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# Emerging Tissue Economies: Personalized Immunotherapies and Therapeutic Value in Cancer

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## ABSTRACT

New personalized immunotherapies hold considerable promise among cancer communities and are touted by many as the future of oncology. Described as a way to enhance the body's "natural defense" against cancer, they are made with antigens taken from patients' own tumor tissue. However, they also set up significant dilemmas for patients who are learning what it is like to participate in an emerging tissue economy and the stakes of exclusion from it. Taking brain tumors as my ethnographic case, I chart the valuations and exchanges that constitute this tissue economy as well as the dilemmas and disparities faced by patients.

## KEYWORDS

Biovalue; cancer; materiality; personalized immunotherapy; tissue economy; United Kingdom

Several patients sit in a cancer ward in the United Kingdom looking onto a curious scene. On one of the beds, Fay sits swinging her legs inches above the ground. Like the others, Fay has a brain tumor and, like most of the quarter million people diagnosed worldwide each year, her tumor is cancerous. A thin scar curls around her head, just above her ear. It marks the place where, months before, surgeons removed part of her skull, sliced through the thin bluish layers that concealed her brain and lifted multiple pieces of reddish-brown tissue that amounted to the size of a golf ball. Her graying hair is slowly covering the scar – fuzzier than it was before she had radiotherapy. To her left, stands a large metal urn covered in bright stickers that instruct careful handling and signal overseas journeys from mainland Europe to the United Kingdom. A nurse wearing elbow-length gantlets prises open the urn and thick clouds of nitrogen spill onto the floor. Surveying the faces of curious patients who themselves await medical assessment or treatment, the oncologist beside me jokes about selling tickets to the next performance. We watch the nurse carefully remove a canister from the urn and, from the canister, a small vial of fluid. She draws the fluid into a syringe, pushes out bubbles of air and flicks the needle, which is now poised before Fay's arm.

This is the intrigue that has produced chattering among patients on the ward and a verve throughout the hospital where I conducted ethnographic fieldwork between 2014 and 2016. The liquid about to be injected into Fay's arm contains, she hopes, one of the most promising technological innovations in oncology's recent history – a vaccination tailored to her tumor by combining her immune cells with her cancerous tissue. Because Fay is having the vaccine through a double-blinded randomized control trial, she does not yet know if she is getting the vaccine or a placebo; there are no clues obvious to either patient or clinician and the performance with the urn would be identical in either case. Fay's ultimate hope is to live ten more years. It is an ambitious hope given that three-quarters of people with glioblastoma tumors do not survive beyond a year (The Brain Tumor Charity 2020) but one shared by her oncologist and countless other patients desperate for innovation in a treatment landscape that has changed little in recent decades.

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I ask the oncologist involved with a trial<sup>1</sup> how much tissue you need for the trial. About three milligrams, he says, but is not sure what three milligrams looks like. He does not know how dense tumor tissue is and it can have lots of blood or dead cells which have to be removed. “There’s no entry criteria<sup>2</sup> based on the volume of tissue removed,” he tells me, “It’s how much vaccine they can make that’s important.” I ask him if patients are having their tumor tissue frozen, which is a prerequisite for the trial but an unusual practice in the hospital. “Some do,” he says, “but it’s not routine.”

Fay was 49 years old when we first met and one of several hundred patients recruited through centers across Europe and North America to a clinical trial testing the vaccine. One of a growing group of cancer treatments called personalized immunotherapies, the vaccine is made with antigens<sup>3</sup> taken from patients’ own tumor tissue, which is harvested by surgical operation, and processed with dendritic cells<sup>4</sup> removed from patients’ blood. It is classed as a vaccine because it attempts to induce an immune response by introducing these antigens back into the body through injection. By contouring public understandings of immunity and the “flexibility” of bodies (Martin 1994), its rationale is easily understood by patients: by combining *their* tumor tissue with *their* immune cells, the vaccine equips *their own* immune systems with the capability to recognize and target *their own* tumor – a vaccine personalized to their tumors and a way to enhance the body’s “natural defense” against cancer. Having drawn significant gains from advances in molecular technologies and immunology, personalized immunotherapies hold considerable promise among those with a brain tumor, clinicians, and advocates<sup>5</sup> for longer lives free of the pernicious symptoms of brain tumors and side effects of other treatments. But they also pose new dilemmas for patients who are learning what it is like to participate in an emerging “tissue economy” (Waldby and Mitchell 2006).

In this article, I outline some features of this tissue economy and the challenges it generates. I discuss patients’ quests for treatment focusing particularly on their dilemmas as they navigate shifting terrains of care, learn the complex nature of scientific progress, the dynamics of treatment eligibility, changing bodies, and the strange logics which render lives as candidate or not for the new possibilities given in a fast-moving medical imaginary (DelVecchio Good 2001).

After discussing fieldwork and brain tumor treatment, I draw comparisons with other medical uses of human tissue to mark the specificities and analogous features which help make sense of this peculiar new technology. I then introduce the cases of two patients – Fay, who was eligible for the study described above, and Matthew, who was not – highlighting their dilemmas and demonstrating how participation in this emerging economy is determined by the hard-to-fathom upstream handling of tissue. I conclude by suggesting that tumors are being inscribed with new positive meanings amid new hopes for longer symptom-free lives and offer several perspectives to guide how we might anticipate the social consequences of personalized immunotherapies.

