

Declercq, Dieter, Dikomitis, Elena, Meinen, Lisanne, Schoendube, Fabius, Shaughnessy, Nicola and Vanhoof, Silke (2026) *Podcasting as scholarly practice of care. Producing, contributing to and listening to Autistic Counterstories*. *Asian Journal of Medical Humanities*, 4 (s1). ISSN 2751-0069.

Downloaded from

<https://kar.kent.ac.uk/112791/> The University of Kent's Academic Repository KAR

The version of record is available from

<https://doi.org/10.1515/ajmedh-2025-0019>

This document version

Publisher pdf

DOI for this version

Licence for this version

CC BY (Attribution)

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in **Title of Journal**, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).



Dieter Declercq*, Elena Dikomitis, Lisanne Meinen, Fabius Schoendube, Nicola Shaughnessy and Silke Vanhoof

Podcasting as scholarly practice of care. Producing, contributing to and listening to Autistic Counterstories

<https://doi.org/10.1515/ajmedh-2025-0019>

Received July 15, 2025; accepted October 10, 2025;
published online December 22, 2025

Abstract

Objectives: This co-authored article examines podcasting as a scholarly practice of care. Our case study is *Autistic Counterstories*, a three-part podcast mini-series which sets out to celebrate and affirm the diverse perspectives of autistic people, informed by research developments and lived experiences. The authors of this article reflect on podcasting as a scholarly practice of care from within their specific positionalities as producers, contributors and listeners.

Methods: This article plays with the form and style of academic writing to capture the affordances of podcasting to both represent individual thought, as well as to stage dialogic exchange. The authors of the article first present their individual perspectives on their engagement with *Autistic Counterstories* before engaging in a dialogic exchange.

Results: The Individual Perspectives of the various contributors reveal a polyphony of engagement with *Autistic Counterstories*, including some unresolved tensions. The Discussion weaves together exchanges about three issues, i.e. the need for critical awareness of podcasting as mediated – and therefore limited – encounter; the specific kind of care involved in podcasting, which differs from traditional research projects; and the real value of podcasting – not as a finished product – but as ‘continuing conversation’ and ongoing process of encountering with care.

Conclusions: This article, we hope, constitutes such a ‘continuing conversation’ in action. One particular value of the encounter we have staged in this article (especially in

the dialogic Discussion section) is that it provides space to critically reflect on limitations, imperfections and tensions in the podcasting process – in a way that they could not be addressed during the production process. Here, there is a clear synergy between the spaces of the scholarly podcast and academic article. This article itself serves to demonstrate that we should not aim for podcasting to deliver a final ‘perfect’ product, but rather that it should prompt continuing conversations, where we take care to navigate the complexities of the podcasting process.

Keywords: podcasting; autism; care

Introduction

Podcasting is booming. Scholars in the medical and health humanities, too, have turned to this relatively easy-to-access and cheap-to-produce medium to engage academic and non-academic audiences. Some examples of podcasting projects in the field of medical and health humanities include (in alphabetical order) *Bioethics in the Margins* (2021-pres.), *BMJ’s Medical Humanities podcast* (2014-pres.), *Conversations about Arts, Humanities and Health* (2021-pres.), *Docs with Disabilities* (2020-pres.), *Drawing Blood* (2021–2024), *For the Medical Record* (2023), *In the Same Vein* (2024), *Massively Disabled* (2023), *The Graphic Medicine Podcast* (2015-pres.), *The Nocturnists* (2016-pres.) and *Visible Voices* (2020-pres).

The scholarly podcast is somewhat of a “semi-formal” space [1]. On the one hand, podcasting is less formal than traditional scholarly outputs, like books, articles, conference presentations and grant applications. The medium also has a lower threshold for participation and inclusion. While it may be difficult for someone working in French Literature, say, to publish in a journal devoted to Respiratory Medicine (or vice versa), it is easier to curate an encounter between people from disparate fields in a podcast. The conversational nature of podcasting is particularly valuable to an interdisciplinary and interprofessional field like the medical and health humanities, as it lends itself to setting up encounters between researchers from diverse disciplines,

*Corresponding author: Dr. Dieter Declercq, University of Glasgow, Glasgow, Scotland, E-mail: Dieter.Declercq@glasgow.ac.uk.

