Living in Queer Cancer World: Our Stories

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About the Project

This project brings together and amplifies the voices of a diverse group of people living with and beyond cancer from the LGBTQIA+ community, at the intersections of class, race, religion, age, and disability. The aim of the project is to help increase the visibility of LGBTQIA+ experiences of living with and beyond cancer. The project identifies some of the common themes of our lived experience and the range of creative and critical ways participants have responded to a cancer diagnosis. *Living in Queer Cancer World: Our Stories* celebrates our creativity, criticality, and achievements despite and sometimes even because of our cancer.

Project statement

> "Cancer world is of course bloody awful. This was not a surprise. But the fact that it was so weird, alienating, and at times, scary for me as a LGBTQIA+ person was a surprise. So this is a story about what it's like being queer with cancer, and feeling like the system that is trying to reset you to a pre-cancer version of your body is also mashing the factory reset button on your sexuality and gender, trying to put you back into the box you've fought your whole life to get rid of[1]."

Queer Cancer World

Receiving a cancer diagnosis not only confronts a person with their own mortality, creating ruptures in how one might have lived previously, but also thrusts the person into a new world – what Nancy Kelley, the human rights activist, and former Executive Director of Diva magazine calls *Cancer World.* Nancy's story highlights some of the issues LGBTQIA+ people grapple with as we try to find a map to navigate this strange and shaming environment. This includes its brutalizing treatment, and the politics that shape the social, cultural, and historical dimensions of different cancers as they are lived and experienced. Following her diagnosis of breast cancer, the black feminist lesbian poet and writer Audre Lorde asked an important question which has guided this project: Where are the models for what I am supposed to be in this situation? (Audre Lorde, The Cancer Journals). Lorde's question prompts us to look outwards, to other people's experiences, and to the narratives that are available to make sense of this question.

The project, *Living in Queer Cancer World: Our Stories,* brings together queer storytellers and creative practitioners and artists who in different ways are using their experiences of living with and through a cancer diagnosis to explore, unsettle, and transform normative narratives of health and illness. They give voice to LGBTQIA+ experiences of cancer care and treatment using different forms of writing, artistic and creative practice, performance, and photography. Many are also involved in cancer advocacy, activism, and community-

organising, as well as academic research, media work and public speaking. In response to Lorde's question, we explore in different ways what queer cancer narratives might look and feel like. The contributor stories have been shaped through the work, research, and creative enterprise of a team of collaborators. This includes the queer Hong Kong film maker, Dr Kit Hung, whose amazing skills come through in the films in multiple ways. Having recently completed a practice-based PhD at Goldsmiths' Kit's 'hauntological editing' works at an affective and emotional level, to provide a space for grieving, loss, pain, joy, and humour.

We have also established and practiced *an ethic of care and attention,* which rejects transactional relations. We have worked hard to forge connections through shared vulnerabilities, and the creation of bonds of solidarity and camaraderie. These affective relations were an important part of the storytelling process, with a long process of relationship-building and rapport prior to the filming. These relations are captured through the banner headline of the project website, which includes a reel of clips which show the relationships between me, as the Project Director and interviewer, with our participants or storytellers. We laugh, hug each other, and delight in the experience of talking with somebody who "gets it", which enables rehearsed narratives to dissipate and for something else to emerge.

Queer Cancer Narratives

One of the storyteller's, Cengizhan Sen, has explored the question of what queer narratives might look or feel like in a moving article, *Cancer Hits, The Queer Spirit Returns Fire*[2]*,* which provides a document and testimony of his lived experience of cancer. He writes as a young person from the LGBTQIA+ community, who received a cancer diagnosis and treatment for lymphoma at the age of 24. He incisively interrogates some of the complexity of what it feels like to live with and beyond cancer as a queer person.

> "A disease like cancer can sully the colours of the rainbow and disrupt the control queer bodies establish for themselves. This, by all means, does not exclude heterosexual patients, but for the queer case, it can be far more threatening".

