feel less opaque and give a sense of ownership over the data.
- Better healthcare for whom? Is it universal healthcare? Universal benefits are often utilized to benefit one specific group.
- There is potential for benefit but will they be abused?
- What happens when ethics impede a commercial, capitalistic drive? Can they actually impede this capitalistic drive?
- This healthcare system is limited to a specific "westernized" healthcare system.
- What bias is being codified into the AI health systems? The questions around BMI.
- There needs to be a reciprocation of the ways of knowing — a colonial acquisition of knowledge.
- There is no guarantee that this will lead to better healthcare outcomes. Which communities will choose to opt-out due to the history of eugenics?
- What does it mean when we are receiving information in absence of interpersonal care — there is a real benefit with one on one human contact, especially as it relates to sensitive data and health outcomes. Does this establish a two-tier medical system?
- What data can be anonymized when the data is aggregated? Is there any actual privacy? (No)
- Data custodianship vs data ownership. Google doesn't have custodianship, they have no responsibilities to the user, there's no mandate to act in the public interest.
- There is an ethical duty to explain data. Meaningful consent is making it plain-language, transparent, and understandable. In User Agreements, the only option is opt-in or opt-out — there is no ethical consent if there is no real choice presented. A staged opt-in consent option could be helpful.

Data and Patient Rights (Facilitated and reported by Fahim Hassan)

Key themes from the discussion:

- In general patients should have access to their own data (depending on their mental state). Rights can be extended to immediate family members and caregivers.
- "Data Rights" is a moving target. The concepts evolved over time. Now we are in a time where data is being commodified. We need to rethink and redefine the rights.
- Consent, access to data - these are all moving targets. As new technologies become part of our everyday lives, we need to revisit these definitions/rules/legislations. Technology is changing rapidly whereas legislation/regulation is struggling to keep up.
- The trade-off between convenience of free use of applications vs sharing data with private companies is becoming a "Double-edged sword". As users we enjoy how easy it is to use various applications with a click but then we are voluntarily sharing a lot of information, including

health data, with private companies.

Key questions that were discussed during the session:

- What exactly is Healthcare data? What does it include? What is the scope?
- What is the history of privacy (in the context of healthcare data)?
- We are constantly asked to provide consent on data collection. How can we even make better decisions about providing consent?
- What is the role of government and health organizations in protecting the privacy rights of the patients/citizens?
- What are the near-term solutions? What can we do about these issues?

Other topics/miscellaneous threads:

- China and its role in citizen surveillance - briefly mentioned. Didn't get a chance to unpack due to lack of time.
- Future of data rights - role of government in protecting health data from being sold/exchanged but shared for research (didn't get a chance to explore how can it be enforced or what would the process look like).

Potential solutions:

- Long-term: Literacy and awareness among people. Create a sense of urgency and advocate through public interest groups on data rights.
- Short-term: Leveraging technology. For example - using applications such as SkritSwap . Its strength is summarizing information in large texts for quicker consumption. Similar technology can be used (with caution) to have a better understanding of the terms and conditions.
- Another idea is to create "smart" contracts with easy-to-understand explanations for the users (similar to the web cookie policies in UK). (Fahim - to simplify things, how about including a check box that says do not sell my data to any third parties).

Conclusion

Overall, great discussion on the data rights. Majority of the conversation was focused on the challenges associated with lack of active consent and transparency on data rights. Ran out of time before the participants started discussion on medical scan data.

Medical Scan Data (Facilitated and reported by alissa rossi)

- No one had firm opinions on these issues, but several people expressed suspicion about who owns the information, especially with health info and particularly with how someone could own health info and have control over it (this might have been in particular when the "ownership" falls to an entity that is not the person whose body produced the information, but that was not explicitly said).
- The idea of the commons came up and the idea that healthcare is a universal right and perhaps health info should be seen as a commonly held set of data and in that case, there would be no ownership (but then no ownership over the developments made from it either).
- Does privacy actually matter? When does it matters? There was a comparison to public recordings where there is no expectation of privacy in the public realm but that very private information can be disclosed in public spaces and recorded.
- The idea of the commons again but discussion about how who uses the data and what the intentions of that use affects how data should or could be handled/treated.

- The commons should not be a default and that there are lots of ways to have data accessible but privacy maintained.
- Individual situation where someone would be willing to give up privacy for access or in exchange for care—this was not meant as a case of access predicated only on giving up information but that in the course of care, private data would be willingly given up to improve their care. Discussion of the altruism of providing data as a way to improve the health of people in general; discussion shifted to the problems in user-pay healthcare where data is being extracted (legally, knowingly or not) and commercialized.
- Two problems were identified: that consent should be limited (ie consent should expire at some very well defined point and should be limited to very specific uses); and that the exchange of privacy for care must also provide protection.
- For medical scan data specifically: it might start as diagnostic but there is a culture in some places where patients actively seek diagnostic scans that are not necessary and there is pressure for doctors to provide scans not for diagnostic reasons per se but as far as liability for not catching a diagnosis, or just keeping their patients happy.
- The needs of the individual or the community vs the commercial objectives of the corporation/institution.
- Facebook's Oculus and the fact that you cannot opt out of providing data if you want to use the VR; there was then conversation about when privacy is important (a person may need health care; a person doesn't need VR) and that maybe that exchange is not as important.
- Discussion then turned to capitalism and how the monetization of health is a huge problem and how it impacts privacy and control over one's own data but also the differences that exist between societies that are individualistic compared to ones that are communal, and also communities that are wealthy and ones that experience much more poverty and reduced access to health care.
- Discussed the imbalance between healthcare professionals and patients or donors; patients/donors might not fully understand how their data might be used while healthcare professionals have an obviously deeper understanding of the medical uses; also an imbalance between individuals giving up or keeping their privacy vs the corporations and what the value of privacy is to an individual vs the value of the data to the corporation.

