DONATE YOURSELF

an AR trail exploring the future of organ, tissue and body data donation

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1. INTRODUCTION

Donate Yourself is an Augmented Reality (AR) experience that blends sound and 3D visuals with non-linear narrative to spark debates about our organs, tissue and body data. It was created through a year-long collaboration with interactive design collective body>data>space and scientists from the Human Cell Atlas project (HCA). The HCA is a multidisciplinary scientific research project that aims to map the function of all 37 trillion cells in the human body. This international consortium involves 2,000+ researchers from over 75 countries. The project was one of four larger commissioned works by *One Cell At A Time* (OCAAT), a public engagement programme which brought together communities, patients and researchers to build the HCA. Funded by the Wellcome Trust and led by the Wellcome Sanger Institute and Project Curator Dr Suzy O'Hara, with Newcastle producer Dr Dominic Smith. The OCAAT programme had a total reach (from July 2020 to December 2021) of at least 7,047 in person and online engagements. OCAAT had two key strands. Some of the programme explored *"what it is to be normal?"* while Donate Yourself, among other outputs, focused on *"what influences peoples' value and trust in research involving tissue donation and open access data?"* Donate Yourself AR was collaboratively created by Dr Stacey Pitsillides (*Creative Co-Direction and Design Research*), Ghislaine Boddington (*Creative Co-Direction*), Tadej Vindiš (*Project Development and Production*), Dr Nick Rothwell (*Sound Design and Technical Development*) and Ivor Diosi (*AR Development and 3D Animation)*. With research interviews and insights from Dr Holly Standing and Luke Sellers.

2. ORGAN DONATION AND COMMUNICATION

Organ donation has been at the centre of a range of recent communication strategies across the UK. These strategies have shifted since the UK's change of law in May 2020, which moved from 'opt in' where people needed to register as an organ donor, to 'opt out' where registration is automatic. Advertising campaigns aim to inform and persuade UK publics of the importance of organ donation, bearing in mind that there is a shortage of organs for transplantation. Most campaigns centre on a the key simple message that *your organs could save a life.*

Figure 1: *'Kill Jill' Scottish Government: The Union agency, 2009 (left) NHS Blood and Transplant campaign: The Marketing Society, 2010 (right)*

Recent examples include a hard hitting 2009 TV campaign *Kill Jill*, where the viewer is placed at the centre of an ethical quandary where Jill glitches, fading into a dark background. The viewer has 20 seconds to save her life. While the NHS Blood and Transplant 2010 campaign used a central persona back-to-back with their alternate selves in a hospital gown considering their past choices. Both campaigns focus on influencing personal decision making, including a call for action – to register as an organ doner.

'Pass it on' was a campaign created for the change of law. It portrays organ donation as a gift in an immediate and visual way, with a red and blue colour palette, reminiscent of the NHS. The surreal representation of organs as balloons shifts the campaign from dramatic decision making to a dreamlike landscape (particularly in the TV advert).

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This approach is softer than previous examples, reflecting the new law where no action is needed to be an organ doner.

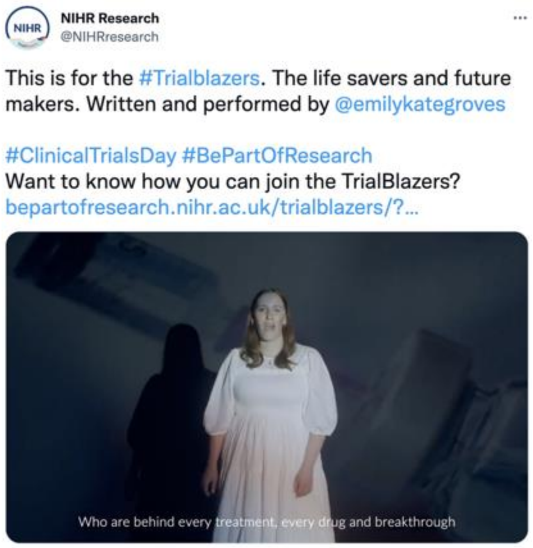
***Figure 2:** Year-long NHS organ donation and law change awareness campaign called 'Pass it on' (2019 – 2020)*

UX design has also been employed by the NHS in 2021 to bring educational conversations about organ donation to younger audiences (ages 16-20) via snapchat. Using an Augmented Reality (AR) lens it shows users infographics about which organs can be donated.