## Fieldwork

The fieldwork informing this article was conducted over 18 months (2014–2016) and mainly in an elite cancer center in the United Kingdom (NHS REC #20/LO/0032). This involved long-term participant observation and interviews with 16 people with a brain tumor and their families, who consented to be interviewed and observed during routine care and at home. I was interested principally in how they navigated care under conditions of radical change – bodily, technical, institutional – and amid a care landscape of few treatment possibilities (Llewellyn et al. 2017). I charted their hopes, aspirations, apprehensions, dilemmas and decisions, and how these changed in response to their changing situations. Most were in their forties and fifties, and most had been diagnosed with glioblastoma tumors very recently. Nine of the 16 were women. I also spent considerable time with hospital staff in settings including consultation rooms, wards, laboratories, and multidisciplinary team meetings, and attended conferences about oncology research, policy, and practice. I conducted formal interviews with clinicians about their daily work and visions of future care. Overall, I spent many hundreds of hours observing care and medical decision-making and recording my observations in detailed fieldnotes.

My interest in the nature and differing interpretations of evidence and shifting knowledge took me to the neuro-oncology “evidence-base” – the thousands of articles informing care. Healthcare policy was a key data source given my interest in NHS care commissioning. I am interested foremost in what these articles and commentaries reveal about the social, political, ethical, and financial commitments built into research and innovation and how they are used by patients as a key technology to perform scientific literacy, communicate (usually off-standard) treatment options, or as sources of information that inspire their hopes.

In this article, I present the cases of two patients treated in the same institution by the same team and with the same standard treatment (surgery, chemotherapy, and radiotherapy). Beyond these base similarities and the fact that they lived for similar lengths of time after diagnosis, their cases represent very different sets of experience regarding treatment and engagements with the broader institutional phenomena through which they took shape. Together, their cases demonstrate the varied opportunities and constraints encountered by patients and how they seize them or improvise alternatives. It does not mean that these experiences are entirely typical in their specifics; nor do they represent the full gamut of trajectories. I have used these cases as entry-points into the broader institutional processes, practices, and discourses which organize people’s lives and inform their subjectivities.

### The production of possibility

Primary brain tumors – that is, tumors originating in the brain – are comparatively rare. They are not all considered cancerous, yet they are all potentially deadly and can cause major physical and cognitive disability. In any case, because brain tumors typically transform and become more aggressive, so-called benign disease is often regarded by clinicians as “pre-cancerous.” It is estimated by the International Agency for Research on Cancer that 296,851 people worldwide were diagnosed with brain and central nervous system cancer in 2018 (2020). Approximately 12,100 new cases are registered in the United Kingdom each year (Cancer Research UK 2020). More than half of brain tumors are cancerous and mostly glioblastoma – a particularly aggressive tumor, which carries a “with treatment” prognosis of 15–17 months (Liau et al. 2018). Only 12% of adults diagnosed with brain cancer live beyond five years, regardless of tumor type (Cancer Research UK 2020).

The last 50 years have seen a virtual moratorium on treatment innovation in brain tumors, a phrase commonly repeated among patients and clinicians. Deficient funding, complex physiology, and underpowered clinical studies have contributed to the desperate place of brain tumors among other cancers. The National Institute for Health and Care Excellence (NICE), which publishes national care guidelines in the United Kingdom, currently recommends four standard chemotherapy regimens to treat cancerous brain tumors (temozolomide, PCV, lomustine, and carmustine) in addition to surgery and radiotherapy.<sup>6</sup> Some commentators lament these conditions reporting research in neuro-oncology – the clinical subspecialty which manages brain tumors – to be 100-years behind other cancers, a point echoed in recent UK parliamentary reports on research funding (House of Commons 2016). In this comparative context of scarcity and ineffectual treatment, people with a brain tumor seek innovation, and their searches, while hopeful, are often complex and desperate.

For most patients I met, experimental trials offered the most ready means of accessing innovation, at least initially. Yet, it is estimated that fewer than three percent of brain tumor patients in the United Kingdom actually enter a clinical trial; a figure below other cancers (NCRI 2016). These determinations and illustrations of constraint articulate the complex ethical terrain of experimental treatments, where trials are no longer regarded simply as hypothesis-testing instruments but “operative environments that redistribute public health resources” (Petryna 2009:30). As such, experiments occasion “new and often tense medical and social fields,” in which hope is articulated in the absence of sanctioned evidence (Brown 2013; Petryna 2009:30). As I learned, the theoretical allure of treatments is key to establishing a semiotics of hope in this context and, as I mentioned previously, the theoretical workings of the vaccine study were eminently convincing and relatable to common cultural understandings of immunity.

DCVax-L – the brand name of the vaccine – is distinguished from other immunotherapies by its producers, the US-based Northwestern Biotherapeutics, in its mobilization of not just one immune agent but “the whole immune system ‘army,’ in combination with each other and in their natural relationships to each other.”<sup>7</sup> The use of dendritic cells, commonly referred to as the “sentinels” of the immune system by immunologists and oncologists, or its “masters” by NW Bio, is critical to this approach and indeed the metaphor of organized military assault. According to NW Bio, these cells “convey the tumour biomarker information to the rest of the immune system agents (T cells, B cells and others), as ‘marching orders,’ and the immune system agents then fan out through the body searching for anything with these biomarkers and attacking it.”<sup>8</sup> It is thus personalized to individual cancers and rather than taking “rifle shots aimed at just one target . . . is designed to target the full set of biomarkers on a patient’s cancer.” The vaccine signifies the immanent power of the body, well-captured in descriptions commonly used by both clinicians and patients that describe it as a way of “enhancing” or “harnessing” the body’s natural defense against cancer.