Rejecting sanitized accounts, his writing gives form to what is often excluded or marginalized within LGBTQIA+ communities in the context of illness and disability. He also identifies and navigates the intersections of queerness, cancer, and intergenerational histories of migration and religion in a way that shows the resilience of queer/trans communities in the face of oppression. He explores the importance of inventing narratives that can carry and articulate our experiences to others. His writing practice acts as a communal project of self and social storytelling that *queers* the cancer experience. Like many contributors to this project, he argues for the need to invent narratives of health and illness that cogently give shape to what is felt and lived beyond heteronormative cancer tropes and representations.

Storytelling is an important part of the cancer experience that enables us to seek connection and solidarity. We can find others, and build community and networks, establishing important relations near and far, whilst developing friendships of solidarity and support. These are especially welcome or needed when you feel alone or isolated as a queer person

navigating cancer. You might post on social media, write blogs, or publish articles on Substack, or in other media supportive of queer cancer experiences (Mel, Cengizhan, Nancy, Hannah, BLKGEEZER). You might develop a drag performance persona and new storytelling rituals, inspired by queer/trans club, and arts scenes, to carry and communicate difficult feelings, amplifying pathos and humour (Amy). You might find your peers in queer cancer support groups, such as those run by OUTpatients.org, where you don't feel your experiences are erased or made invisible[3].

Some participants give voice to their experiences by becoming ambassadors for charities that accept the specificity of their LGBTQIA+ identities, as it intersects with the politics of the specific cancer that they were diagnosed with (Mel, Louise, Hannah and Cengizhan). New forms of kinship can be made through advocacy, activism, and participating in research, or leading PhD projects on cancer kinship and the lived experience of teenage cancer patients (Hannah). We can invent creative and artistic projects as important ways in which cancer can be de-shamed and the burden is interrogated, shared, and hopefully lessened (Amy, Cengizhan, BLKGEEZER, Gordon). We can invent new rituals to face death and mortality, drawing inspiration from previous queer mourning practices, such as the AIDS quilt.

We have explored some of these issues in a digital storytelling workshop, with some participants responding to the question of what would be in your queer survival kit to navigate cancer. The responses have echoes with similar projects, developed in the context of living with HIV and Aids. One of our storytellers, Gordon, for example, had previously been involved with *Through Positive Eyes,*[4] a "collaborative photo-storytelling project by 200 people living with HIV and AIDS in cities around the world". Gordon created the *Bag of Shame* project documenting some of the ways in which he had been shamed as a person living with HIV[5]. Like Gordon's *Bag of Shame* project, storytelling projects can help to create new narratives whilst banishing the shame of cancer, creating new knowledge and imaginative forms of public engagement. For many who have contributed to this project, there is a need to write, or produce artistic work, which explores the nuances of our cancer stories as they intersect with other issues, such as histories of HIV and AIDS, and of disability and neurodiversity (Gordon, Hannah), of trans rights and disability activism (Nancy), of the politics of cancers, such as the increasing diagnosis of lung cancer in women who have never smoked (Mel).

Other participants in this project have responded to a cancer diagnosis by creating or inventing the kinds of communities or social projects that they want to see, rather than wasting precious time waiting for others. Louise Dalglish's founding of *Butch Revival*[6] in Manchester is a good example of how her lived experience of cancer and disability intersected and provided the catalyst for their role in a queer community-building project. *Butch Revival* is a social networking hub and monthly club night Influenced by Louise's interest in butch-femme histories from previous eras, including the infamous *Rebel Dykes*[7]. Louise lives with a rare congenital condition that was diagnosed at the age of 6, known as *Falconi Anaemia*. Falconi Anaemia is a life-limiting condition, which predisposes a person to a range of different cancers, requiring constant interventions and treatments. Unable to study a BA in Photography because of the effects the chemicals would have on her body, Louise took inspiration from photographs that documented butch-lesbian scenes in the

1980's and 1990's, including the book, *Stolen Glances: Lesbians take Photographs* (Boffin and Fraser, 1991).

The artist BLKGEEZER, responded to their diagnosis of breast cancer through inventing an artistic and writing practice which visualises how their creative practice and lived experience of cancer have become entangled[8]. They have invented generative powerful abstract paintings and speculative concepts/experiments, such as *Black Nausea* and *Breastistentialism* that speak to Audre Lorde's question in the context of being a queer black working-class artist living with cancer.

