

# Which patient takes centre stage? Placing patient voices in animal research

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## Dying for the other

We hear the patient before we see them. Beatrix De Costa is performing. There is purpose and poise. It is not clear if the patient is leading or being led.

The split screen tells us we shall be exploring options and experiences, as well as spaces and how to navigate them.

The screens fill with containers of knowledge, concrete ones, plastic ones. Hands, arms, bodies, controlling substances in controlled environments. The coordinated effort of Hope.

Three screens. Three choices. Look directly at what is affecting you. Look at something different. Look away entirely.

As we travel deeper into this patient journey, some decisions are taken for us and choices are taken away from us.

Time is counted down. Three fingers are splayed on the floor. Two fingers are held up for counting. One mouse is being prepared for death.

The patient decided what they wanted to confront, which patient takes centre stage, troubling the narrative of who is dying and who is other.

The triptych is culled, panel by panel. And so is the mouse. There is only one panel. There is only one voice.

Reflections on Beatrix Da Costa (2011) *Dying for the Other*<sup>1</sup>

This opening commentary describes a film by artist, activist, and academic Beatrix da Costa, who died in 2012 after 'negotiating with cancer for many years' (Kelley 2017, p. 230). Her work, *Dying for the Other*, with its multiple screens projecting patient perspectives, clinician interventions and animal experiences, makes strikingly visible the companion species and questions of relation that connect 'suffering, remedy, and harm' (Kelley 2017, p. 233) in health care and research. Patients'

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<sup>1</sup> <https://vimeo.com/33170755>, last accessed 24/09/2018

experiential knowledge is increasingly emphasized by those seeking to calculate remedy and harm, improve health care delivery, and translate biomedical research. However, the animals underpinning pre-clinical research, used in safety and efficacy trials, or standing in for patients as mouse avatars within personalised treatment rarely appear in these accounts. Laboratory animals are usually kept offstage, silent and unseen. Da Costa's film oscillates between triptych and single screen, giving us choices about where to look. And, as the animal is killed, it acknowledges we may choose not to watch: "the moment of looking away becomes an integral part of viewing the work" (Kelley 2017, p. 238). Her film introduces a series of questions we want to address in this chapter: How is the idea of patient voice articulated and transformed in relations with animal research? How does personally and publicly addressing the companion species whose suffering you share change patient experiences and responsibilities? And, how do subject and object positions shift when there is an enduring anxiety over which patient takes centre stage?

In what follows, we describe extracts from four further films, which involve listening to patients<sup>2</sup> talk about their encounters with biomedical research and laboratory animals<sup>3</sup>. These emerging interfaces present a challenge to scholars seeking to expand the inclusion of patient voices within science (Boenink et al. 2018) and animal voices within society (Srinivasan 2016), respectively and collectively. These encounters have the potential to shape research priorities, understand animal experiences, and remake narratives around health. They also produce tensions. Moves towards making animal research more public through patient voices may also make it more intimate, as the 'somatic sensibilities' (Greenhough and Roe 2011) of patienthood are shared across sentient beings who have in common a 'physical vulnerability' and 'susceptibility to injury and illness'. We suggest the interface of the geohumanities and health geographies offers an important space to explore how these novel expressions of patient voice are emerging and to reflect on how they augment, fragment or refract with ideas of giving voice for and about animal others in the production of health. Whilst health geographies are attentive to how health, medical research, and care are situated and mobilized, the humanities offer an attentiveness to practice, which does not follow theory, and holds onto the indeterminacy of voice, preceding the settlement of these meanings. This openness to "when voice happens, how voice happens, or where voice happens" (Mazzei 2008, p. 45) is essential for these often ambiguous encounters between patient experiences and animal research. In seeking to listen carefully, we draw on our embodied experiences, as researchers, patients, and

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<sup>2</sup> 'Patient' is a complex, dynamic, and relational category, contestable and temporally located, sharing boundaries and imbrications with other advocacy movements (Epstein 2008). Here, our use of 'patient' is as a gateway to consider the entanglements of a wide range of people with animal research, and consider how people's experiences of, and encounters with, disability and illness acts to influence attitudes to animal research. The growing transparency of animal research produces new entanglements and knowledges, producing an arena of debate amongst all those who are directly or indirectly involved in such networks (Callon and Rabeharisoa 2004).