Analysis

In many ways, the workshop raised more questions rather than providing concrete answers, which was expected. However, it also offered some clues with respect to directions to investigate and that was a key purpose in hosting these scholars. These are a few observations and questions that can feed into the next step in the process:

- Medical scan data is pretty much always a secondary use of data scenario as it pertains to artistic creation. Medical scans are typically obtained by a person in order to address a healthcare issue or medical problem. The equipment needed to provide a medical scan is part of a healthcare system. Artists are not, for the most part, doing their own data collection process of medical scan data.
- If an artist/creator obtains medical scan data, it will either be an aggregate, anonymized dataset or data submitted by individuals who have provided informed consent about the data. Typically, the individual consent in the former scenario is gathered by the researchers collecting the medical scan data. However, is there traceability of data curation for creators to ensure

that the purpose for which they will use the secondary data is acceptable to the individuals represented in that dataset? How can consent be reobtained by the secondary data user in a practical way? Data traceability can help to link context/purpose to consent, rather than just a blanket use of data.

- There are varying degrees of legal protection surrounding medical scan data depending on the jurisdiction. What does this mean when artistic works are shared across boundaries (ie on the internet) giving access to people in different countries)? Should data used within artistic creation be governed more like film rights in order to keep data "safe" within a particular jurisdiction? Or does that place an unnecessary restriction on artistic creation?
- Current REBs view consent as a one-off occurrence (as the study is approved), but in Dr. Cox's guidelines, she talks about consent as an ongoing process of negotiation. This also came up in the workshop. It might be important to consider consent as a process in the context of the guidelines and then discuss what the process might look like.
- Traditional approaches to ethics in a western context centre on the individual's rights/values (ie individuals values around autonomy, beneficence, non-maleficence, autonomy) with consent given by an individual. What are the limitations to this model? Is there a role for collective rights, collective consent vs individual and what might this look like?
- Is there a parallel between the human ingenuity that creates a new, patentable, biological tissue entity from "raw" human tissue and the human ingenuity that uses medical scan data reinterpreted to create a new work?
- Traditional approaches by REBs focus on protecting individual research subjects from physical or psychological harms. There is a sense that if a person has anonymity that their identity is sufficiently protected, however with increased data aggregation, guaranteeing anonymity is becoming more difficult. Is it more transparent to say that anonymity cannot be protected, thus if content is given, could there also be consent to use a person's name/identity? This is a radical departure from traditional approaches.
- Should medical scan data from deceased individuals be given the same rights/protections as that of a living person? What rights should family members have (if any)?
Should the medical scan data of vulnerable people (children, those who cannot consent) ever be used for artistic creation?
- If commercialization is involved, how does that change the nature of using medical scan data in an artistic work?

LIMITATIONS

The workshop was highly successful both in terms of attendance and it met the organizers objectives to share critical perspectives on the issues from a range of scholars. Given the vastness of the topic and the amount of dense information presented, even a full day workshop felt insufficient to fully engage with participants on these complex issues. We would have liked more time with participants. Also, hosting the workshop at the end of a long day meant that fewer participants stayed for the breakout sessions. Those who did participate were very engaged and we had a good discussion, but it would have been nice to have more participants for this session.

Artful Provocations

During the breaks 'artful provocations' were streamed for the participants, both as a way to demonstrate how the KTVR software tools are being employed and also to offer different ways of seeing and thinking through the issues being discussed. The artful provocations were screen capture videos of the virtual reality artworks that are currently being made as part of the project, My Data Body (one with sound by Scott Smallwood and Stephen Moore and another without sound showing different interactive elements and Your Data Body).

My Data Body VR Project (Work in Progress)

My Data Body has at its centre a high-resolution volume rendered full body MR scan dataset that viewers can enter into and explore. Embedded into this semi-transparent, virtual body are other data corpuses downloaded from Facebook and Google. These textual data corpuses are plotted into cross sections of the body. In the horizontal (axial) plane, Mac terminal data is plotted into bone, Google data into muscle and Facebook data into fat. In the vertical (coronal) plane are plotted data usage agreements and into the depth (sagittal) plane are theoretical texts about virtuality and privacy in the digital age.

The viewer can pull out these cross sections and read them, once they let go the cross sections float away but ultimately and uncontrollably return to the scanned body. Passwords and logins flow back and forth through veins and arteries and hashtags pool in organs. Certain organs can be pulled out of the body and 'drawn with': the heart leaves a trail of emojis and the brain a trail of login pop-up windows demanding usernames and passwords. The medically scanned, passive/obedient semi-transparent body becomes a data processing site that can be pulled apart and dis'organised'. The whole body/data processing site finds itself at the centre of a data cloud generated from social media data.