***Figure 3:** NHS partner with Snapchat to create organ donation filter. OmniGOV at Manning Gottlieb OMD 2021*

2.1 Covid-19: Shifting Narratives of Scientific Research and Open Data

Body donation, or the donation of tissue and body data after death for education, scientific and medical research, has been far less widely discussed within public forums. One notable exception is the 'Trailblazers' campaign which used the momentum and emotion linked to the pandemic to encourage people to take part in clinical research calling them "selfless" "everyday heroes."



NIHR Research
@NIHRresearch

This is for the #Trialblazers. The life savers and future makers. Written and performed by @emilykategroves

#ClinicalTrialsDay #BePartOfResearch
Want to know how you can join the TrialBlazers?
bepartofresearch.nihr.ac.uk/trialblazers/?...

***Figure 4:** NIHR Research campaign to raise awareness about clinical trials via poetry and performance, 2022*

The *Trailblazers* campaign presents a singularly positive message, whereas *Donate Yourself* aimed to open up debates (including concerns and fears) about donation for research. As *Donate Yourself* is not a campaign but a publicly accessible piece of AR interaction design it set its debates against Covid-19 as a critical framework, exploring:

[1] the role of scientific research and the value of being part of scientific research. During Covid-19 scientists became key UK media figures, from the regular briefings with Deputy Chief Medical Officer Jonathan Van-Tam to Dr Chris Smith and Professor Linda Bauld answering vaccine questions on BBC Breakfast. The first person to receive the vaccine was televised but there has also been intense public and media scrutiny around vaccine hesitancy and health misinformation

[2] a period of reflection on death, bereavement and illness. The multitude of stories of people dying during the pandemic has challenged us to consider the role of illness and death talk in our lives (Puri, 2020), alongside this it has led to a re-evaluation of technologies that have shaped our experiences of death during lockdown e.g. virtual memorial and funerals (Pitsillides & Wallace, 2022)

[3.] Data security and privacy of body data have been highlighted. Private medical and location data are regarded by the public as the most personal kinds of data, but this data can be made vulnerable

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through contact tracing apps and vaccine passports (WHO, 2020).

Donate Yourself was released Nov 2021 in the midst of these three powerful meta-narratives that make room for us to consider the space and role of our bodies in society, along with our personal / collective legacies post-death.

2.2 Donate Yourself: Aims, Recruitment and Communication Strategy.

Across the One Cell At A Time programme there were pre-planned points of online exchange between the artists and scientists via a series of Art / Science Salons. These Salons allowed the artists to explore the wider themes of their work with HCA members and exchange knowledge in relation to HCA members own scientific and clinical research. This led the Donate Yourself team to centre on a participatory design (Bannon & Ehn, 2012) strategy for developing the central AR experience, which included 4 design workshops, alongside a series of in-depth interviews with HCA members (April – June 2021) with ethical approval granted by Northumbria University. Collectively, they aimed to identify key thematic and visual anchors that could be developed into a non-linear narrative exploring themes of value and trust in research involving tissue donation and open access data. Desktop research was used to compare and reflect on the context, alongside exploring how debates on tissue donation have shifted across time. With the central research question – can Augmented Reality be used to open debates on who has access to our biological and digital traces beyond death?