<sup>3</sup> This research is part of the wider Wellcome Trust collaborative award on the Animal Research Nexus (205393/Z/16/Z). This programme explores the changing historical and social relations around animal research from different perspectives, including the growth of patient and public involvement and engagement within the practices of animal research. For further information see <https://animalresearchnexus.org/> (last accessed 28/09/2018)

publics to reflect on how patient voices are created and animals related, and how we are interpolated as audiences<sup>4</sup>.

We start and close with the work of artists and poets reflecting on the entanglements of human and animal health and the intermingling of patient perspectives with creative practice. In the next section, we introduce the policy developments creating interfaces between patients and animal research, before considering how films from patient groups, research advocates, and research institutes connect people affected by health conditions with the animals that share their condition. In our accounts, we want to draw attention to the multiplicity of places in which patient voices are being crafted and the different ways these position who is responsible for whom and to whom in interspecies relations of care (Davies et al. 2018). We explore the different ways in which patients and animals are attributed rhetorical and political power in deploying and (re)signifying multiple discourses around health, research, and embodiment (Ganchoff 2008). We do this with the aim of adding understanding to how different voices are mobilised in public debates around science (Michael 2009) and helping develop careful ways of speaking for and with multiple others in health research (Dam and Svendsen 2017). We also seek to use the creative methods of the humanities to hold these spaces and narratives open and recognise that conversations between patient voice and animal research may start with not knowing what to say.

## Patient voices and animal research

The question of how to place patient voice in relation to animal research is not an easy one to answer, yet it is increasingly being asked, both directly and indirectly, through the conjunction of two developments that are opening up new interfaces within animal research. The first is the movement towards increasing patient and public involvement (PPI) with health and care research. Formal practices of PPI are increasingly embedded as an ‘official ideology within legislation’ and ‘widely endorsed by both lay and professional groups within health and social care and in academia and medical research in the UK’ (Gibson et al. 2012, p. 533). PPI seeks to enable ‘patients’ to apply their priorities to the development and delivery of health services (Tritter 2009) and improve the quality and relevance of health research by drawing on the lived expertise of patients, acquired through personal health journeys (Caron-Flinterman et al. 2005). The second is the growing commitment towards openness in animal research after several decades of secrecy and security, especially in the UK. The Concordat on Openness in Animal Research was launched in the UK in 2014 with signatories across universities, medical research charities, and others agreeing to provide greater public clarity about when, how, and why animals are used in research (Understanding Animal Research 2017). This move to increase transparency also has potentially ‘transformative implications for the relationship between science and society’ (McLeod and Hobson-West 2016, p. 791).

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<sup>4</sup> Our professional and personal backgrounds are diverse: spanning veterinary science, art, human geography, policy, gender, sexuality, and experiences of acute and chronic illness. We do not name the different descriptions of films that we have authored. Whilst patient voices have the potential to radically remake these interfaces around animal research, this will not be achieved through allocating meanings in ways that promise the authenticity, fixity, or the singular truth of voice.

To move, at the same time, towards widening involvement in and increasing openness around animal research opens opportunities for reshaping research practice, science policy, and public conversations around animal research. Powerful claims are made for patient voices across these domains. Rothwell (2006) describes how patients and their carers play an increasing role within debates on animal research, with significant impact and media interest. Reporting on emerging trends in animal research within neuroscience, Pankevich et al. (2012, pp. 57–58) note that ‘people living with disease hold particular interest in learning about new research’ and describe how ‘individuals living with disease are knowledgeable about the use of animals in research and can also take part in public engagement efforts’. They suggest patients can help to ‘personalise’ the issue of animal research, shifting debates towards how animal experimentation can help people. However, these dual movements bring an irruption of uncertain new meanings around the place of patient voice in relation to animal research.