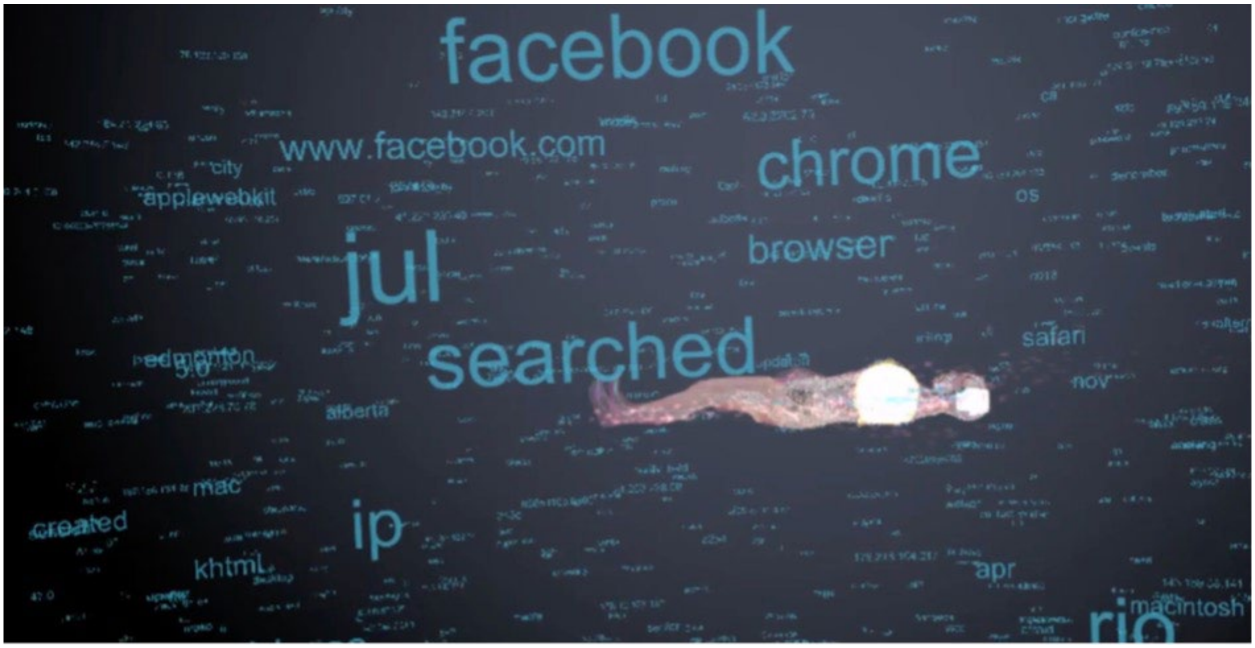


Figure 6. Screen capture of My Data Body project showing scanned body in a 'data cloud' generated from Facebook data

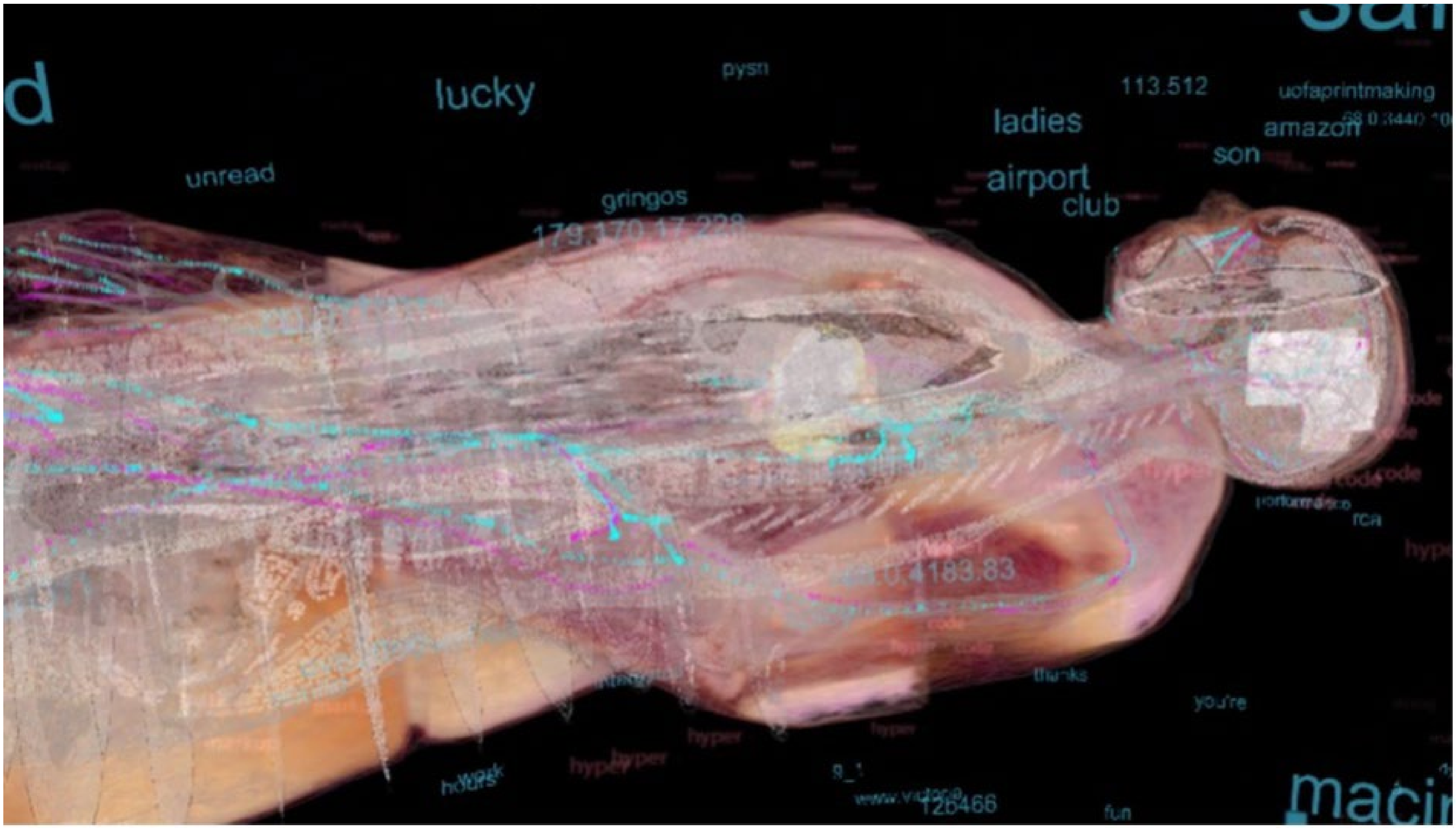


Figure 7. Screen capture of My Data Body.