DCVax-L was among several treatments for newly diagnosed glioblastoma being trialed at the hospital. Now in a North America and Europe-wide phase-III clinical trial, it had performed well in earlier phases. It would frequently be cited by clinicians as a cutting edge personalized treatment, defined simply by NHS England as “[a] move away from a ‘one size fits all’ approach to the treatment and care of patients with a particular condition, to one which uses new approaches to better manage patients’ health and target therapies to achieve the best outcomes in the management of a patient’s disease or predisposition to disease” (NHS England 2016:6). It quickly became a common topic among brain tumor communities<sup>9</sup> Online, forums ran such titles as *DcVax experiences, Anyone on the DCVAX-L Study?* and *New GBM, DCvax-l is it really (sic) good?* further detailing elaborate conversations between patients: articulations of hope and advice in seeking access.

The social and technical arrangements involved in the trial’s enactment were prodigious and illustrative of the global enterprise of scientific knowledge production (Fischer 2009; Petryna 2009). The trial’s protocol required a two-step process of consent from patients: once before surgery, requiring patients to agree for their tissue to be processed and frozen in preparation for vaccine production, and once afterward, requiring their agreement for the vaccinations to be given. Within hours of surgery, resected tumor tissue had to be processed and frozen. It was flown to a laboratory in Leipzig, Germany, where it was further processed at NW Bio’s subsidiary manufacturing facility with dendritic cells, also obtained directly from patients via a complex, often painful, and not always successful procedure called leukapheresis. Weeks later, a vaccine, comprising patients’ own immune cells and uniquely tailored to their tumors, returned from Germany ready to be administered at scheduled times – thrice during the first month, then every two, four, and six months, over two and a half years, if patients survived long enough. However, this could also have been a placebo and this would be unknown to both patient and clinician because the trial was randomized and double-blinded. Beyond receiving the injections, patients were required to attend further physical and neurological assessments, brain scans, and provide blood for testing, every two months. An important trial feature was a “cross-over” option where patients could swap trial arms if their disease progressed. This would mean most patients would have access to the vaccination. As I later show, these arrangements were critical to the lived experiences of patients and their relationships with clinicians. Although the theoretical workings of the treatment might be more or less understood, the actual practices of the trial were largely hidden making it difficult for both patients and clinicians to fully grasp the changing currency of tissue.

While DCVax-L was subject to similar constraints of eligibility as other experimental treatments for newly diagnosed disease – including the receipt of standard treatment, established capacities for informed consent and self-care, and a life expectancy of at least eight weeks<sup>10</sup> – I argue that its use of tumor tissue as a key ingredient of production brought unique challenges to patients and clinicians. Among these challenges was the availability of frozen tumor tissue<sup>11</sup> as an arbiter of access and as such a potential driver of disparity. Another is the complex shift in the meaning of tumor tissue as it became repurposed as a key treatment ingredient. These are not confined to its current status as experimental

but likely to endure if it is to become, as some commentators agree, the future of cancer treatment (Gotwals et al. 2017; Liao et al. 2018). To better understand these challenges and articulate the specificities of personalized immunotherapies like DCVax-L, I now turn to key literatures on the medical use of the body and, in particular, the production of biovalue in what Catherine Waldby calls “tissue economies” (Waldby and Mitchell 2006).

### An emerging tissue economy

Biotechnological inventiveness and the medical exploitation of the body continually reshapes how we imagine our bodies as well as how we are able to intervene in and capitalize on the procurement and distribution of transplantable body parts (Sharp 2006). Staggering figures illustrate the scale of these endeavors with live donors capable of living without one (or more) solid organs – including kidneys, liver lobes, pancreas, and intestine – and with deceased donors yielding more than 15 reusable parts, according to a list maintained by the US Division of Transplantation (US Division of Transplantation 2020). This list extends as modern medicine finds new ways to reuse the dead (Sharp 2007) or reveal riches in what was clinically deemed waste (Fannin 2013; Kroløkke et al. 2016; Waldby and Mitchell 2006).

Anthropologists, among others, have long traced the embrace of these technologies, ethnographically charting the contradictions and ethical struggles which bear on transplant communities. Scholars have investigated, for example, the production and nature of new relations between donor and recipient (Kaufman et al. 2006); the moral ambiguity and obfuscation given in images like the “Gift of Life” (Fox and Swazey 1992; Scheper-Hughes 2007; Sharp 2006, 2007); and the modes of autonomy, empowerment, fairness and exploitation in both licit transplantation and organ trafficking (Kaufman 2013; Scheper-Hughes 2000). Scholars have also given insight into how transplanted organs, initially thought strange or “Other,” become appropriated by recipients as parts of themselves (Ikels 2013). So too have they marked the complex metaphorical renderings of donors – human and non-human – and the naturalization of artificial technologies in the “transplant imaginary” (Sharp 2006). Of donor bodies, Lesley Sharp writes how they are “frequently transformed metaphorically and visually into an array of greenery, including trees and flowers, a set of images that play off the idea that organs are transplanted in or grafted on to new bodies” (Sharp 2006:14). Such images thus allow for the body as a site of rich harvest. Collectively, these analyses draw complex and culturally varied relationships between embodiment and subjectivity, and the fundamentally mutable meanings attached to organs and tissue. They render visible the elaborate sociotechnical apparatuses and symbolic imagery through which novel value is ascribed and seemingly intractable ethical problems neutralized.