The more abstract figure of ‘the patient’ has long been a powerful actor in arguments around animal research, mostly ‘spoken for’ by formal organisations, especially in publicity material making ethical justifications for medical research funding. Here, patient voices make corporeal needs legible, gather expectations and resources, and provide the horizon for embodying future hopes. However, being open about, and involved in speaking about, animal research may bring personal complexities for those patients who now find themselves speaking for and perhaps to animal others, as well as public responsibilities within an often controversial public debate. Individual patient voices address a more complex and uncertain future, with the potential to reconfigure narratives, and (re)gain, (re)possess, and (re)claim moments and experiences of hope (Power et al. 2018). They demonstrate hope is not a universal experience or singular achievement; hopes for health become entangled and contested with hopes around animal lives. That which cures may harm (Derrida 1981), creating ambiguous and enigmatic ‘questions of relations’ around health (Stengers 2011, p. 30). Adding patient voices may not produce clarity or confirmation; meanings are added to the complex intersection between biomedical research, human health, and animal welfare. The divergent expectations around what a patient voice is and does, and the inclination that many have to look away from animal research, may also result in meanings that are missed, silenced, eluded, or excessive.

This complexity is recognised in institutional communications around animal research. The organisational steps towards public openness and patient involvement in basic biomedical research using animals have been hesitant. There are sporadic experiments that speak to the potential of these interfaces. The increasing accessibility of digital media, particularly short films on the websites of patient advocacy groups, research institutions, artists and others, are creating spaces to explore expressions of patient voice in relation to animal research. Patients can be found taking up positions as narrators, tour guides, and commentators, inviting the public to follow them into the previously inaccessible spaces of laboratory animal research. The embodied experience of patients, sometimes severely affected by current absences in biomedical research, authorise their presence in these places, and allow them to ask questions of animal researchers and explain their experiences to wider publics. They also potentially refigure the affective responsibilities around animal research, by connecting the ‘to and fro’ of public debate around the ethics of animal research with the personal experiences of patients. The future expectations personified in the abstract figure of the patient, are rendered turbulent in the ambiguous corporeal encounter between specific patients and their laboratory animal companions. These films show patients moving through the spaces of research, speaking in different configurations to, for, and with the researchers using animals in their work.

## Speaking to research

There is no introduction. The film starts with a man talking, a headshot against a wall, with slightly blurred focus. Two people, a man and a woman affected by Parkinson's, talk about their experiences of being involved with research. Their dyskinesia acts as an affective reminder of the embodied stakes for them as people affected by this health condition.

The woman describes herself and her illness as a valuable commodity to researchers, but also that she enjoys the exchange. She feels empowered to give direction to a research project. She notes that 'patients can only benefit from that sort of input'. Later, she explains 'it's actually humanised the research, it's made them a person, someone I could communicate with'.

The man explains how he gets to have his say. 'If science wants to do something for science sake...' the man begins and the video zooms in "...then you have a voice, and you get the chance to be heard". Patient voice has the potential to hold scientists to account.

The film ends with a sketch of a megaphone and the call to 'have your say in Parkinson's Research'. The address is to other people affected by Parkinson's, using patient voice to champion patient voice. The film emphasizes how patients can shape research direction, but also transform relations, meeting researchers and making new friends.

### Reflections on Parkinson's UK (2017) *How Can You Have Your Say in Research*<sup>5</sup>

We want to contextualize emerging engagement around animal research by starting with the ways patient involvement itself creates and shapes a particular idea about patient voice. The short Parkinson's UK film exemplifies an opportunity for speaking in ways that are empowering. The film amplifies, and the megaphone underscores, this is an occasion to shape the production of scientific research, as well as deepen social relations around science and patient advocacy. The film recognises the transactional, as well as relational, aspects of patient-researcher connections, suggesting these exchanges have value to researchers, as well as being valued by patients. The chance to be heard means these are not necessarily in opposition. The film mobilises a version of 'patient voice' to champion democratic involvement of patient voices in speaking to research.