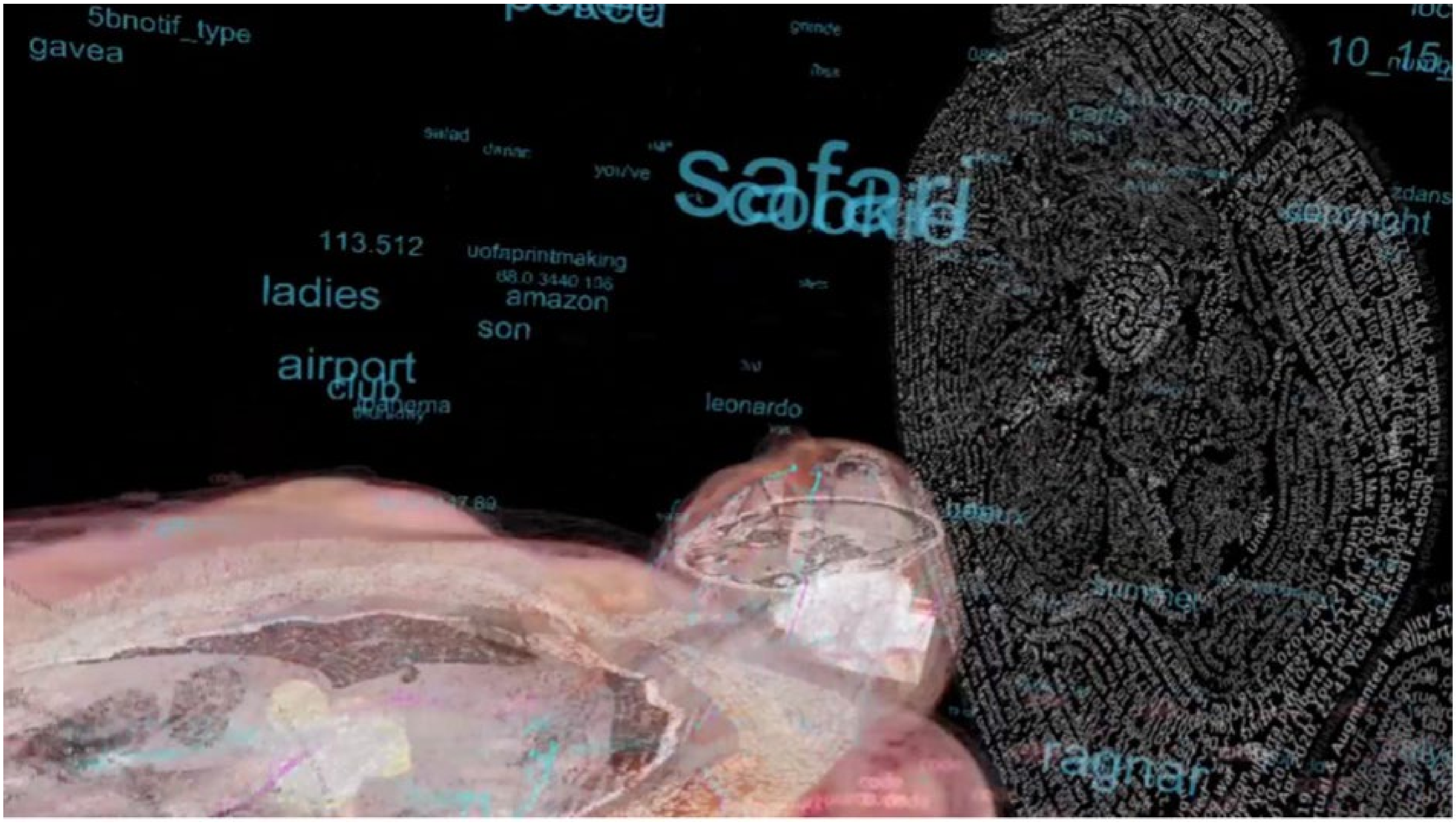


Figure 8. Screen capture of My Data Body showing cross sections of the body made of Facebook, Google and Mac terminal data.