Attention has also focused on the procurement of tissues, like the placenta, for which there is no firm guarantee of therapeutic use, and their storage by people who are hopeful that biotechnology will soon reveal their value (Brown 2013; Fannin 2013). Drawing, for example, on Marxist ideas of capital and commodification (e.g., Brown 2013; Waldby 2002), scholars have traced the micro- and macro-political processes, valuations, and exchanges materializing not only in the wake of more established innovations but those that are emerging. These analyses bring critical attention to notions of waste, as a source of latent value, and the moral and economic imperative of claiming this value. They further mark the various labors of transforming bodily material into something of biovalue, that is, “the yield of vitality produced by the biotechnical reformulation of living processes” (Waldby 2002:310). Catherine Waldby, for example, has documented a new medical industrial complex emerging around stem cells, elaborating the idea of a “tissue economy” to note complex translations and transactions in trajectories from so-called trash to treasure (Waldby 2002; Waldby and Mitchell 2006). This work, and especially the notion of economy, is particularly useful in revealing the tensions in personalized immunotherapies and indeed the emerging notion of tumor tissue as currency. Applied to the study of emerging technologies, it alerts us once again to the symbolic and sociotechnical apparatuses involved in the production of biovalue and the differences between “regimes of truth” – when

possibility is supported by evidence – and “regimes of hope” – when value is emergent and unrati- fied (Brown 2013).

A tissue economies framework thus brings to view the many actors and institutions linked through chains of translation and exchange, revealing how the “human body’s productivity is sutured into social systems of productivity, community, and politics, the various proposals for altering the present arrangements, and the kinds of cultural significance that these proposals carry” (Waldby and Mitchell 2006:30). The tissue economy I show in this in article is an emerging cancer tissue economy through which patients desperate for survival engage with their oncologists about harvesting their tumor tissue to gain access to a medical intervention, which is developed and administered by a conglomeration of bioscientists and venture capitalists and based on speculations about improving treatment and generating profit. It is thus an economy that constitutes a “strange harvest” (Sharp 2006:2): strange in its coupling of divergent knowledge systems, values, and labor practices (Sunder Rajan 2012) and its assembling of new meanings in cancer tissue.

The use of tumor tissue for therapeutic means remains very much nascent and the infrastructures supporting their use far less advanced than with other promissory tissues like placental tissue. However, there are strong resonances. Each promise health through the theoretical possibilities of therapy yet remain in the gray zone of expectation without evidence. Each are autologous procedures – where donor and recipient are the same person – avoiding the complex relations and the particular politics of scarcity and exploitation in allogeneic – or person-to-person – transplantation. And they have undergone major symbolic and practical shifts in their ascendancies “from trash to treasure” (Kroløkke et al. 2016) – no longer considered waste or the simple container of diagnostic information but so-called “clinical gold” with therapeutic value (Waldby and Mitchell 2006).

The symbolic transformation of tumor tissue into therapeutic ingredient, however, is arguably even greater. Indeed, there seem few analogues to the production of tumor tissue as a therapeutic agent in people with cancer. While inoculations for diseases like small pox, flu, and rabies might seem close by similarly introducing antigenic or pathogenic material to the body for an immune response, it does not involve the risky and painful processes of harvesting tissue from recipient nor, as I will show, the strange new paradoxes therein. I argue that it requires a leap of faith that is unusual even in the fast-paced, technologically driven world of biomedicine; it requires that we take seriously a new ontology of tumor tissue amid the promise that disease can become cure.<sup>12</sup>

This, I suggest, exceptionalizes the “regimes of hope” newly associated with tumor tissue and the kinds of investment patients are being called upon to make as they join – or submit to – the bioscientific grail-quests for cure. Their investments are not only speculative by the terms of scientific experimentation but rest upon new meanings that radically oppose taken-for-granted notions of cancerous tumors as unambiguously malign. This presupposes a certain kind of “moral experimentation” (Mattingly 2014) on the part of patients, clinicians, and others, which exists in the absence of commensurate cultural scripts and which forges novel engagements with novel meanings. In Cheryl Mattingly’s formulation, these are the kinds of experiment which confront our cultural imagination; they are experiments that unfold in the messy improvised spaces of social life where what is at stake is possessed of moral and existential significance. Mattingly’s work on moral experimentation provides an important theoretical touchstone for my analysis which focuses on patients’ engagements with experimental personalized medicine, a changing ontology of cancer tissue as therapeutically valuable, and the terms of a tissue economy which is in formation.

Accordingly, I argue that we must understand the emergence of personalized immunotherapies as rearticulating relationships between disease and cure, embodiment and subjectivity, the self to the self, as being capable of intervening in longstanding assessments of risk and benefit vis-à-vis routine practices like surgery, and within the complex semiotics of hope and disappointment implied in treatments that are promising and yet unknown on the terms of established evidence. And we need, I suggest, to understand the materialization of a new tissue economy, with its own technical arrangements and its own articulations of value and exchange and how these are shaped in the broader terrains of progressive disease and treatment scarcity. In the following two cases, I further

detail this new and “strange harvest” (Sharp 2006) focusing on what is at stake for patients as they reckon with new hopes, doubts, and dilemmas in this emerging tissue economy. These developments and dilemmas I consider as exemplars of the changing nature of cancer care, with its progressive overlap of the experimental and the standard. I first return to Fay, on the ward and with the nurse poised to inject.