The Parkinson's UK film does not talk about animal research but is indicative of aspirations for work on public involvement. Involving patients in research has been a growing trend in health research, aiming to 'give voice' to the people affected by the health conditions that the research aims to benefit. As Callard et al. note, there is growing recognition that 'knowledge 'from the bedside' must feed back into the laboratory if the translational endeavour is to have any real success' (2012, pp. 390–391). They argue decisions over future drug design ought to take into account patients' lived experiences rather than solely drawing on scientific representations and forecasts of presumed therapeutic value. Involving patients in setting research priorities can ensure that research is most relevant to those who might be characterised as its 'end users'.

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<sup>5</sup> <https://www.youtube.com/watch?v=F8fDYCEEE0Q>, last accessed 24/09/2018

Patient involvement activities themselves are varied, ranging from the identification of research priorities and questions, the appraisal of study design, to the dissemination of research results. Patients can become involved at multiple points within the research pipeline and increasingly further 'upstream'. The accessibility of digital media has created additional and alternative spaces for voicing these patient interfaces with research, offering platforms that legitimise, stabilise, and encourage patient involvement in research. These films serve many purposes: they are voice-pieces for medical research charities to highlight moves embedding patient centricity, for scientists to further demonstrate the importance of research, and for fundraisers to produce affective and emotional connections.

The format of the film authenticates an emerging genre of giving voice through patient involvement. People affected by health conditions sit facing the camera and voice their opinions about the researchers they encounter and the research that shapes their lived experiences of embodiment. The presentation conveys why it matters what they say. The talking head format underlines the authenticity and authority of the spoken patient voice: the direct camera angle locates the voice in the affected body, whilst simultaneously emphasizing the value of articulate speech in having your say in the practices and relations of research.

The next film echoes this format. Yet, something is different. Introducing animals as another participant in this conversation shifts the relations between patients, researchers, and publics. The ways in which patient voice patterns the subject and object of conversation shifts, as further subjectivities are introduced.

## Speaking for research

The voice-over starts with footage of a white mouse in a cage nibbling a cardboard tube. We're told that Genetic Alliance (an umbrella patients association) and Understanding Animal Research (a group promoting openness in animal research) took patients to a UK teaching hospital to learn more about the animals used to study their conditions. The film cuts from the mouse to a headshot of a man against a wall.

The man begins to talk, the other voices in the background give his voice an informal authenticity. None of the people are named, nor are the health conditions they are affected by. The man explains he was interested in finding out about the high animal welfare standards, the day to day routines, and the researcher's relationships with the animals. He says he is reassured by this, having previously taken on faith the animal care within research. He values being able to see this in practice and in person.

We switch to a woman, sat in the same spot. She echoes it was her first time seeing laboratory animals and her impression was the animals seemed cared for and happy. She articulates her concern from the standpoint of her condition, that it does involve and require research using mice. Whilst it was an eye-opener to see what this involved, 'they all looked fine'.

The next person launches into an energetic discussion about using animals as models for deafness research, noting their advantages in basic research and the later stage of a drug

development and regulatory testing. He speaks less about visiting the facility and mounts a robust defence of the necessity of animal research. He concludes by stating how 'well-husbanded' the animals are, laughing that the animals 'have better living conditions than I do at home'.

The final man, younger than the others, starts from a different position, talking about enjoying meeting the researchers themselves, rather than the animals, though inexorably the conversations comes around to the mice in the room. He says researchers were enthusiastic about the welfare of the animals and explains the enrichment strategies they used. He notes the 'respect' the researchers showed the animals, 'rather than just being, this is an experiment, this is something living as well'.

Reflections on UAR & Genetic Alliance (2012) *What Do Patients Think of a University Animal Research Lab?*<sup>6</sup>

In this film, as before, the patients appear before the viewer as a sequence of perspectives, their voices conveyed by the commanding conventions of the talking head. Many of the roles in this conversation about biomedical research are the ones encountered before: around the potential of patients as spokespersons, around roles of researchers, and the economics of drug development. But there are also mice: as research models, as something living, as happy and well husbanded. Everyone mentions the mice. These are animal bodies that matter, to patients, to researchers, and to the public too. Yet in talking about these other animal bodies, something changes in the way that patients are granted authority to challenge the nature and direction of scientific research that uses animals. The speaking voice of the patient is transformed to give recognition to the animal subject that cannot speak.