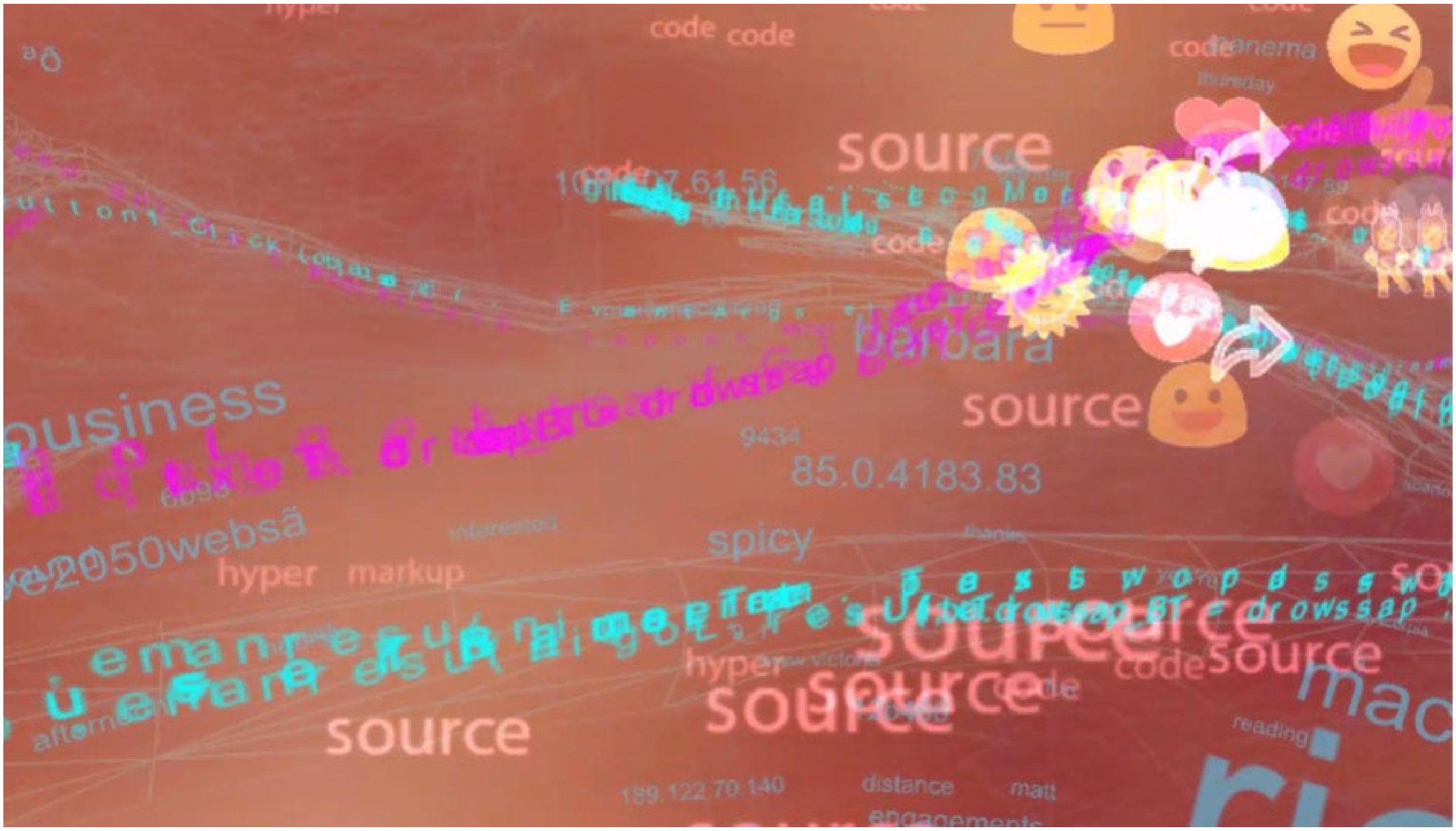


Figure 9. Screen capture of My Data Body showing programming code to call and receive login and password information flowing through veins and arteries and emojis being generated in the heart.

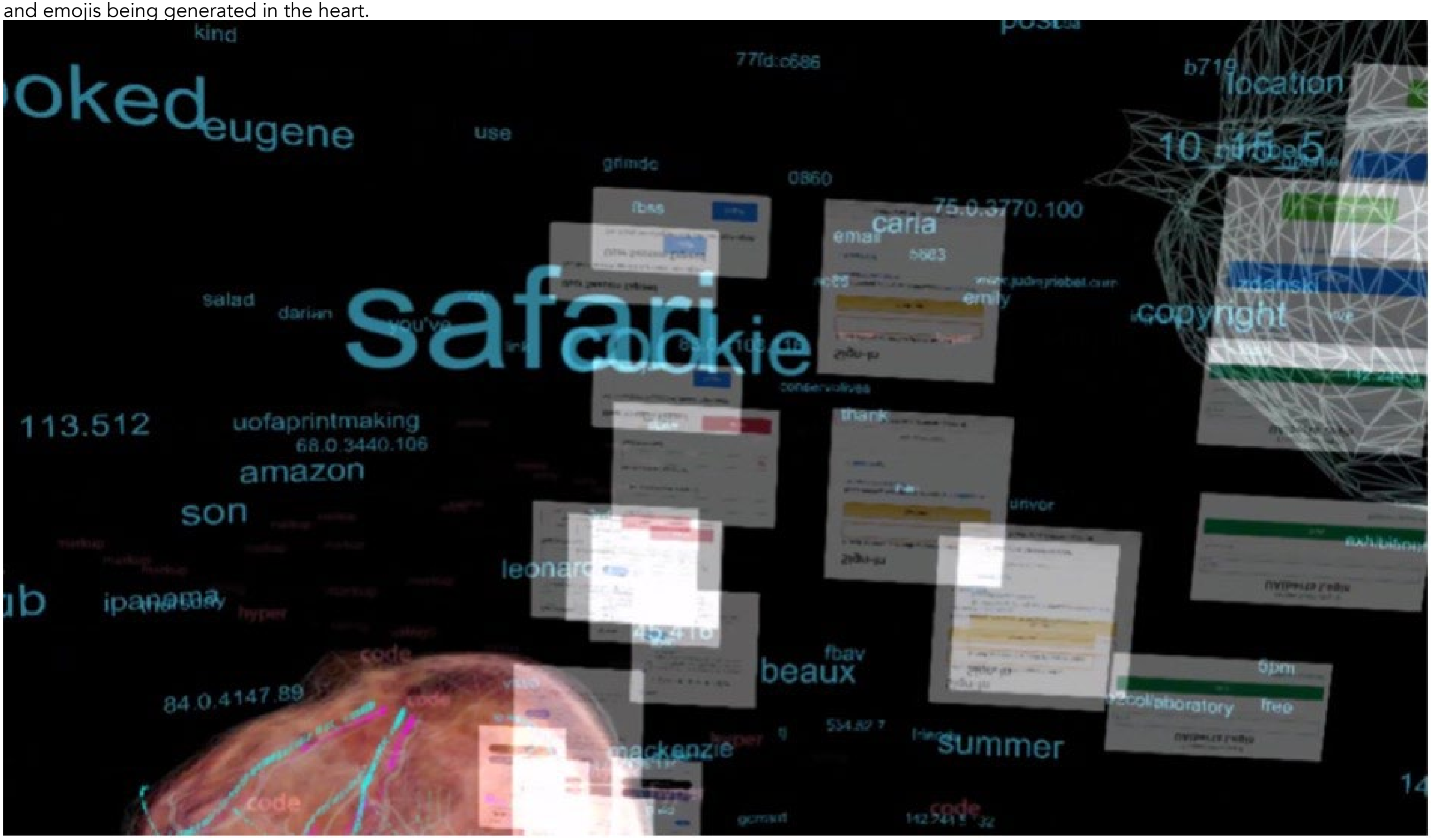


Figure 10. Screen capture of My Data Body showing login and password pop-up windows being stored and generated in the brain.