### **Saving and spending: the case of Fay**

Fay winces when the vaccine is given, her eyes closed and squeezing her sister, Maria’s, hand whose finger tips turn white. It takes a minute per injection and there are two of them given intradermally<sup>13</sup> in the upper arm. “At least we know it’s going in properly,” the oncologist says. The nurse bends the needle of each empty syringe and puts them in a tray. She completes some paperwork and calculates the volume of vaccine going in. Maria tries to get Fay to eat but Fay is now distracted with a patient across the room.

I hear snippets of their conversation. “How long does the trial last?” “We saw it on TV.” “It’s for brain cancer.” “You’ve got to be thankful there’s someone somewhere out there with the brains to make it,” Fay says. Adriana, the trials practitioner who has been watching closely, tells me she’s training surgeons to manage tissue for the trial: they cut it into tiny pieces, put it in special tubes and grind it for exactly four minutes. It must be done the day of the operation before the tissue is sent to a laboratory in Germany for further processing. She says that the “trial people ship out the vaccine as needed – they don’t tell us how much they make.”

Having listened to our conversation, Fay asks Adriana how long the trial will last. Adriana doesn’t know exactly: “We just keep going as long as possible.” Fay asks how much they make. “We don’t know – they won’t tell us. You’ll get crossed over at some point, and if we knew how much vaccine there was then we’d know when you were being crossed over.” Patients “cross-over” to the other arm of the trial at some unknown point – from treatment to placebo once the vaccine is finished or placebo to treatment if the tumor progresses. If the team knew how much vaccine was made they could infer which trial arm patients were on – experimental or standard care – and, as I mentioned before, this is a randomized double-blinded trial – neither Fay nor the team know if Fay is getting the vaccine.

I first met Fay just over a week after surgery and days after she was diagnosed. We met in clinic as she discussed chemoradiation (chemotherapy plus radiotherapy) with her oncologist – the clinical standard for glioblastoma since 2005 – which she later agreed to and which was a precondition for the trial. She was shell-shocked, yet trying with her five sisters to quickly assemble information about the high-stakes of intervention or inaction and whether to enter the trial. Cancer had already featured prominently in the family and Fay had devoted herself to care for her parents who died slowly of the disease; in so doing, she forewent other employment.

Fay was approached about the trial the night before surgery and when there was only a suspicion of cancer from a scan. She had consented to the trial’s early stages then because the hospital needed her agreement to process and freeze the tumor for the vaccine.

While she worried about delaying intervention, her doctors also needed an answer. Because of her indecision, they were concerned that she might not be the “reliable subject” they had thought. With increasing pressure to make a decision, Fay fully consented.

Eight months after fully consenting to the trial, Fay and I sit in a consultation room with her oncologist. It is her last chemotherapy appointment but she will continue with the vaccine for now. The treatment seems to be working and Fay’s mood is light after seeing the improvements on a scan. Whether vaccine, chemotherapy, radiation, or a combination is anyone’s guess. Now she is being asked about another trial should the tumor progress. To check her eligibility, the hospital needs to test some of Fay’s tumor tissue – it is framed by the oncologist as “an option for the future.”

“I’m not sure,” Fay says after reading the study information sheet, “I don’t want to go through again what I’m going through now. But I don’t want to feel like I’m missing out either.” The vaccine trial has been hard work with painful injections, frequent appointments, and the uncertainty of not knowing if



she is getting treatment or placebo. “It doesn’t bother me doing tests on my tissue. But if it’s a case of operating again to get more tissue I definitely won’t do it.”

Eventually, Fay agreed to release some tissue for testing from the samples already collected. She is not told how much tissue will be used or how much is left, neither does she ask.

One month later, Fay attends another appointment. Her tumor has shrunk again. Looking at the black and white image on the computer screen, she asks, “Is there a chance it can disappear?” “There’s a chance – with the vaccine there is a chance,” her oncologist says. Fay keeps telling herself she is getting the vaccine and not the placebo.

“I don’t know how many vaccines we have left,” the oncologist says, “I don’t know how many they made – they don’t tell us. It’s at least five.” He mentions nothing about the other trial.

Several weeks later, Fay tells me she has been thinking more about how much vaccine is left. It’s hard not knowing and she’s been trying to find out:

I want to know what happens when the vaccine runs out, so I asked [my oncologist] again. He said they’ll find out how much is left. And then he said once it’s done, it’s done. They don’t make any more vaccine. Now I wish I hadn’t said they could use whatever was left of my tissue for the other trial. . . . Maybe if it’s run out they’d make more vaccine. So now I don’t know what happens when it’s finished, whether it’s just standard care, I don’t know . . . I mean *I* understood that by consenting to the trial the tissue could be used for decades—for however long it lasts. They said it would be kept for 30-years or something.

This response by the oncologist struck Fay as odd because she knew the vaccine was not one shot but an ongoing schedule of injections. She knew that the amount of vaccine produced was dependent on the amount of tissue harvested. So she couldn’t understand why the hospital would not make more vaccine. She never knew how much was made nor how much tissue she had left, and she had no idea how much was required per injection. For Fay, it was a case of economics – when to save and how to spend her tissue. Yet lacking important information about the reserves she had or whether she would need more for the trial, her moral experiments with these decisions were made blind.