<https://orcid.org/0000-0003-0422-694X>

Elena Dikomitis, Studio De Nok, Kortrijk, Belgium

Lisanne Meinen and Silke Vanhoof, Independent Researcher, Antwerp, Belgium

Fabius Schoendube, Leiden University, Leiden, The Netherlands

Nicola Shaughnessy, University of Kent, Canterbury, England

non-HEI partners like healthcare professionals or charity workers, as well as community members and service users. Moreover, despite increased investment in open-access publishing, academic publications – as specialised, disciplinary contributions – remain generally inaccessible to a large majority of people. As a medium which does not rely on the written word, podcasting is a means of democratising information. In this respect, audio has been at the heart of much inclusive education. Because of its relative ease of production, low cost, and ‘semi-formal’ nature, the medium of the podcast can serve to promote social justice, as it more readily facilitates the inclusion of perspectives from underserved communities.

On the other hand, scholarly podcasting is not a completely informal or ephemeral form of encounter, like a chat in the corridor or a meeting at a conference dinner. Podcasting ‘enshrines’ conversation into digital artefacts that people can engage with in casual ways, but which are nonetheless accessible for scrutiny and analysis. Making a podcast also involves an intentional production process that differs from mere ‘recordings’ (say, of a conference talk), which might find their way online in an unedited form. While such recordings make an event available for someone who may have missed it (often in a limited fashion, e.g. with unclear audio or without editing), podcasts are purposefully designed as the main event. This purposefulness of podcasting creates a distinct form of scholarly encounter between producers, contributors and listeners. We therefore set out to examine the podcast, not primarily as an aesthetic artefact, but as a specific practice of care that facilitates scholarly encountering in and beyond the academy [2]. Such an investigation is necessary because podcasting is still a relatively new scholarly medium. In this article, we set out to identify how it can constitute a scholarly practice of care through producing, contributing and listening. Moreover, the academic structures we have in place to safeguard carefulness in scholarly encounters – like the Ethics Reviews – are not necessarily set up to accommodate the novelty of this practice (as we reflect on in the Discussion).

Our case study in this article is *Autistic Counterstories*, a three-part podcast mini-series produced by some of the co-authors, which sets out to celebrate and affirm the diverse perspectives of autistic people, informed by research developments and lived experiences. *Autistic Counterstories* was commissioned by the Autism Ethics Network at The University of Antwerp in Belgium. It was awarded a Community Voice Award and Anthem Silver Award at the 2024 Anthem Awards (Category: Diversity, Equity & Inclusion

– Podcast or Audio). Its three episodes present a selection of ‘counterstories’ to dispel myths and counter oppressive narratives about autism, and honour the diversity of autistic lives [3]. Episode 1 looks at late diagnosis, the validity of self-diagnosis, and the intersection of autism, race, and gender. It introduces stories from Imane, Leila, and Silke, three people who found out they were autistic later in life. Episode 2 introduces perspectives from autistic people who communicate in different ways. We join Gabriel and his family for a piano class; we listen to Silke as she reads us some poems by the autistic poet Birger Sellin; and we hear from Christiane, a friend of the Sellin family, who uses facilitated communication to talk to her own autistic son, Christoph. In Episode 3, Terre, Sym and Maysa reflect on the connection between gender, queerness and autistic identities, while assistant producer Louis reflects on his own autistic experiences growing up.