YOUR DATA BODY VR PROJECT (WORK IN PROGRESS)

Your Data Body is a partner project to My Data Body made using a combination of open source and donated datasets. This project focuses on issues of data privacy and ownership, playing on the etymology of the word data meaning 'given'. The user can pick up and move datasets around. The scanned body parts can resized and re-colored, inviting a playful stacking of the body parts to make a whole Frankenstein-like figure. Attached to each body part is an audio file which is triggered when the user holds and manipulates it. Anonymized open source datasets are accompanied by an automated voice which reads the study data published alongside the dataset, whereas the donated datasets will have different conversational AI characters/chatbot that the user can 'discuss' different issues relating to data ownership, privacy and virtuality with.

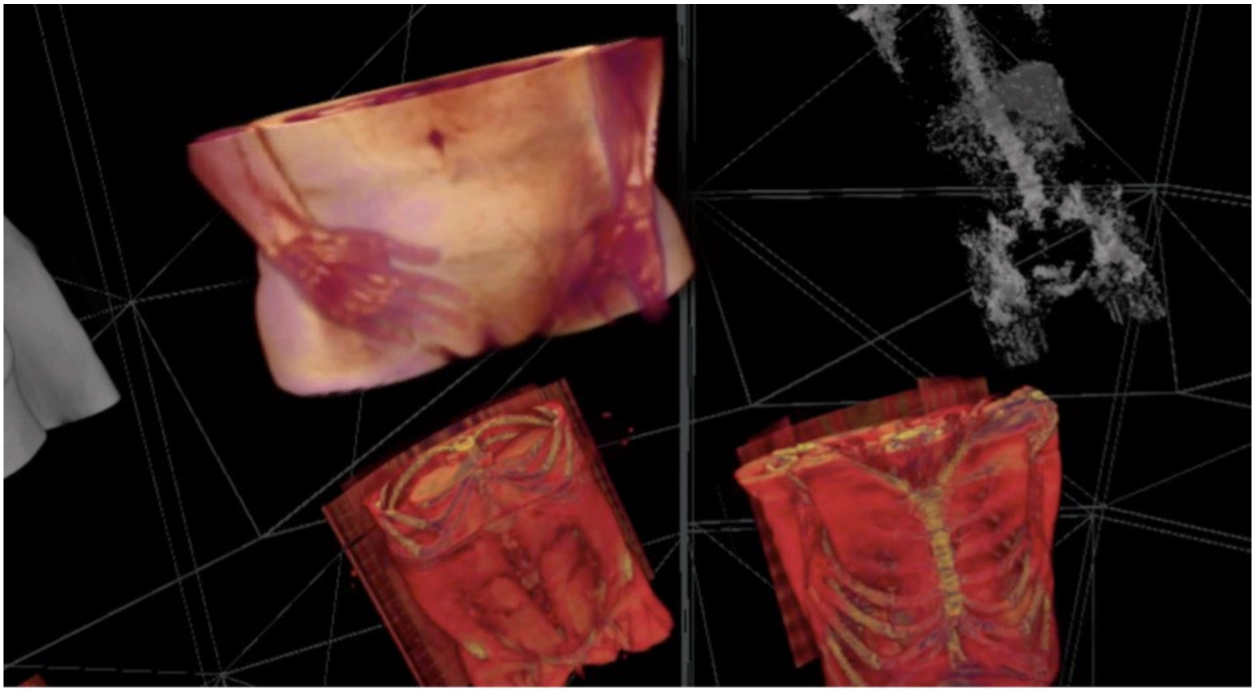


Figure 11. Screen Capture of Your Data Body.