The recruitment process included two distinct calls:

One that was distributed within the Human Cell Atlas membership which asked scientists to share their experiences of working with data and human tissue. Five HCA members were interviewed for 40 - 50 minutes. These included: an immunology and cancer biology specialist (S1), a researcher who collects samples and works with human tissue (S2), a Parkinson's clinician and researcher (S3), a data wrangler (S4) and an Emerita professor (S5).

And a second open call that asked people to share their views on donating body, tissue and medical data. This was sent to specific groups like Sunderland medical anatomy students, advertised at local digital arts events called Datarama and promoted on BBC radio Newcastle among others. As we were unable to recruit physically due to the design workshops being run during the pandemic, we used these diverse spaces to both promote and build trust in the research. Post kits were developed and sent to workshop participants as a means of engaging physically with the research and showing care during a pandemic, which aimed to support and structure online discussions. As the research touches on intimate and emotional topics of death and dying, the tone of recruitment and activities were particularly important, especially as we were not able to be physically with participants.

This participatory approach to developing the AR experience was guided by principles of Data Feminism (D'ignazio and Klein, 2020) aiming to open the work up to a plurality of voices with different levels of experience in donation for scientific research. Participants shared experiences of giving and receiving human tissue and body data, alongside opening up conversations about power structures and how these sit against the deep emotions that are connected to post-death donation, now and in the future. Data Feminism also underpinned the communication strategy which worked on finding a simple yet accurate approach to communicating the themes and concerns of participants into the AR artwork. Within this strategy AR was used as the medium to animate and embody this language so it becomes a felt experience, which is implicitly two-directional, opening a series of questions and provocations. Of the five compositions that create the Donate Yourself experience, only the AR piece FUTURE includes a gentle call to action in the spoken word composition – which ends:

Only you can choose.
As all others who have come before.

Donate Yourself;
invisible,
in cells,
in data,

but something carries on.
Into a distant future.

Figure 5 : *FUTURE, artwork 5/5, 2021, AR part of the One Cell At A Time hybrid exhibition.*

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2.3 Tissue or Sample – the Materiality of the Body and Identity

In contrast to organ donation for transplantation – tissue donation (and organ donation) for research lacks a simple tagline. Because although uncountable lives may be saved through scientific breakthroughs, this is often abstract and difficult to link to an individual's donation. The complexity of its communication is also due to the uniqueness of the scientific research being consented for, and the fact that this may be asked for at the time of death to next of kin. Science communication in this area is already challenging, but particularly when working within communities of scientists and members of the public, it is important to tackle the turbulent history of human tissue usage that addresses public values and trust:

> *“What [would Henrietta] think about cells from her cervix living on forever—bought, sold, packaged, and shipped by the trillions to laboratories… scientists had begun doing research on Henrietta’s children, but the Lackses didn’t seem to know what that research was for… her son… wanted to know if the immortality of his mother’s cells meant that he might live forever”* (Skloot 2010: 2)
>
> *“I always explain to a patient what their tissue will be used for … they might say, yes we’re happy [for you] to do experiments with the tissue, but we don’t want you to make slides that can be kept forever… [or] cell lines… that’s really important, the trust and transparency [but there are risks in] collaborations between academia and industry pharmaceutical companies … letting [them] get their hands on your samples”* S2 (2021), zoom interview. L. Sellers, 29 April.

These quotes showed the contrast of a scientist's approach to care in relation to consent in 2021, where the focus is on explaining the process of using human tissue, to Skloot’s account of the Lacks family members who did not receive any information about Henrietta’s cells being taken in the 50s, a time when black men and women were being used in scientific research often without their consent, including biopsies containing their cells being cultured and in the case of Henrietta made into the first immortal cells.

Even though ethical standards have improved, S2’s fears are more structural. She reflects on how commercialisation in her own institution may shift consent, through the sharing of samples collected by academics. Using the trust people place in academic institutions, she identifies a tension in the increasing reliance of some academic institutions on pharmaceutical funding where collaboration agreements can be put in place post-consent raising ethical questions about how data from samples may be used.