The patients in this film similarly explain why they appreciate the opportunity to have their say: they value talking to researchers, listening to researchers, and talking about research. But, in the final cut of voices, there is less here on how patient voice might be empowered to contribute to health research, through the embodied experience of living with disease and challenging the science. Rather, the focus is on who is speaking for the animals and how they account for the ways ethical research is enacted in practice. By entering into the animal research facility, and reporting back, the patient gains a privileged position as witness to the experiences of animals. They are reassured from their own personal positions, as someone potentially in a position to gain from this research. Yet, they also gain an uneasy responsibility, in public and in private. The responsibility taken for animal care that lies with the research establishment is conveyed, via the patient, to a public audience. The patient bears witness and provides a public warrant that what they encounter is acceptable care. Responsibility may also have a more personal dimension, as the potential to understand their own condition through research and through animal's bodies opens the potential for shared suffering (Haraway 2008). Their voices convey some anxiety as they make frequent and specific reference to how well looked after the animals are, and the necessity of doing animal research. The patient voices becomes one of speaking for, rather than to, animal research.

It is possible to speculate about this redirection of patient voice, drawing on the two dimensions of responsibility above. The first is the recognition of animal research as a matter of public concern and

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<sup>6</sup> <https://www.youtube.com/watch?v=j2RRnwtnsjw>, last accessed 24/09/2018

debate. Public discussions around animal research are conventionally framed in relation to an ethical debate between pro and anti-positions. This polarised debate leads to the expectation that patients should take sides. It is necessary to add your voice to one perspective or another rather, to speak for animal research in the pursuit of further understanding of disease and therapeutic possibilities, or to speak against, as in the case of Animal Aid campaigns where people affected by health conditions stress animal research is not done 'in their name' (Animal Aid 2017). The UAR film is a powerful and public counter to this, through which patients act as advocates for research in general and offer ethical assurance around animal research in particular. However, the second question of personal responsibility is more uncertain. The encounter with the animal model may also bring to mind the responsibilities that come with having a body that is vulnerable, and to consider how suffering is shared not just with other patients, but also with animals too. There is no easily accessible vocabulary or socially acceptable script to articulate these aspects of experience. They may be expressed as either hesitancy or a move quickly into the conventional frameworks of ethical debate. It is also possible to speculate that this absence of language leads to a further absence, this time around the potential for patient voices to challenge researchers about the direction and nature of animal research in the same way they might question other aspects of health and care research.

This film thus changes the content and address of the patient voice. Patients are empowered to speak for research in public, though not necessarily to shape research in practice. The patient voice is a powerful actor in public arguments around animal research, providing assurance as a privileged witness for the experience of the animals and humanity of the researchers they have met. This is a distinctive contribution to ethical justifications for animal research, but it may come at the cost of the power of patient voices to reshape research directions, even as personal encounters with research animals may become increasingly common.

## Speaking to the other

"Tom, this is one of the alco-mice", a man we take to be a scientist explains, as he pulls a cage from a rack of individually ventilated mouse cages. "Ah this one? This is our man?" replies Tom, his voice clear. The scientist launches into a description of 'the blueprint of life, our DNA', his gloved hands gesticulating as Tom looks into the cage. We cut to a close up of a mouse stretching and climbing on the roof bars. The scientist explains the experimental design in everyday language. It hinges on a "very simple choice, very much akin to if you or I went into a pub and said to you 'what would you like to drink?'" . The shot switches to the Tom's face staring into the cage, as the scientist explains that one bottle of liquid contains water and one "10% alcohol, so the equivalent of a strong beer".

Tom's face is hidden by his facemask. Only his eyes are visible as he glances to affirm the scientist's continued description, then back to the AlcoMouse. The scientist tells us most mice won't touch the alcohol, whilst the AlcoMouse will take 85% of their daily fluid intake from the alcohol containing bottle. We see a mouse drinking. The scientist stresses the importance of choice. "He chooses the ethanol all the time basically", Tom comments. "85% of the time,



yeah”, the scientist confirms and corrects. He explains this experimental set up reveals the choice is largely driven by genetics.