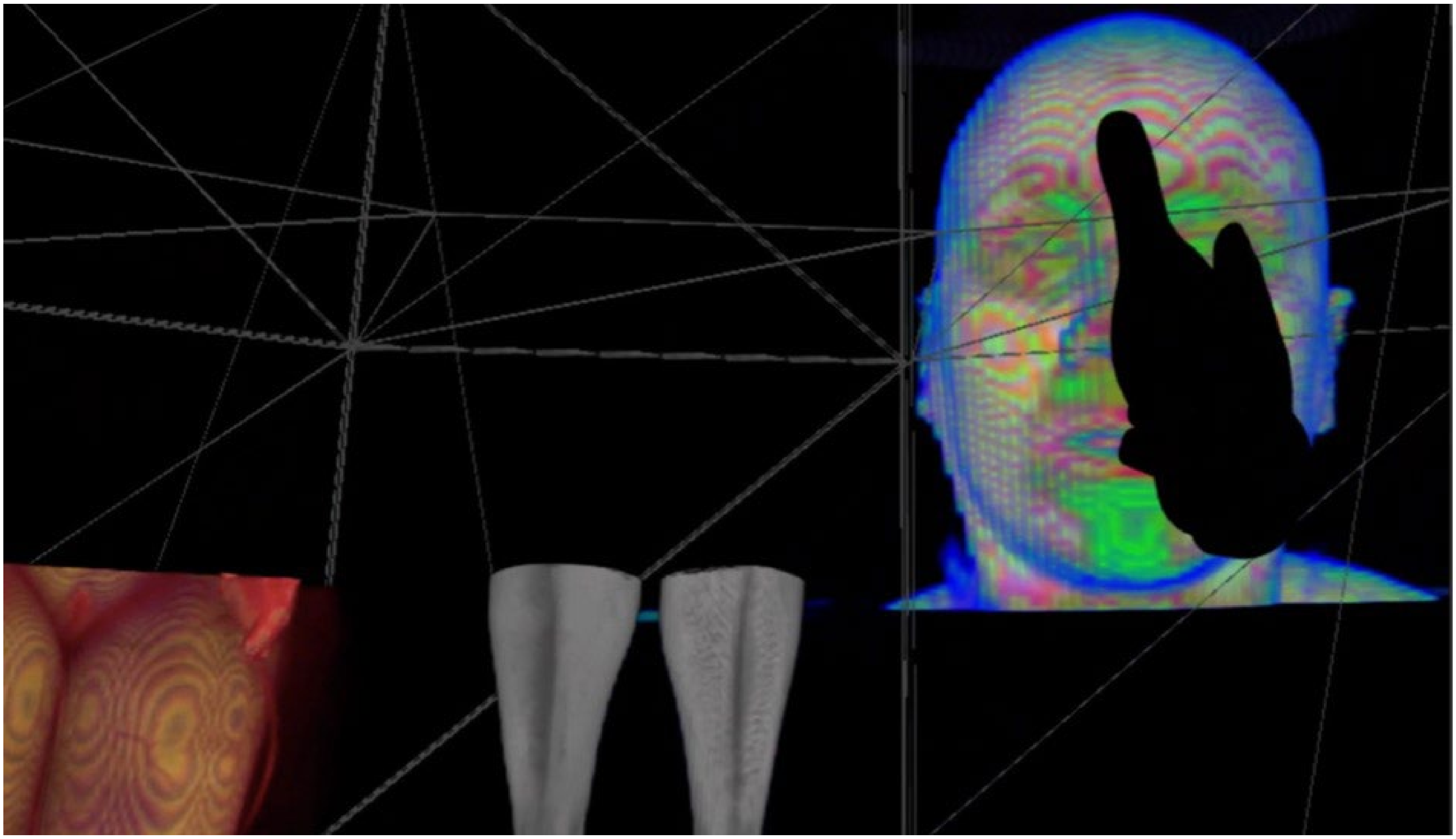


Figure 12. Screen Capture of Your Data Body showing a head being picked up.

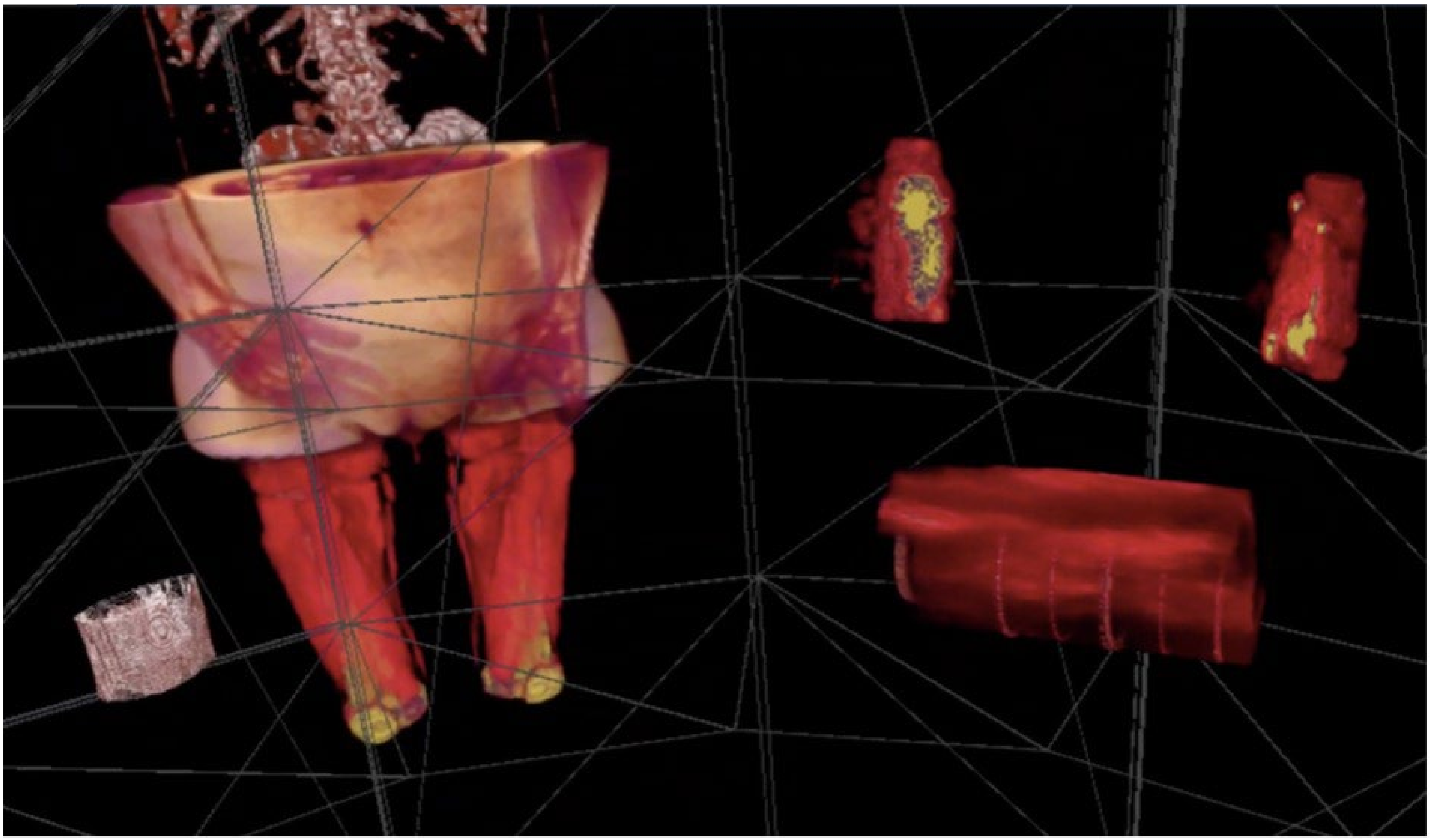


Figure13. Screen Capture of Your Data Body showing the body parts being stacked.

CONCLUSION AND FINDINGS

Overall, the e-symposium provided an important opportunity to hear from leading scholars about the legal issues related to the use of healthcare data as well as ethical best practices for visual data methodologies.The afternoon workshop session on emerging issues related to facial recognition technologies and the aggregation of data by large corporate entities, showcased some of the current and emerging challenges for researchers in using big data. The afternoon session also spawned a fruitful discussion and those notes will be further analyzed as part of the next steps in the project. The overall proceedings from the day will be valuable input into the development ethical guidelines for the use of medical scan data in an artistic work.