Henrietta Lacks is one of the few people whose tissue legacy, through de-anonymisation, can be linked to massive breakthroughs in scientific research – through the HeLa line of immortal cells. But that legacy is inextricably linked to the fact that at a time of segregation in Baltimore, the removal of these cells (among other malpractices) placed a deep wariness of scientists, medical practitioners and research in communities.

As potential doners of human tissue or data, we are asked today to put our faith in the ethical standards of scientists. But even people that are familiar with the benefits of tissue samples, like the scientists themselves or patients with incurable diseases, stated in our interviews and workshops that they find it challenging to consent when imagining parts of their/families bodies being removed and placed in a lab environment (S2, S4) or when being asked to consider donating specific organs like eyes or brains (S2, S3). They also question what will happen to this data in the future, with S4 stating that: *“even after your dead you still have rights to how your data is being used... we don’t actively [use] the data from living European donors or GDPR donors”* and how open data may shift decisions from personal to communal with S5 suggesting that: *“it’s a bit like creative commons I could be happy with it as long as any data being generated was then available to everybody in an anonymised fashion [and] … same as creative commons if I make a donation I expect the outcome of that to be donated as well.”*

One insight that kept cropping up and was discussed by the team as part of the AR visualisations, was that humans, at a cellular level, are often regarded as both human and non-human. This is most stark in the case of HeLa but more blurry for our contemporary scientists. This duality was expressed by reflections on the practice (of collecting and using human tissue). S3 for example, comments that when using a brain bank, if a whole brain is requested it has to be buried, whereas a few milligrams of tissue can be disposed of. This small distinction points to our concern over how we care for the dead, ritually and literally, and whether the dead can continue to engage with the living through their biological make-up as a part of a personal/ collective legacy?

Internally, the HCA comms also queried the *Donate Yourself* team on its use of two key terms. One was the use of the word **immortal** as the title of one of the AR pieces, which they believed could be misleading and controversial but as previously mentioned links into rich historic debates around the role of ethics and consent when collecting scientific samples of human tissue and therefore is an important insertion in scientific and public debates. The other was the use of the word **tissue** vs sample. S1 explored this distinction by describing themselves as a sample owner rather than an owner of human tissue. Stating *“tissue isn’t owned by anybody in that sense... tissue generates data and that data whenever we can, we make it open public access.”*

2.4 Participatory Research: Post kits / Online Workshops / Maker Jam / Zine

The participatory phase of the research aimed to weave interviews with HCA members and the four design workshops with the visual/written/spoken data that were collected from participants in the form of post kits and design probes. This data was thematically analysed using a reflexive approach (Braun and Clarke, 2022) and distilled, using key quotes to create the spoken word, sound briefs and concept art that underpinned the development of the five AR experiences.

Design probes are “objects that are usually small …[and] are designed to relate specifically to a particular question and context” (Wallace et al, 2013: 3441). They are particularly useful in helping people to breakdown complex and unfamiliar issues into simpler questions that can be answered visually or textually. Our design probes were developed into a post kit that could be distributed safely during the pandemic. They were designed using research into public attitudes of: biobanking (Locock & Boylan, 2016; Domaradzki & Pawlikowski, 2019) brain donation for Parkinson's Research (Harris, Kiger & Counsell, 2013) and cultural perspectives on organ donation (Sharp & Randhawa, 2014) among others, and were further developed through a workshop with HCA members. The kits aimed to ask a range of questions linked to personal identity and donation, on the row of paper people, and attitudes to scientific research in the circular prompts housed in a petri dish.

Figure 6: *Post kits: “Donate your body, bequeath your data” sent via request to groups and individuals.*

Our first design workshop engaged 12 scientists from the HCA membership online, using Miro to develop and shape the post kit (above) – additions directly as a result of the workshop included: a glossary and links to different kinds of donation, more explanation of data donation as a concept, and clarifying that one can choose what parts of their body to donate.