In this article, we bring together critical perspectives from people who have engaged with *Autistic Counterstories* in different ways as producers, contributors and listeners. Silke Vanhoof (SV), who features in the podcast, examines how podcasting can perpetuate neuronormativity in subtle ways. Lisanne Meinen (LM), who was part of a listening event, develops an ethics of care in the listening encounter with podcasts. Similarly, Fabius Schoendube (FS) engages with *Autistic Counterstories* as a listener, and explains why it is so difficult to fully capture autistic-trans embodiment. Nicola Shaughnessy (NS), who both features in the podcast and offered consultancy in an advisory capacity, reflects on how we can represent autistic perspectives with care. Elena Dikomitis (ED), *Autistic Counterstories*’ executive producer, wonders how we can get listeners to engage with podcasting stories about autism. Finally, co-producer Dieter Declercq (DD) reflects on how podcast production can stage encounters across Difference. The formatting of our article reflects the ways in which podcasting expands the formal and stylistic possibilities of scholarship. The next section shares Individual Perspectives from the six co-authors, followed by a Discussion Dialogue, where we pick up on and respond to our different modes of engagement with the podcasting process. Three key themes around podcasting as a practice of care emerge from this Discussion, i.e. it involves critical awareness of its mediation and limitations; it presents different ethical challenges than standard research projects; and its success lies in the cultivation of an ongoing encounter between producers, contributors and listeners. In the Conclusion, we highlight the importance of framing podcasting as a practice of care in terms of a Continuing Conversation.

Individual perspectives

How can podcasting perpetuate neuronormativity? (SV)

Following my participation in *Autistic Counterstories* as a participant (interviewee), I was invited to reflect on the uses and limits of podcasting as a medium for representing autistic perspectives and perspectives about autism.

Prior to turning to the question at hand, I wish to critically reflect upon the nature of this invitation. The suggested binary of use(fulness) vs. limitation inherent to it, first warrants scrutiny. This juxtaposition recalls the failure by the widely applied medical or individual model of disability to recognise the meaningfulness and functionality of certain autistic behaviours such as echolalia (repetition of phrases, words or syllables, immediate or delayed) and stimming, the “tendency to engage in repetitive physical movements or other actions that provide forms of sensory stimulation” [4]. The medical model renders these “echophenomena” undesirable traits, claiming they limit the autistic individual and their surroundings [5].

Rooted in “ableist ideologies”, these assumptions must be countered by models that do more justice to the complexities of dis/ability, such as the “political/relational model of disability” [6] and the more widely recognised “social model of disability” [4]. These models acknowledge the political, relational nature of disability as well as the societal complicity in its construction. It is against this backdrop I wish to complicate the suggested dichotomy of use and limitation. Drawing attention to the complex realities behind these seemingly self-evident categories, seems appropriate in the context of discussing the representation of neurodivergent perspectives, which hold experiences of being and meaning making that differ from normative frameworks.

I will now turn to the medium podcasting, reflecting on its (in)ability to represent autistic perspectives. As I am not familiar with the production side of podcasting, the following consideration will only reflect on the medium in relation to my role of autistic participant and, to a lesser degree, autistic audience.

My interview for *Autistic Counterstories* was conducted by the award-winning podcast maker ED and was intended to be part of the second episode of the three-part podcast, which focuses on autism and communication. The producers had heard of my connection to the work of the non-verbal autistic writer Birger Sellin and were interested in integrating it into the podcast. Although I was honoured to, with permission of the Sellin family, bring attention to Birger’s work – and the podcast made this possible – it

was only through mediation that his perspective could be included: because Birger does not speak, I read excerpts from his poems aloud. Autistic individuals are not a monolith, and some autistic perspectives are, evidently, easier to include than others through a particular medium like podcasting. Certain modes of communication align more readily with the affordances and expectations of audio storytelling, while others may resist such framing.

Autistic author Leah Lakshmi Piepzna-Samarisinha distinguishes between different rhetoric forms such as “Autistic Long Form”, “Autistic Short Form”, and “Autistic No-Form” [7]. I primarily use Autistic Long Form, which is akin to what is termed “infodumping” and, unfortunately, is often met with impatience or anger [7].