Tom finds his voice: “So that gene is basically, that’s the one that’s saying this isn’t socially driven, it’s not driven by peer group pressure, it is basically, that’s their make-up, that’s the way they were designed, and that’s what they are going to choose”. The camera pans around. Tom’s face is clear for the first time, directly in focus. “From my point as an alcoholic, that’s something that is great for me to hear, that if there is a similar gene in adults, or humans, this gene would say that it’s not just my peer group pressure, it is the fact that I need to drink, and I want to drink, and I actively seek to drink, rather than seeking water”. It’s the first time Tom acknowledges this condition, though it’s been implied throughout. The voice-over picks up this connection to explain the AlcoMouse gene is also present in humans and this is a small, but important step towards understanding “the disease that blighted Tom’s life for 15 years”.

We see Tom again, facemask down, his voice full of emotion, “I came in here thinking I was just going to look at a mouse that had been fed alcohol”. His voice starts to break. “And this one mouse, has given me in 15 minutes, a better understanding of my own illness, than 15 years of trying to search for answers. To be told, that there’s a possibility that there’s a link to a signal in my brain that was making me crave the alcohol more. For me it’s ...” He’s emotional now. “... I can’t get it through how, how, both upsetting, that it’s never been told to me before, but also liberating that I’m getting answers. Just from that mouse.” Tom’s eyes fill with tears. “One mouse.” The camera moves from the mouse and back to Tom. Off screen we hear some ask if Tom is okay. “Nah I’m alright. I’m fine. Just got that off my chest. I’m sound. Happy. Happy. That’s the thing. Happy.” We see a final shot of Tom, his face a mix of different emotions.

Reflections on BBC Horizon (2010) *Miracle Cure? A Decade of the Human Genome, Alcomouse & MRC Harwell*<sup>7</sup>

Within the animal facility, the nature of the encounter, the address to the other, and expressions of voice around animal research are radically transformed. The exchange is not directed to the public, as an outward expression of support for research, though that may be implied. Mediated through film, face-masks, and the cage face, this is a deeply private and personal conversation, which changes the corporeal and social understanding of what it means to live with a condition and to live with another with that condition. Ganchoff (2008) suggests that patienthood can act like a collective identity. Animal research opens up this collective identity beyond human socialities to remake patienthood through interspecies relations. These entanglements are multi-faceted, reflected in the affective sometimes faltering position of patient voice in this encounter.

The animal other becomes a companion to the unfolding understanding of a condition for scientists and for patients. These animals are not simply ‘furry test tubes’ (Garner et al. 2017), even and perhaps especially whilst inserted into experiments designed to reduce environmental complexities to bring out genetic cause. Animals are responsive beings, bred to share some biological similarities to human disorders whose validity is always located within the experimental situation (Ankeny et al. 2014). Animals are also powerful figures in cultural narratives that contribute to reallocating

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<sup>7</sup> <https://vimeo.com/118265337> - last accessed 24/09/2018

responsibilities around health. The alcoholic mouse model offers a new narrative to reframe the 'biographical disruptions' (Bury 1982) experienced around illness like alcoholism by anchoring them in biology. The unworldly innocence of the experimental animal, removed from social interactions and peer pressure, yet still repeatedly needing to drink, offers a different account of the person's experience of their own condition. The animal gives the patient a new kind of voice, in the placing of a craving within biology, in the authority to speak as a patient, in the feeling of it being 'liberating'. Tom speaks directly to the mouse, mediated by experimental situation and scientific interpretation: "this is our man".

The conclusion of the film reassures us that having processed this complex journey, Tom is happy. We are also told, by the scientist this time, that the animals are also happy. The film leaves us with this note of ease, despite acknowledging there is a long way to go before this animal model will yield results with clinical implications. For the patient, the experience of seeing their illness reflected, embedded, and embodied in another living being opens up a position to place their voice within the discourses of biomedical research. This is a new conversation in which there is the potential for different kinds of answers and for finding hope.