> THERE IS NO MANUAL TO BE AN ARTIST WITH CANCER.
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> THERE IS NO MANUAL TO BE A BLACK ARTIST WITH CANCER.
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> THERE IS NO MANUAL TO BE A YOUNG BLACK ARTIST WITH CANCER.
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> THERE IS NO MANUAL TO BE A YOUNG QUEER BLACK ARTIST WITH CANCER.
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> THERE IS NO MANUAL TO BE A ONE BREASTED YOUNG QUEER BLACK ARTIST WITH CANCER.
>
> THERE IS NO MANUAL TO BE A NUANCE.
>
> THERE IS NO MANUAL TO BE ME.

BLKGEEZER's art and writing practice responds to social gaps, and haunting silences, including transgenerational traumas of racism and misogyny in the context of illness and disease. They have created a powerful urgent voice that confronts the viewer and listener with structures of feeling and knowledge that shapeshift through their creative and critical forms. The images and text communicate and confront audiences with the stigma, discrimination, and oppression of their and many others' lived experience of cancer and racism. The artist recounts in their story how an encounter with a play about Henrietta Lacks, called *Family Tree,* changed their life. *Family Tree* was the winner of the 2021 Alfred Fagon award written by the queer Black British playwright Mojilsoa Adebayo. It brings the African American woman's story into the present; a story which explores how her cancer cells were harvested and used without her consent or knowledge. Mojisola's imaginative retelling speaks back to how Lack's body was appropriated and used for extraction, reminiscent of the practices of the slave-owner.

Henrietta Lacks has made an enormous, largely unacknowledged contribution to the advancement of treatments for cancer, such as chemotherapy. As Mojisola states in an interview about the play and Henrietta Lacks' legacies,

> "If you have ever taken medication or had a vaccination, a treatment for Cancer, IVF, HIV - just about anything really, it has been tested on Henrietta's cells[9]"

BLKGEEZER saw the play in August 2021, around the time we were both diagnosed with breast cancer. I was there, having been diagnosed just two days previously, reeling from the

news, and in a state of shock and bewilderment. BLKGEEZER saw the play, perhaps even on the same night, where it was being performed in the beautiful gardens of Eltham House, London, as part of the *Greenwich and Docklands International Festival.* In the preparation for BLKGEEZER's story, I asked whether there was anybody they would like to voice their own writing, which speaks so powerfully to hidden and displaced racist and misogynist histories of both the past and present. I was thinking of queer black working-class writers, including Mojisola who is a friend of myself and my partner, the queer novelist, Isabel Waidner. Mojisola is a significant role model for BLKGEEZER, and so it has been a wonderful gift for Mojisola to voice some of BLKGEEZER's incredible writings as part of her story.

These examples from Louise and BLKGEEZER's stories illustrate transformative moments of shared inheritances and powerful exchanges across time and space. They show how queering cancer narratives might involve drawing and reanimating our ancestors, allowing us to repurpose existing archives, stories, philosophies, narratives, books, films, plays, art, and photography, bending them into new shapes that can hold and convey how we feel and what might be possible in the context of living with and beyond cancer.

The participants in different ways also experiment with and make visible the contradictions and ambiguities of the lived experience of cancer at different intersections and histories. They speak back to what is often presented as the binary of a pre and post cancer self. We are supposed to emerge unchanged, or present cancer as a gift for self-transformation, or at least this is a popular mainstream representation. However, gift in this context can mean very different things depending on your politics and ethics. It is not simply a form of recuperation of a previous self, now changed or even improved in some way, but can enact new forms of connection and meaning. We can create radical subjectivities that unsettle boundaries between self and other, past and present, and life and death, as with the queer poet, Andrea Gibson's sharing of their own experiences of cancer through poetry to create a sense of collective emotional intimacy[10].

In other contexts, presenting cancer as a "gift" is an impossible and unwanted framing, which does not do justice to what it feels like to live with and beyond cancer. Navigating the different thresholds that a cancer diagnosis and treatment brings is not easy, with the potential to activate previous histories of both disability, ill-health, trauma, and inequalities. Many people, such as some of the participants in this project, live *with* cancer, they are on continual treatment, dealing with daily side-effects, and living with visible and hidden disabilities due to the cancer and treatments. Cancer is a disability issue for life, which intersects with other experiences of social inequality and discrimination. Cancer manifests through the anxiety of scans, in prognosis and survival rates, and numerous uncertainties, often alongside managing other people's perceptions. "But you look so well", a complement or reassuring statement in one context, can hide or minimise the physical, emotional, and material challenges.