### **Possibilities foreclosed: the case of Matthew**

I became fully aware of the strangeness of using tumor tissue for therapeutic means in conversations with Matthew about trials and exclusion. Unlike Fay, Matthew was ineligible for the vaccine trial, even though their diagnosis was the same. I met Matthew when he was in his fifties at an information day for newly diagnosed patients organized by a prominent UK cancer charity. Nicky, his wife, had been invited speak on *The Experience of Being a Carer*. She had spoken authoritatively about Matthew and the nature of cancer care. Both were highly educated, medically savvy, with a determination for inquiry and insistence; Matthew had continued working in the city early during his diagnosis. “Don’t believe your oncology team know everything,” Nicky told an audience of new patients, “they’re human too . . . ask questions, ask about trials and freezing tissue.” I was struck by her authority and the lengths she and Matthew had gone in their quests for cure.

Several weeks after Nicky’s talk, speaking about trial design and how he was continually cast as ineligible, Matthew said to me: “It seems to really discourage initiative.” He and Nicky searched for trials through multiple platforms, though grew increasingly cynical: “The first thing we do is look down the exclusion list and I’ll be excluded by something *always*.” The design of trials contradicted their ideas of equitable care and, moreover, what a patient should be – proactive. As Matthew explained:

We have a family friend with a rare form of bone cancer. *Now he’s on a trial*. I don’t *know* but I suspect he’s not as proactive—he’s just gone along, had his standard treatment or whatever the doctor says. He hasn’t been doing what we’ve been doing which is trawling the internet, trying this, trying that. He’s just sat there and taken what doctors have doled out. But because of that he’s qualified for a trial in Belgium. It seems very unfair to me—we’re the ones really trying and yet by doing that we’re excluding ourselves from trials.

Like Fay, Matthew underwent the eight-month standard therapy for glioblastoma the year before we met. It was toward the end of treatment that they started to think of other options and, like so many I met, their instinct was “to attack.” This was when they first encountered immunotherapy, which they were told was “the treatment of the future.” But then, there were complications, as Nicky explained:

‘The future’ was immunotherapy. Everywhere we turned, that’s what people were saying. And funnily enough I’d even asked [Matthew’s surgeon] before his surgery two years ago. I’d said to him, what’s the future? What should we be looking at? He said “immunotherapy.”

She continued:

I was infuriated. No one had alerted us to the vaccine trial. It would have been a lot better to have had the option to have Matthew’s tumor frozen because then it could have been used for future trials. And no one ever said that to us either. So it was just done in the wax which means it’s pretty useless. If I could go back two years, what would have been incredibly helpful at that point would be to have had someone who knew the situation and could say, “These are some of the things you need to think about – is it operable? Okay, it’s operable. Well consider having it frozen – it might cost you some money – but it’s a good choice for down the line. Have you looked at all the trials *before* you go into surgery?” You needed someone who could help open up your horizon.

Matthew agreed:

People weren’t at all forthcoming with information. We didn’t know. We didn’t even know about freezing tissue – nobody said anything about that to us. That set how we’re now used to it: we’re used to options being closed to us. Especially trials because of something we’ve done in the past without realizing the implications – that’s very frustrating.

Matthew was excluded because his tumor had been processed according to the routines of the pathology laboratory. As I described earlier, tumor tissue is processed differently for the vaccine. Tumors are typically set in wax after surgery because this makes the tissue into a workable material, which can be sliced wafer thin for diagnostic slides and stored for decades. However, the wax also changes the tissue in ways that make it permanently unusable as an ingredient in the vaccine. To be used in the vaccine, tumors must be *frozen*; tumor tissue must therefore be handled by pathologists in ways that contradict routine laboratory practices across the world. Given tissue is processed almost immediately after surgery, decisions about the trial must be made *before* surgery, when first consent for the trial is taken. And given surgery happens often within two weeks of a tumor being suspected, this decision is made in the midst of a confusing and frightening time: when patients are naïve about the possibilities of trials and how to navigate them, when they are struggling to grasp the stakes of their situation let alone understand the implications of things like tissue handling.

Had he known about the vaccine before his first operation, Matthew said he would have insisted on his tissue being frozen. Others I met shared this disappointment and lamented the fatefulness of an operation after which their tissue was not frozen.

Matthew and Nicky never let go of the possibility of the vaccine. When I saw them again a month later, days before Matthew was due for a scan, they were nervous as always. But, unlike the usual fears of new growth, new growth was precisely what they hoped for. They hoped for his tumor to grow enough for a second operation to harvest more tissue for the vaccine to be made privately; such were their hopes in the trial and such are the paradoxes of a strange harvest.

## Discussion: experimenting in ethical matters

These cases reveal how, in a treatment landscape which has barely changed in decades, new hopes are materializing for people with a brain tumor through an understanding of immunity which can be “tuned up” to attack individual cancers. They show how patients, families, clinicians, and multiple other stakeholders are investing financially and emotionally in the promise that disease can become cure, and how contingent these investments are. They also demonstrate how such investments are juxtaposed with major new dilemmas, not least for patients. All this is embedded and wrought through

the broader institutional arrangements of experimentation which have little to offer patients and families by way of certainty or moral clarity. It is indicative of what a number of scholars note as a new style of care in much of contemporary biomedicine, one forged in the progressive overlap of experimentation and standard care (Fisher 2009; Keating and Cambrosio 2012; Petryna 2009). This occasions, to quote Petryna again, “new and often tense medical and social fields” (Petryna 2009:30), a major feature of which is the entailment of particular kinds of patient work (Arteaga 2021). Increased hospital appointments, increased tests, new responsibilities to report adverse sensations, and the burden of facing less than perfect dosing all constitute this work. Significantly, it also includes participation in the uncertainties intrinsic to experimental medicine, as patients reckon with unfathomable odds of success and harm, and encounter a complex ethics in double-blinded designs, where both patient and clinician are uncertain about interventions being given.