Yet hope can be elusive, and identifications can also involve estrangements. The final film we introduce is an animation by Nate Milton of Poem to My Litter by Max Ritvo. The film of Ritvo's poem was completed posthumously, after his death from cancer in 2016. In the poem, Ritvo writes of an experiment in which cells cloned from his tumours were placed in mice in the hope of finding more promising and personalised treatments. The development of these co-clinical trials introduces a direct relationship between patients and animal research. This unexpected, and likely for some unspeakable, intimacy is articulated through the haunting lines of animation and poetry.

## Embodying the other

On a medically beige background, handwritten in black, all caps. POEM TO MY LITTER.

A scratchy outline of a Max Ritvo appears, looking directly at the camera, addressing the viewer personally, there is no difference between their skin tone and the background, flattening the image, this is only an outline. Max is only one dimension of this story, but the contrasting white rims of their spectacles frame their eyes, telling us this is from their perspective.

Max shrugs and touches their chest at the mention of "men's" and "my tumours" gently signalling that Max is human and Max is sick. Tactile ownership is consistent. The perspective shifts to a profile.

Max is replaced, or refracted into 12 white mice, nestled together. The narration explains "My doctors split my tumours up and scattered them into the bones of twelve mice"

A purple gloved human hand holds a mouse by the scruff of the neck for inspection, its body hangs, orb like, one dark eye marking the centre of mass, because, as Max explains, they watch each mouse like a crystal ball, unreadable in this telling.

Death; “I wish it was perfect”. Flesh is replaced with a skeleton, explored by wriggling white lines, the animacy of tumour cells, darkly yet honestly foreshadowing the path of the narration.

A white dot starts in the right femur and then to the lungs, down the legs and up to the throat, hovering and trembling with potential momentum, like a laser pointer in medical lecture, charting the history of the colony. The anatomy and autonomy of narration.

Max, shirtless, in denims and floating. A shadow under their feet confirms they have a physical presence, even if they have begun to transcend the weight of their story.

Reflectively, we are watching fireworks with Max. Exploding from some central foci and radiating away, an optical metastasise, not exactly Brownian motion, pure white, but the path feels familiar.

As the background colour changes, it dawns on us that the shadow is blood, the skin flayed, a mouse exsanguinated, quite dead. One more breath here.

You are the soft point, 4 or 5 feet away that Max, in the Vrksasana position, is gazing at. Voice and posture are centred, their eye contact with you is tethering. Two more breaths here. Contemplative.

“To complicate the story” another mouse is held by the scruff and injected, defences have to be lowered to allow the full story to develop.

We leave the violence of the last two stanza and look down on a personalised scene. All the mice cradled in Max’s arms. “No playing favourites”. Clumped together, seemingly identical, held just above heart level, a macro manifestation projected from the thyroid beneath. Max the Human, Max One, Max Two. United, divided, dividing over several scales.

“They are like children you have traumatised and tortured so won’t let you visit” is narrated over strobed images of Maxes, flickering lighting, anxious, like Shelly. Monsters are not the only things we are creating.

Rubbing their head Max confesses a hope. That, even when transplanted and grown in another, good will come of suffering.

A red mark dances over the words, a bouncing ball to reveal the cadence of this multispecies empathy.

If this is not familiar to you then this is how you voice this rage. Rubor, tumor, calor, but no hubris, that has been shed along with all the fur.

“That’s peace. Which is what we want. Trust me.” Trust Maxes.

Reflections on Nate Milton’s animation of Max Ritvo (2016) *Poem to my Litter*<sup>8</sup>

## Conclusions

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<sup>8</sup> <https://www.youtube.com/watch?v=NGr44gikoxc> last accessed 24/09/2018