FURTHER WORK

We recognise there are many other ways to approach data ownership and protection that have not yet been addressed by KTVR such as Ownership Control Access and Possession (OCAP), a tool that helps researchers understand First Nation principles of data collection, protection, usage and sharing. We will continue to review guidelines from related fields and keep abreast of the shifting and evolving technology both through secondary research and by inviting guest speakers to present to the KTVR team (and sharing these presentations on the KTVR website and ERA repository). In the short term we will be producing and synthesized and condensed set of ethical guidelines that are easy to read and digest, much like Cox et al's Visual Research Ethical Guidelines. Longer term we will also conduct a series of interviews with a diverse range of artists and creatives working in this field to find out how they approach the ethical issues arising in their work.

BIOGRAPHIES

Dr. Remigius N. Nwabueze is an Associate Professor of Law at the School of Law of the University of Southampton, UK. His primary areas of scholarship are the legal regulation of the biotechnological utilisation of human body parts and dead bodies; the ethical and legal regulation of biomedical research involving human participants; and equity and trusts law. He is the author of numerous journal articles and the books and his works have been cited by the US Federal Court of Appeals (2nd Circuit), Nigerian Court of Appeal, the Federal High Court of Nigeria and the High Court of Kenya.

Dr. Ubaka Ogbogu is an Associate Professor in the Faculty of Law at the University of Alberta and a Pierre Elliott Trudeau Foundation Fellow. Ogbogu's research interests are in health law, public health law, science and health policy studies, law, bioethics and biomedicine, and the legal history of public health and health care. He is particularly interested in the points of confrontation between ethics, morality, economics and law in relation to the governance of novel and controversial health care technologies.

Dr. Susan Cox is an Associate Professor in the W Maurice Young Centre for Applied Ethics and the School of Population and Public Health at the University of British Columbia in Vancouver, Canada. She is sociologist and ethicist and is Director of the MSc and PhD programs in Population and Public Health. Her current research employs arts-based and qualitative methods to understand and represent lived experiences of health and illness (such as dementia) and to identify and explore challenges in graduate supervisory relationships especially as these relate to inclusivity and diversity. Susan is also keenly interested in research ethics and brings a critical lens to identifying potentially troublesome aspects of arts-based inquiry. With colleagues in Melbourne, she developed Guidelines for Ethical Visual Research Methods (a free online resource available at https://vrc.org.au/), co-edited a special issue of Visual Methods on ethics and collaborated on the book Ethics and Visual Research Methods: Theory, Methodology, and Practice, published by Springer in 2016. She is currently collaborating in the development of ethical guideposts for research-based theatre.

Fahim Hassan is a Ph.D. student at the School of Public Health at the University of Alberta. His research interest is to study the application of machine learning in public health surveillance, risk communication and health promotion. He is also currently working at the Ministry of Advanced Education at the Government of Alberta. As a civil servant, he has contributed to various government initiatives on open data, social determinants of health, and health informatics. In addition, he is serving as the Vice-chair in an advisory council member for Alberta Health Services in the Greater Edmonton Area. As council member, he works with local communities on health promotion activities and shares their voices to healthcare service providers.

Katrina Ingram recently completed her Master of Arts at the University of Alberta with a focus on Communications & Technology. Her research is in the area of Artificial Intelligence, ethics and healthcare. Since completing her degree, Katrina has founded a company called Ethically Aligned AI which is an extension of her graduate research and aims to help companies build better AI. Katrina has previously held senior management roles in media, technology and the cannabis sector.

Walter Ostrander is a 3rd year Computer Engineering CO-OP Student from Jasper, Alberta with a love for the outdoors. Walter is currently working on the Know Thyself as a Virtual Reality project as a software developer.

alissa rossi is an MFA candidate at the University of Alberta in Printmaking focussing on colonization as an imaginative occupation of land. They have an MLIS from McGill University and BFAs from UBC (Creative Writing) and Concordia University (Printmaking). They previously worked in public and health science libraries in Vancouver and Montreal. Their interests in libraries focussed on issues of privacy and access, institutional memory and knowledge retention and the ways that changes in technology impacted how these issues should be addressed. Their work with Know Thyself as a Virtual Reality looks at how issues of ethical practice and privacy on the local level are complicated by a digital interconnectedness that does not observe political boundaries.

Erin Ratelle is a PhD student in the Faculty of Kinesiology Sport and Recreation at the University of Alberta, Canada, specializing in sociocultural studies. Her research interests include the intersections between sport, physical activity, health, and technology from a post-structuralist perspective. Her current projects include Falls Prevention in Long Term Care using Wearables and Algorithmic Bias in Fitness Self-Tracking Applications. Erin is a competitive cyclist, runner and former representative for Team Canada at the Duathlon Age Group World Championships. Erin takes her experiences in sport and recreation to advocate for women's and youth cycling and the development of cycling infrastructure in her community.

Dr. Scott Smallwood is a sound artist, composer, and performer whose work spans from acoustic concert music to interactive installations. Dr. Smallwood is currently working on Lost Garden, sound-focused VR game for which he is developing ambient compositions to be experienced in virtual reality. He also has expertise in field recording and interactive sound.

Marilène Oliver is Assistant Professor of Visual Art at the University of Alberta in Edmonton. Her work is at the crossroads of new digital technologies, traditional print, and sculpture. It focuses on producing objects that bridge the virtual and the real worlds. She uses medical scanning technologies such as MRI, CT, and PET in works that allow us to materially contemplate our digitized selves. She has exhibited internationally, at the Royal Academy in the UK, the MassMoCA in the US, and the Copernicus Museum in Poland. Her work is also held in a number of private and public collections around the world. She leads LASERAlberta, a series of Arts-Science public talks affiliated with Leonardo ISAST.

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