The anxiety and shame that follow such experiences structurally, are part of the reasons I requested that ED send me the interview structure beforehand. This way I could condense my answers to gratify the allistic demand for transparency, that the neurotypical world has trained me to obey: “We risk losing ‘legitimacy’ or ‘legibility’ when we turn away from the allistic eye” [7].

The polished version of my answers as a result seemed desirable at first, with: ED describing my preparations as “a gift” during the recording. But when I reflect on an authentic representation of ‘my native language’ or spontaneous use of Autistic Long form, our approach privileged intelligibility over authenticity.

Reviewing my participation in *Autistic Counterstories*, I contend that internalised normative voices incited a willful act of translating autistic rhetoric into neurotypical speech. This intentional ‘weeding’ of what Erin Manning refers to as the “complex ecology of autistic perception” [8], is exemplary of masking my autism. While I imagine this act may have benefited the (perceived success of the) podcast, paradoxically, it moved me away from an authentic representation. Nevertheless, this aspect of masking is a sacrifice I am sometimes willing to make, to facilitate the accessibility of what I wish to communicate from my lived experience of autism. It leaves me wondering: is it possible to simultaneously honour authentic representation *and* create the conditions in which an autistic voice has the best chance of being heard by mixed audiences?

How do we listen to podcasts with an ethics of care? (LM)

Many podcasts I listen to involve a dialogue between different people: little else is needed other than a few microphones, participants and thoughts. As a listener to such a podcast, I am mostly a spectator, somewhat the same as when I read an article or watch a video interview. In the

podcast *Autistic Counterstories*, this is different, because a more direct line is created. New knowledge and alternative stories about autism are conveyed by letting the (autistic) narrators themselves speak to me, without intervention. It has something paradoxical: as listeners, we are invited to become part of a dialogue, but cannot speak back directly. Here, I want to share some thoughts on what I (and others with me) have called the ethics of listening.

A podcast is a flexible tool, but it does carry the risk of one-way traffic. We can listen to a podcast anywhere and ‘consume’ a dialogue but are not physically present. Do we listen to the stories with our full attention? How do we listen to these stories, and what is our motivation to listen? To have our own biases confirmed? This is the result if we do not adopt an attitude of radical openness. Similarly, Lisbeth Lipari proposes an “ethics of attunement” as the preferred attitude of the listener in encounters [9]. This involves practices of listening and feeling, a slowed-down focus on the encounter itself, with a sensitivity to the context instead of following abstract ideals. Attunement becomes an embodied way of attending to difference without predefining it. *Autistic Counterstories* certainly invites that, as it responds to different senses.

When we then listen to the podcast with an attitude of attunement, whose voices do we acknowledge as such? What counts as voice? Piano play, poetry, a speech computer: can these count as ‘voice’? Many autistic people are labeled nonverbal or minimally verbal because they do not meet normative ideas about communication (e.g. using voice, using words in a specific order, tone of voice). However, this says more about our oppressive neurotypical understanding of subject and voice than about the autistic voice itself, as Leni Van Goidsenhoven and Elisabeth De Schauwer write [10]. The same is also true for autistic people who might be verbal, but still use language differently because they do not have the possibility, ability or desire to access a standard register of language. Ideas might be phrased differently, or speech happens at a different speed. Not having standard ways to phrase things means taking your time to search for words: the labour and creativity connected to inventing ways to express yourself, because you have to ‘invent the wheel’ yourself are not acknowledged often enough. The deficit is not in the autistic people who express themselves differently, but with the listeners who fail to meet autistic people in the middle. Do we let the expressive and creative qualities of autistic people labelled nonverbal or minimally verbal truly challenge our normative ideas about communication?