Patients’ participate, then, in moral thinking or what I have called “moral experiments” about the nature and value of treatments without mature evidence (Mattingly 2014, 2017). In Cheryl Mattingly’s characterization, these experiments are “socially grounded interventions into everyday experiences” (Mattingly 2017:310), unfolding not within the controlled spaces of experimental science but rather the messy improvised spaces of social life. They are “challenges to cultural imagination” and they bespeak moral experiences possessed of existential significance (Mattingly 2014:157). Such experimentation is common in contexts of care given the often profound challenges people face in these circumstances. But it perhaps takes on particular weight where innovation possesses a more forcible potential to intervene in ordinary understandings of the body, disease, and sociality. For, as scholars of medicine and the body have shown (e.g., Kaufman 2013; Scheper-Hughes 2000, 2007; Sharp 2006), these contexts are loaded with ontological significance and often lack well-established cultural scripts which might offer a way forward.

The moral experiments peculiar to Fay, Matthew, their families, and indeed others engaging in personalized immunotherapies, lie in the terms of a new tissue economy and, critically, in how we understand cancerous tissue. They are particular for patients either side of the line of having their tissue frozen and processed. Those, like Fay, who have tissue reserves, conduct moral experiments in how to spend and save a valuable and finite resource; while those, like Matthew, who do not, experiment with strange hopes for their tumors to grow enough to be harvested and processed with new value. The issues at stake in these moral experiments are failed hopes and the anxieties intrinsic to knowing when to save and when to spend. As I argue in this article, the use of tumor tissue in personalized immunotherapies is changing its very meaning and value. No longer simply regarded as life-threatening disease, tumor tissue is being inscribed with new positive meanings as a therapeutically valuable material associated with its new role as a key ingredient in personalized vaccines. This, I suggest, is a change of such magnitude that it constitutes a shift in the ontological status of tumor tissue: that is, tumor tissue is becoming fundamentally wrought otherwise by new sociomaterial practices.

A tissue economies approach that takes novel uses of tumor tissue in treatments like personalized immunotherapy seriously as an object of study helps challenge the passive receipt of biotechnology and anticipate potential disparities. It provides a focal point at which we see various actors – including biotech companies, venture capital, clinicians, regulators and advocates – converge, and how their competing value systems, routines, and imagined futures gather in manifesting new norms and incentives (Sunder Rajan 2012). It thus reveals the broader social and technical formations into which patients are thrown, the expectations thrust upon them, and the myriad contingencies which foreclose, demand, or steer their choices, ever-complicating their capacities for navigating care. Here, I have focused more closely on how patients engage in this economy. The economy of cancerous tissue remains in-formation. Consequently, the symbolic (for example, regarding hope), technical (regarding treatment efficacy) and economic value of cancerous tissue as a treatment ingredient, and its corresponding status as currency, is yet to stabilize by the terms of scientific evidence and clinical routine. As evidence emerges, either way, and values mutate, it requires further ethnographic documentation of the lived experiences of patients encountering these new technologies alongside accounts of the emerging micro- and macropolitics that bear on their lives. If these technologies enter the field of standard care, as many assume, how will this new tissue economy unfold and how will it be regulated?

How will legislation steer patient and public rights through standard care protocols and what of tissue ownership? How will commercial interests influence tissue storage and use? And perhaps most pertinently, how might the calculus of surgical operations be influenced as the relative worth of an operation – in both survival and economic terms – markedly increases?

I saw Fay again, just over a year after fieldwork and after she had been re-admitted following a seizure. We had kept in touch. I knew that her recent scans had been bad and for the first time – like her – I knew for certain that she had been given the vaccine and not the placebo. After it was noted that her tumor had progressed, she had been taken off the trial and offered a second line intravenous chemotherapy.

Now, she lay in bed, her eyes closed, and when I approached she gave a muted hello. We hugged and sat in silence before the story of the last few weeks tumbled out. The trial had not worked, the chemotherapy she had started a month ago was on hold, her eyesight had worsened, and she had just been told she “might never need to go home.” Her mood was flat, her voice empty of its usual energy and spirit. She kept circling back to the trial, to the sadness, to how her “world has come crashing down.” Everything now was at a hiatus.

Fay died several months later, almost two and half years after diagnosis.

Matthew died shortly after I left the field, nearly three years after diagnosis. His tumor had also grown as he had once wished. But it had grown skein-like through the tangles of his brain and was no longer operable. He was treated with a controversial drug called Avastin, which he funded through crowdfunding, and made several trips to Germany for another course of a different, non-personalized immunotherapy shortly before he died.

Nicky and I met recently about collaborating on another project. Reflecting on how she and Matthew understood and sought places on trials, she spoke of hope and told me how hope is more than just a sentimental thing; it becomes very real. Knowing early on in Matthew’s disease what they came to know about trial access and eligibility, and the various databases and patient forums, Nicky said they might have “stumbled on” the personalized immunotherapy earlier. This brought home the feeling of exclusion by an earlier set of decisions they were not part of, and it was the treatment they so desperately wanted. Nicky’s reflections bespeak the timeliness of care and the multiple rhythms one encounters and comes to know along the way.