Sometimes you lose friends that you thought had your back, captured by the concept of *cancer-ghosting*, a phenomenon explored cogently by Cengizhan in their writing and story. Everybody in this project can speak to this phenomenon, and the sense of rejection that is felt. We hope more awareness of this amongst LGBTQIA+ communities will help open a space and more dialogue about these issues, often amplified for those who do not have

family support or rely on the support of their chosen families. Cancer-ghosting can add to the sense of shame and stigma that still surrounds the lived experience of cancer for many, enacted by those who they previously had close relationships with.

On a different note, the lived experience of cancer, and its social dimensions can also drive community-building projects. These projects of care and generosity can also benefit and reach out to those from the non-cancer community who can learn, listen, and help us all to shape more inclusive cancer care and treatment. Cengizhan's *The Poorly project*[11] is an exemplar of how our skills and expertise in one context (previously working as a producer and arts administrator for *The Sarabande Foundation,* currently an arts administrator for Creative Health Camden) can be translated into art projects, which centre the voices and creative practices of artists exploring sickness, health, and wellbeing, informed by their own experiences of illness and disease.

Cancer Trauma

Telling our stories through different creative mediums and practices highlight issues that still need attention and urgent change if we are to improve health disparities and social inequalities. Cancer is traumatic and trauma is capacious. The trauma of cancer intersects with the traumas and social injustices of racism, disability, class, sexuality, and gender in ways that demand our attention. We need more research, and meaningful inclusion of the voices of those who have lived experience to tackle these issues. Cancer can collect up previous traumas and histories of being shamed and humiliated, a lingering or latent homophobia and transphobia, or histories of more overt attacks on one's being that are both spoken and unspoken, or transgenerational histories of racism which intersect with the histories of racism in the healthcare system.

Cancer threatens, reminding minoritized communities of the accumulated threats carried in the body and their deep histories. These traumas sometimes return when you least want them or can cope, often when we are at our most vulnerable, dependent and in need of care and support. As Nancy Kelley, has cogently said in relation to her own and other people's experiences of cancer in the LGBTQIA+ community,

> "Cancer drags up everything in its wake: our histories, our identities, our trauma. And then for LGBTQIA+ cancer patients, cancer world – cancer culture – puts the boot in, making it clear that we do not fit, and if we want to be a "good patient", we should get back into our neatly gendered boxes. It doesn't have to be that way. A queerer cancer world is possible. Not only that, it is necessary"[12].

Storytelling can act as an antidote, and as an act of collective care and kindness. We can help lessen the after-effects of poisonous toxic environments of treatment, and counteract unwanted experiences of being misgendered, or misrecognised, neutralizing them with queer love, care, seriousness, and sometimes joy, even if just for a moment. Storytelling in all its multiple forms and mediums creates conditions that can be contagious, leading us to seek out and find inspiration from other people's experiences. Engaging with Andrea Gibson's poetry provided a constant background of feeling and sense during my own cancer treatment, for example[13].

We can become part of collective storytelling projects, such as this one, amplifying each other's voices, and helping to create and find shared hope and solidarity. We can find ways, together, to name some of the things that are more difficult to say publicly or to those who don't "get it". This might include experiences of family estrangement or difficult family bonds, which bring unwanted discrimination and a "cancer burden", often translated into risk factors (smoking, addiction, risky behaviour, obesity). The challenges are stark, especially when we consider the lived experience of teenage people diagnosed with cancer, who, are "not quite adult, not quite child", as Hannah argues, and the traumas that are part of navigating such difficult issues.

It is recognised within the medical and related literatures that there are specific traumas that are associated with LGBTQIA+ increased cancer risk and burden, but sadly the language feels pathologizing. It is shaped through an old history, bringing with it a moral sense of failure, or shame, with the long association between so-called deviant sexualities and deviant lifestyles hanging over us. If we add race, class, and disability into the mix, we can see how important it is to create new languages of risk and "cancer burden" that do justice to our experiences of social inequalities and health disparities and can help lead the change that is so needed. This need comes through powerfully in different ways in all the stories represented in this project, with important messages and information for healthcare practice and for professionals committed to delivering more inclusive cancer care and treatment.