The second and third workshops were recruited via a public open call, 22 people were sent post kits, with a series of design probes as critical prompts to reflect on. Of these 9 agreed to take part in a 1-hour online workshop where they shared their thoughts as a group discussion, while one preferred to be interviewed. Participants came from a range of backgrounds including a graphic designer, retired nurse, medical student, an academic et al.

Figure 7: *one response to post kit prompts in petri-dish.*

Different views were shared in the workshops and field notes were taken due to the sensitivity of topics discussed. Pseudonymised quotes were documented in a Zine, for example: *“when I was younger I said I would donate everything but my*

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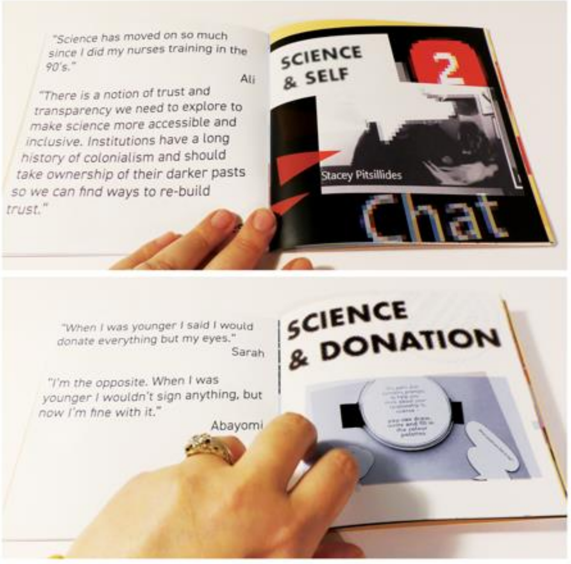
eyes” and *“I’m the opposite. When I was younger I wouldn’t sign anything, but now I'm fine with it.”*



"Science has moved on so much since I did my nurses training in the 90's."
Ali

"There is a notion of trust and transparency we need to explore to make science more accessible and inclusive. Institutions have a long history of colonialism and should take ownership of their darker pasts so we can find ways to re-build trust."

SCIENCE & SELF

2

Stacey Pitsillides

Chat

"When I was younger I said I would donate everything but my eyes."
Sarah

"I'm the opposite. When I was younger I wouldn't sign anything, but now I'm fine with it."
Abayomi

SCIENCE & DONATION

Figure 8: *This zine by Dominic Smith is a creative record of workshops for Donate Yourself.*

The fourth workshop was part of an online Maker Jam, organised centrally by OCAAT, which aimed to include members of the public in artist challenges, which for *Donate Yourself* focused on embodied and data mapping, which linked the Human Cell Atlas as a core conceptual guide.

Following thematic reflection, insights from both the participatory process and HCA interviews were woven into a collection of 5 short 1-minute spoken-word pieces that each focused on key themes: CARE, TRUST, IMMORTAL, CONSENT, FUTURE. These themes (that also became titles) were matched with bespoke sonic compositions, that aimed to immerse the viewer in debates overlaid with 3D compositions of organs/ cellular material onto environments using AR e.g. CARE became an unsettling image of eyes to explore the balance between care, identity and collectivism.

Figure 9: *CARE, artwork 1/5, 2021, AR part of the One Cell At A Time hybrid exhibition.*

3. VISUALISING DATA

Before embarking on the project the Human Cell Atlas was not familiar to us. Nor was the process of collecting and separating human tissue to be used in scientific research. However coming from design, media, and dance backgrounds the concept that data from human tissue can be transformed into a coloured dot on a collaborative and generative moving image was intriguing as an alternative form of collective legacy, reminiscent of early new media arts (Manovich, 2003).