Although the immunotherapy vaccine ultimately fell short of Fay’s hope to live ten more years, it remains promising among the brain tumor community (Lui et al. 2020; Mastelic-Gavillet et al. 2019). A May 2018 article published promising interim results for DCVax-L, with a six-month increase in median survival among all trial participants (regardless of trial arm<sup>14</sup>) compared with usual survival after standard treatment observed in past studies and clinical practice (Liau et al. 2018). The Brain Tumor Charity – a prominent UK-based advocacy group – issued a statement in their news blog on 29 May 2018 immediately after publication of these results and heralded a possible “paradigm shift in the treatment of brain tumors.” Others have been more temperate. Another UK-based charity, Brain Tumor Research, countered the following day in their blog with concerns over the high cost of the vaccine, the ethics of making treatments available for private use, if they are not publicly fundable, and the risks of “giving false hope . . . when the data is hopeful but not yet clear.” So far, NICE have remained silent on the question of DCVax-L. Their review has remained suspended since September 2018.<sup>15</sup> As reported on the Brain Tumor Charity’s news and emerging treatments pages, if NICE approves DCVax-L, and if full regulatory approval is granted, the NHS would be obliged to make DCVax-L available to patients with newly diagnosed glioblastoma within three months. Importantly, hopes in tissue-based therapies have also informed calls from UK advocates to standardize the flash freezing of tumor tissue in post-surgery protocols and prompted the US-based National Brain Tumor Society to include an item about freezing tissue for vaccinations among a list of 10 recommended questions for patients to ask their surgeons.

These responses outline the stakes of promissory technologies and their integration in routine care. They highlight the complexity of access to costly treatments and the desperation among cancer communities for new ways to deal with an extremely aggressive disease amid an extremely impoverished treatment landscape. They articulate the fine line between hope and hype.

## Notes

1. Many hospital staff participated in research programmes, including the study described here, as principal investigators, collaborators, recruiters. Such collaboration is common worldwide and reflects styles of care in which research and treatment are increasingly elided. To my knowledge, no individual clinician nor researcher I met had any financial relationships to the vaccine's producers, nor did the hospital, beyond service support costs routinely payable to recruiting organizations.
2. Study entry criteria, or inclusion/exclusion criteria, are items in trial protocols which distinguish eligible patients by the terms of study design.
3. A molecule capable of inducing an immune response.
4. Tree-shaped cells that initiate adaptive immune responses.
5. Personalized immunotherapies are also being trialed in colorectal, lung, and prostate cancers.
6. For comparison, NICE supports immunotherapies and “targeted therapies” to treat both breast and lung cancers, alongside surgery, radiotherapy, and standard chemotherapy regimens, which are also more numerous than in brain tumors (NG101, NG122). NICE encourages clinicians to advise patients that available evidence does not support immunotherapy in brain tumors (NG99). Strikingly, the US National Institute for Health lists six approved drugs for treating brain cancer, compared with 43 and 38 for breast and lung, respectively (<https://www.cancer.gov/about-cancer/treatment/drugs/cancer-type>, Accessed 3rd March 2021).
7. <https://nwbio.com/dcvax-technology/>, Accessed 3rd March 2021.
8. <https://nwbio.com/dcvax-technology/>, Accessed 3rd March 2021.
9. By “brain tumor communities,” I refer mainly to diverse groups of people affected by tumors, both patients and families, as well as advocates and healthcare professionals involved in care, treatment, and advocacy. The invocation of community is used similarly by such groups, both in conversation and print. For example, the International Brain Tumor Alliance (<https://theibta.org/who-we-are/accessed> 3rd March 2021) and the UK-based Brain Tumor Charity (<https://www.thebraintumourcharity.org/about-us/who-we-are/our-history/accessed> 3<sup>rd</sup> March 2021) both state their goals of bringing a brain tumor community together.
10. Other criteria included being aged 18–70 years, no progressive disease after radiotherapy, adequate liver and bone marrow function, and willingness to forego chemotherapies other than first-line temozolomide.
11. Another eligibility criteria required sufficient vaccine (≥5 doses) to be available after manufacturing, contingent upon the amount of tissue obtained by surgery and its viability in vaccine production.
12. By calling attention to a changing ontology of tumor tissue, I am drawing on theorists such as Annemarie Mol who cite ontology to reside in practice, not simply in the “order of things” given in abstract reference. For Mol, ontologies “are brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices” (2002:6). This bespeaks the overwhelming embeddedness of disease in sociomaterial practices, and as such its reconfiguration in new practices. It further points to the magnitude of change in how we might understand tumor tissue through personalized immunotherapy, its broader industrial enterprise, and the hopes and dilemmas inspired therein.
13. Intradermally meaning into skin.
14. Interim results were published without unblinding trial data, meaning investigators analyzed data without knowing which arm trial participants were on. Investigators reasoned that inferences of promising results were valid because most of the sample (86.4%) were known to have received DCVax-L at some point (due to the “cross-over” design). NW Bio had resisted unblinding trial data because an insufficient number of deaths had occurred and data monitoring was incomplete. In October 2020, the database was locked and arrangements made for independent statisticians to access unblinded data.
15. NICE’s review was suspended because NW Bio could not submit appropriate evidence for appraisal.

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