Cancer Futures

We hope to build on these important issues in further research. One aspect will be to consider and help invent a *new language of risk and cancer-burden* that is fit for purpose. This updating of an old framing of deviancy should be informed and led by queer people who are living with and beyond cancer. There should be nothing done without us if we want to make meaningful change. The research that underpins this project has significant policy implications for improving health and wellbeing and for reducing the disparities in healthcare and medical research for minoritized communities. Queer cancer storytelling and the use of creative methodologies has the potential to provide new ways of exploring health disparities in cancer care, prognosis, and outcomes, that have and continue to shape, what I call the wider *body politics of cancer.*

I hope that you will join us by supporting the project and sharing the stories of those who have contributed their time and energy. We all hope to make a difference to how queer cancer issues are perceived and understood and to support the work of queer cancer charities and organisations, such as *OUTpatients.org.uk*, our partner in this project. We have presented a small fraction of the footage we have filmed and hope to produce more content as the project develops. We also hope that the resources that our participants have made available will offer comfort, support, and knowledge from our own lived experiences. This project is for everybody, including friends and partners of those diagnosed, and researchers and professionals committed to understanding and delivering more inclusive cancer care. It is for those outside of LGBTQIA+ communities who want to learn about the specific issues facing queer people living with and beyond cancer. Importantly, this project is for anybody

within our community who is diagnosed or living with and beyond cancer. You are not alone.

I will finish with the words of Cengizhan who provides a rousing call to action and a vision for how queerness can and arguably should meet cancer on new terms that are of our own making.

> "The appropriate care from our community and medical professionals may allow us to understand the necessary measures to establish a life conducive to one's well-being. We begin to harvest the elements needed for a fruitful, self-driven existence, bountiful in love and fuelled by conscious attention to our emotions, needs and wants. An existence not centred around the expectations and outlooks of others who are illiterate about the queer narrative….So raise your flags; don the rainbow; be heard and be seen. Many areas of cancer care still don't meet the needs of LGBTQ+ patients. It remains to be seen how treatment will evolve. Until then, I envision scenarios where LGBTQIA+ survivorship is shared, discussed, and brought out from under the shade."
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> "I hope to walk through the treatment ward and hear the voices of community members expressing their concerns, joy, and pride as they re-discover themselves in the face of cancer. In that moment, I will see the soaring band of colours once again.[14]"

Professor Lisa Blackman, Project Director.

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[1] Nancy Kelley (2025), 'What it's Like to be Queer with Cancer'. *DIVA magazine*, Pride issue (June/July). Available at: https://diva-magazine.com/2025/07/07/what-its-really-like-being-queer-with-cancer/
[2] Cengizhan Sen (2024) 'Cancer Hits. The Queer Spirit Returns Fire'. *OUT FRONT Magazine, OFM* (22, August) Available at: https://www.outfrontmagazine.com/the-queering-of-cancer/
[3] https://outpatients.org.uk/event/peer-support-for-people-living-with-and-beyond-cancer-nov-2024/
[4] https://throughpositiveeyes.org/
[5] https://throughpositiveeyes.org/gordon
[6] Shannon Moyce (2025). 'Meet the photographer keeping butch history and community alive', DIVA magazine, 7 April. Available at: https://diva-magazine.com/2025/04/07/louise-dalgleish-butch-revival/
[7] https://www.instagram.com/rebeldykes/?hl=en
[8] https://almapearl.com/exhibitions/13-blckgeezer-black-nausea-24/
[9] https://www.theatrebythelake.com/2023/04/17/family-tree-interview/
[10] Available at: https://substack.com/@andreagibson
[11] https://www.instagram.com/poorlyproject/
[12] Nancy Kelley (2025), 'What it's Like to be Queer with Cancer'
[13] See for example, https://andreagibson.substack.com/p/love-notes-from-the-chemo-room.
[14] Cengizhan Sen (2024) 'Cancer Hits. The Queer Spirit Returns Fire'