As listeners must adopt an attitude of radical openness, but where does that take us? What do we do with the

things we hear, especially in neurotypical-neurodivergent contact? In the cultural imagination of neurodivergence or other minority positions, empathy is often evoked for ‘the other’ by looking for common ground with the viewer. Do we indeed prefer empathy built on similarity, but that erases difference, or a type of empathy that actively takes into account difference? Maria Lugones writes about the importance of maintaining these differences in her formulation of “loving perception”, where we actively try to maintain the multiplicity of the other, and are also open to being changed ourselves [11]. This, to me, is the true radical openness which I think is fundamental to an ethics of listening.

Why is it so difficult to fully express autistic-trans stories in podcasts? (FS)

Autistic-Queerness embodiment as dancing

If there is only one thing you can learn from the third episode of *Autistic Counterstories* podcast, it’s that Autistic-Queerness is an embodied phenomenon. In many ways the speakers give us certainty that to exist is to be as, through, and with a body. The disembodied mind is a fiction [4]. And yet, while listening to these stories told by bodies I felt a sharp, unpleasant awareness: as much as the episode got me thinking about embodiment, there are dimensions of my own Autistic-Queer experience which speech struggles to convey, let alone reproduce for a listener.

What led me to this realisation was a short tangent which Maysa went on in the third episode. While there is a lot to unpack in this episode in this interaction, what caught my eye, or rather ear, was the way in which Maysa put into words aspects of Autistic-Queerness embodiment which I have not often seen discussed. Namely the desire for authenticity by way of pain. (Listen [here](#))

There is this drug that in America they give to children even like eight-year-old autistic children to make them more manageable. I was in psychiatry for a couple of months after I got my diagnosis. They gave it to me for like a month or a month and a half and it completely—it numbed everything. I... it numbed the bad things, but also the good things. I just—I never want to go back to that. Let me experience my pain with the lights or with everything but I want to feel, I want to feel myself and be myself and have my autistic joy and autistic pain and everything of it and I think the drug definitely makes me more manageable to others, but I don’t care about being manageable to others. I care about feeling OK within myself, feeling connected with myself and finding accommodations to handle the light and the noises, like there are noise cancelling headsets.

This is a concise and very well-worded way of describing this phenomenon. The image of authenticity as opposed to ableist numbing of Autistic-Trans lives as exemplified by the option to take the noise-cancelling headphones off and immerse oneself in the painful loudness of the world being especially resonant. And yet, while Maysa managed to put into words this experience, at the moment it entered me I began to thirst for the thing itself, not just its implication. Words were not enough, speech was not enough. I needed to dance.

What I want to expand upon in this piece is then this desire to experience the pain of being Autistic-Queer as a way to embrace authenticity and refuse the ableist enforcement of flat numbness. At the same time as I hope to explore this experience, I also hope to hint at the limits of both podcasts and speech itself as the expressive mediums of this desire. A limitation which this text is dancing on the edge of as well.

To speak of being

In place of a hermeneutics we need an erotics of art [12].

I am Autistic-Queer, someone who revels in movement, moshpits, and the intoxication of a sweaty workout. Yet, when asked to explain my reality – what's happening as I stare into the void while throwing down on the edge of pleasure right before pain – I fall back on tropes that would make the most shallow Autistic and Queer representation call me a stereotype:

I was lost in my own world, hyper-focused, completely immersed. Trapped in the wrong body, flooded by hormones, tormented by a flesh I cannot escape.

These descriptions are not lies *per se*, but they importantly aren't truths. They are nothing more than pale shadows of the vibrant reality they attempt to represent. Breadcrumbs scattered in the hope that someone will follow them into a shared world.

But why don't I speak with honesty? Why is it so difficult to tell our stories, especially when they are a little weirder, in full without shame?

One answer is strategic necessity. We simplify our truths to survive, quite literally so within Trans healthcare, where conformity to tidy, familiar narratives is often a prerequisite for safety, care and literal survival [13, 14]. Another cause lies in the inherent limitations of language – a tool that cannot reliably express the experiences of the most "normal" humans imaginable, let alone those it was designed to silence. And finally there is the libidinal pleasure and material gain an ableist worldview offers for those which express and engage with being Autistic-Trans as a heroic tragedy [6].