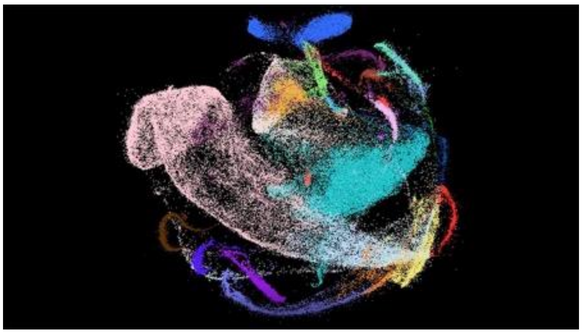


Figure 10: *Sanger Institute. Human Cell Atlas. The developing liver 2019: https://tinyurl.com/4bsz5xbk*

Donate Yourself used this as a starting point to reflect on the principles incorporated in the HCA project. To build an Atlas of cells that is open to being queried relationally and visually by scientists around the world. It allows the scientific processes

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to be discovery and taxonomy led, where you can see the connections between different cell types that give insight into e.g. how immune systems are developed, or allow for the comparison of how different organs are affected by disease (Human Cell Atlas, 2017).

3.1 AR Experiences

Dead bodies have historically been used in art and education. Historic imagery like memento mori by Andreas Vesalius' in 1543 offered a visual treatise on the human body (San Juan, 2012), using images of skulls and skeletons to explore themes of mortality. Cellular bodies offer a different gaze on mortality, humanness and altruism. Artistic works that inspired our visual exploration of cellular / human material perspectives include: Heather Dewey-Hagborg's *Spirit Molecule* which imagines a future of biotechnologized mourning, Gina Czarnecki's *Palaces* that explores body regeneration – as stem cells can be extracted from milk teeth. Combining science, magic and rituals. And Anna Dumitriu's body of work on *The Mutability of Memories and Fates,* which responds to the concept of cellular memory and cell fates, is another example.

Augmented reality (and specifically WebAR) was chosen as a medium for *Donate Yourself* as it allowed for the layering and bricolage of scientific imaging with artistic 3D models using a transmedia approach (McErlean, 2018). These AR scenes could be interacted with gently by scaling or turning the 3D models to see different angles that merged with material architecture and environments. Non-linear narrative was used as a technique to link spoken-word vignettes with atmospheric sonic compositions across five conceptual and geographical markers that can be experienced individually or collectively. The AR itself acted as a representation of how the scientist's move from physical tissue, extracted from the human body, to a map of data that can be used to find correlations between different genes or expressions of disease.

Figure 11: *AR walking trail,Ouseburn Valley, Newcastle Upon Tyne. 2/5 TRUST. Documentation films: Pitsillides, 2022*

During lockdowns many people found pleasure in the simple act of walking and feeling their bodies in the physical world. A 20-minute AR walking trail in the Ouseburn Valley, Newcastle Upon Tyne, aimed to provide thinking space between each stop, to reflect on key themes and questions. The scale, composition and positioning of AR elements – that present larger than life organs, cells bopping on the river and body data dancing in the sky – offered the viewer an artistic gaze on the scientific visualisations, aiming to situate themselves between human and non-human with the voice and sound emphasising an intimacy in the interaction. The signage was also used strategically to present aspects of the stories from interviewees / post kits which helped to ground the experience, giving a physical maker for the AR to be accessed by the public via QR codes, which had become commonplace during the pandemic.

Figure 12: *IMMORTAL, artwork 3/5, 2021, AR part of the One Cell At A Time hybrid exhibition.*

The use of WebAR via XR.+ platform was also chosen due to its wide accessibility, because people can use their own smartphones to access the experiences via the web browser app. However, this came with its own challenges. While in principle, the AR could be accessed by any smartphone that had a web browser, the real-time rendering of AR is limited to the age of the software and hardware specifications of the smartphone (those released after 2016/17) and to the available strength of the cellular network. Furthermore, on mobile phones that used an ad blocker some assets were treated as advertising and blocked and phones on silent did not play the audio track. Additionally, it was challenging for some users to disable specific security settings to see the AR experiences. To sum up, it is in the nature of such projects that technological incompatibility or malfunction prevents teams from being fully in control of how audiences interact with the project. Although some technical issues were reported to us, the project did not collect a wide-cross section of audience responses. Most users interreacted with the work independently via their own mobile phones and no personal data was collected.