We opened and end this chapter with voices produced through artistic practice, poetry and animation to underscore the current uncertainty around the place of patient voice in animal research. Voice can 'elucidate, clarify, confirm, and pronounce meaning' (Mazzei 2008, p. 47). Voice can provide truth, fixity, knowledge, and authenticity. Voice can also challenge and remap truths, stability, and ideas of authentic meanings. Voices slip, escape, refuse to become pinned down or perceptible. Voices intrude into discourse, capable of bringing discomfort and uncertainty (Mazzei 2008). The work of da Costa questions how we speak about illness, who leads the conversation, who has choices and who does not, as she journeys through treatment. Ritvo interrogates who 'we' are, in our relations of living and dying together, resituating a public debate around balancing harms to animals and future benefits to patients within a complex and specific present where disease outcomes are affected by the simultaneous trajectory of tumours in one person and their personalised mice. The artists voice both connection and disconnection. Da Costa presents a narrowing frame as options and tissue are removed from both patient and animal on their journey together. For Ritvo, narratives of kinship show mice as traumatised children who won't let him visit. They both signal the ambiguous relations of personal experiences around animal research and the uncertainties that come with communicating these in public.

These discussions bracket three more conventional presentations of patient voice in relation to biomedical research where meanings are seemingly more organized. In these, patients voice their experiences to guide research practices. They speak publicly about their support for animal research. They find new ways of understanding the conditions that affect them from within the animal research facility. They speak to, for, and with animal research. The preposition alters as perspectives shifts and experiences, assurances, and authorities are exchanged. Yet here too, we hear echoes of the ambiguities that art is able to express within the complex and changing patterns around patient voice. Who guides and frames the conversation and to whom is the discussion addressed? How does speaking for and with animals in research remake personal subjectivities and identities? And what are the absences and erasures as subject positions shift around the central uncertainty of how to give voice to changing relations with animals? This is an unresolved conversation that merits further consideration in the spaces of the geohumanities, drawing as it does on the construction of meanings across species, the changing location of health and knowledge, and the possibilities of an altered horizon for political practices.

In concluding, we indicate some of the openings and closings associated with these possibilities. We want to acknowledge first what is positive in the way patient voices are being mobilised, framed, and most critically, listened to, as part of an evolving relationship between people affected by health conditions and biomedical research. The encounters between patients and animals can alleviate concerns and worries patients may have about being reliant on research involving the use of animals; witnessing the care deployed for animals gives confidence and reassurance around their intimate entanglements with the worlds of laboratory animals. The animal model may offer new commonalities to speak about a health condition formerly associated with individual stigma, offering novel resources through which to narrate biography, as well as opening up future horizons in which biological trajectories may be reversed. With appropriate care and caution, we suggest there is the potential for further conversations here in which patient voices may have a direct role in speaking to

the research priorities, protocols, and particularities of animal models that might best represent what is important to them about their health<sup>9</sup>.

However, we also want to acknowledge the significance of these cautions. It is often implied that patient voice helps to 'personalise' the issue of animal research, shifting the focus of debate from animal suffering towards how animal experimentation can help and benefit both patients and publics. Such claims imagine a certain kind of patient and actively enrol patients as having public responsibilities and duties around articulating animal research. There are cautions here about how patients are made to stand in as public witnesses, when Fredriksson and Tritter (2017, p. 96) and others argue it is inappropriate to use 'patients as proxies for the public' in healthcare decisions. There is also careful consideration needed around how the situated act of speaking about animal research changes expressions of patient voice. These do at times align easily with the economies of hope and humanisation that go to support the pursuit of more research, better treatment, and pharmaceutical value (Sunder Rajan 2017). Yet, the dominance of affective tropes around hope in relation to patient groups (Coyle and Atkinson 2018), can make it more difficult to express ambivalence or uncertainty. Past histories of protest against animal research seem to amplify these tendencies. The distinctive and disruptive voice of the artists comes from outside. Their experiments with the expressive qualities of film and language outlive their experimental encounters with the biological sciences. As the ongoing work of translation between patient, public, and animal bodies in the biosciences continues, we argue these should be joined by increasing attention to the translation of meanings across species and spaces in the geohumanities.

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<sup>9</sup> Davies and Gorman are doing further in-depth interviews and ethnographic work, as part of the Animal Research Nexus programme, with engagement professionals, researchers, patient groups and publics to understand how PPI may be able to engage meaningfully around animal research. We would like to thank those medical research charities, communications organizations and research institutions whose conversations have informed our reflections in this chapter here.

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