Just imagine the horrid response of a jolly nice boomer working in healthcare, trying to tick their little boxes, as I answer their questions with examples that could have fit into Freud's exploration of the death drive. We queers just barely beat the pervert allegations, so us young Autistic-Queers are not coming in with the steel chair and get weird with it.

These forces conspire to create a communication landscape, one filled with much paranoia and hermeneutic violence, where even Autistic-Queers often default to reductive narratives meant for outsiders when speaking to another. Instead of meeting as whole embodied beings we encounter one another as abstractions – concepts and images rather than hot flesh and boiling blood. We get it, but we rarely really understand.

With that in mind, how does one express the embodied experience of this pain which Maysa described so well? How does one receive it? There clearly isn't one way, just as there isn't one true mirror to any experience. Just as the podcast I am also running up against the limits of language itself. But, because we have come this far, let me at least try to point at what for me Autistic-Queer embodiment really is defined by – luminous moments of carnal-religious eroticism.

How souls connect through bleeding ears

We find the state of affairs that binds us to our random and ephemeral individuality hard to bear. Along with our tormenting desire that this evanescent thing should last, there stands our obsession with a primal continuity linking us with everything that is... Eroticism opens the way to death. Death opens the way to denial of our individual lives [15].

I like loud sounds, overwhelming sounds that mess with my sense of reality and replace it with a stranger realm. With that I don't *per se* mean that I am in love with high volume art, even if my partner often complains about the noise. What I mean with loud is a style of sonic art which employs cacophonous and richly textured sounds, which carry in them disparate memetic references that force one to keep track of what is said by this organised chaos.

The most immediate response to these sounds by the uninitiated will probably be repulsion and/or a headache. And yes, listening for too long will make the balance of pain go more towards the unbearable. But it is the moments before that, the moment when the painfully loud, horrifically deep and achingly shrill sounds bury themselves into your tensed up body, that is when you feel it.

It, maybe id, a primal rage that boils your blood, the hateful sorrow you felt for the first time when you came into this world knowing that you were born to die. It, the flash of

light your nervous system hits you with when you hit your head and punch a wall out of instinct. It, the driving force you push down every time you push yourself into a role that works even though it feels like needles on your skin.

You see it, you feel it, you are it. Sonic art like the ones I am describing puts you at a crossroad. You can either try to push it down and let your system flood with pain, or you let it flow and move you. Choose the former and you will get another gold star for shaming yourself into numb submission. Let the latter happen and you will be free, if only for a moment. But a moment of moments it will be.

The internal result of this type of painful sonic art is then a full immersion of a body in the form of alarmed senses and uncontrolled dance moves, as well as a mind by way of the rich tapestry of images and stories being smashed together. Your thoughts hungry for the melody, your heart pounding with the beat, both desire nothing but each other. Emotive storytellers like DJ Re:Code, Fraxiom, Porter Robinson, The armed, HEALTH, Deafheaven, Sewerslv, Underscores, Vylet Pony... conjure a space which transcends the limitations of language to reach a truer reality. One that is simultaneously below the everyday through a sort of primal sweaty ecstasy, as well as ascended from it by overstretching images into a new extra-sensical post-nihilistic fun house spiked with thorns I love to get pressed against.

The external result will be that we will look like we are feeling that music more than anyone else in the room. Like we are having the time of our lives releasing what has been pent up for years. And while we may look a little silly doing it, I hope we never gave you the impression that at this moment we give a f*ck about what you think.

In short then, these painful autistic-depressed-aggressive-trans-furry sounds, manage to cut through all the baggage of ableism and transphobia to let me know that we, all of us, can really bathe in being alive. When Autistic-Queer embodiment is dance we can only speak by jumping.

And those who were seen dancing were thought to be insane by those who could not hear the music [16].