However, three artist tours were run whose experiences of the AR were shared. They were a mix of audiences. Some audience members were familiar with the project e.g. HCA scientists, and others had no prior experience of it. Audiences, overall, were excited by the appearance of the AR in familiar environments and on public landmarks, eager to question the meaning of particular symbols and titles of the works. And to link the sonic compositions with sounds they knew from films, particularly science fiction. Audiences preferred to share screens on tours and have the volume on which supported in-situ discussions about the AR and inspired other people passing by to ask about the project. They grasped the significance of the projects focus on the future of donations and linked this to their own experiences of donating blood or carrying an organ doner card. At the forth stop CONSENT, one group had a vivid conversation about the age of consent that children can make choices about donating their tissue to research following a routine biopsy. And related this to the age they can consent to having the Covid-19 vaccination. HCA Scientists reflected on their own hopes that the pandemic had positively enhanced people's trust in scientists after the success of the vaccine development and that this would encourage more people to consider donation if they were asked.

3.2 Public and Internal HCA Reception

Donate Yourself used artist tours to deepen the core debates within the works with small groups of people. The AR experiences were also accessible via three QR poster sites in Oxford, Cambridge and London that used advertising space like bus stops to engage a wide cross section of the public, and the experience has engaged over 1.2K users to date. Others have accessed the AR through the One Cell at a Time exhibition website (One Cell At A Time, 2021).

Figure 13: *Image of advertising QR sites used in Cambridge in collaboration with Cambridge Junction.*

The overarching aim of the OCCAT project was to improve the value and trust people place in research, with a consequent desire to impact on public willingness to donate tissue for research and share their data. *Donate Yourself* was part of exploring this area of communication research, alongside generating dialogue and transparency between HCA members, including use of language, GDPR and consent. Reflections in this section are from the OCAAT engagement report, delivered to the Wellcome Trust and shared with partners. External evaluators Helix Research collected the data.

Feedback from participants indicate, that although small in scale, this approach could be expanded on and built into other communication strategies for tissue research:

> *"I was … impressed by the way that the project has touched upon ritual and belief systems and the ways in which our bodies or our people are remembered …embracing, you know, multiculturalism in many belief systems. So it felt quite warm in a way. And it certainly made me feel more engaged with it and … appropriate for me to be involved because, you know, I was slightly reticent about joining in because I didn't feel I knew enough about it… [but I could] be involved because it is so broad and so inclusive."* (public participant)
>
> *"I'm very keen to just contribute and participate in any research and anything I can do to help the world. So you know, if there's a way that my body can be used,*

> *when I've died, then I would … I spoke to my family about the workshop after I had it. And so we all talked about donation and things.”* (public participant)

3. CONCLUSIONS

Donate Yourself used a range of engagement strategies to activate public debate around organ, tissue and body data donation. By simplifying and separating these debates in a range of key themes the work aimed to be accessible to a wide cross-section of the public, with opportunities for deeper or shallower interaction using WebAR. Covid-19 was used as a critical framework to further public and internal debates with members of the Human Cell Atlas on 1. perception of value and trust in scientific research 2. personal legacy in relation to donations and 3. contemporary understandings of data privacy in relation to the use of human tissue. The research will be expanded through repeating the installation in different national and international environments, with a focus on festivals and scientific venues. This will be used to encourage audience participation, while also capturing post-experience evaluation. WebAR will be further explored through geo-location and interaction with the AR scenes. We will also use the participatory phase workshops, post kits and tours as a means to deepen the core debates within audiences. Overall Donate Yourself was well received, both by members of the public and scientists from the HCA who reflected on how the AR helped them to consider their own and others experiences of donation, consent and care for future generations.

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