How can we represent autistic perspectives with care? (NS)

My experience of podcasting brings into dialogue (and debate) the personal and professional which I have negotiated from a dramaturgical position in roles that support content creation and production processes through my knowledge and experience of autism, neurodiversity studies and socially engaged creative practices. My position has combined ethics and aesthetics through concern about and care for the representation of lived experience and the integrity

of the personal stories that become public through the podcast. As a sonic medium it foregrounds voice, so that representation is focussed on the auditory, and the visual aspects are provided by the listener (although not all listeners think in pictures). This also affords podcasting an intimacy which can be allied with authenticity, making it even more important to ensure the story being told is appropriate to the subject.

In *Autistic Counterstories*, my autistic son is featured in a piano lesson, as music is one of his modes of communication and helps us to understand and engage with his experience of being in the world. The music lesson offered an encounter, a meeting space in which words were secondary. As one of Gabriel's parents, I was in an entangled position between the researcher and the researched. Historically, definitions of autism have been based on observations of behaviour without reference to the qualities of subjective experience [17, 18]. This is due to the evolution of understanding and the original diagnostic criteria being based on predominantly young boys with complex communication needs. The rise of the neurodiversity movement, increased diagnosis in girls, women and adults and a wealth of scholarship and autobiographical testimony offers experiential insights, contributing to a revolution in autism studies [5, 19–22]. However, the turn to 'neurodiversity in autism science' and the calls for a phenomenology of autism [17] bring the challenge of including the diversity of autistic perspectives and this means moving beyond questionnaires, interviews and text-based accounts of autistic experience. Hence the need for alternative forms of scholarship that transcend conventional written formats to make space for difference through the use of multimodal accessible platforms such as podcasting, a form which contributes to a democratisation of knowledge. My position is informed by James Thompson's work on an ethics of care [23] in the context of socially engaged arts, positioning care as both an aesthetic and ethical practice, emphasising interdependence, relational sensitivity, and embodied solidarity through the form and process of participatory creative practices.

I have a responsibility to question how *carefull* our work was in terms of Thompson's conceptualisation: *carefull* work is reflective, responsive, and ethically attentive in how it relates to others, mindful of the potential harms, power dynamics, and responsibilities embedded in arts-based research. Gabriel's experience and perspective was in dialogue with his parents and his piano teacher, Adam Ockelford. His lessons involve a structure he shapes with playing punctuated by short breaks to jump up and down. He seems to need this vestibular feedback as he is so focussed and in flow when playing with Adam; he plays by ear so

the lesson is a musical conversation with either Gabriel or Adam initiating a piece and the other responding; Adam scaffolds Gabriel's playing, rather than teaching him in a conventional way to conform to a particular technique or interpretation; Gabriel seems to understand the shape of the music and improvises, producing his own adaptations to overcome technical complexity. During the recording, Gabriel occasionally interacted with the production crew and clearly enjoyed and responded to his audience. He has agency in these interactions, cheekily sneaking in a carol to tease his dad and get a reaction. When the Executive Producer ED first heard the recording, having not been in the room, she was worried by the dynamics as Gabriel's playing was in counterpoint with conversations between the production team teacher and parents in which Gabriel arguably became the object of attention, his presence in the background as he jumped, chattered and stimmed. Yet the stimming is also how he communicates and self-regulates and this was foregrounded through editing as ED and DD ensured Gabriel's voice was a throughline. A further challenge to the ethics of co-production was how to seek Gabriel's feedback and endorsement of what had been produced. We played him the podcast and he seemed engaged with it for a short period, before doing what he did in the lesson, jumping up and down with excitement, smiling and laughing. We think this was acknowledgement and recognition of the memory of the experience but we couldn't sustain his attention and this couldn't be forced. Perhaps a video would have held his attention for longer? How do we assess engagement when neurotypical criteria may not apply?

This experience deepened my understanding of *carefull dramaturgy*, building on my prior consultancy role with Audible's adaptation of Katherine May's *The Electricity of Every Living Thing*. The book follows May's journey to understanding her autistic identity while walking the 630-mile South West Coast Path – a metaphorical and physical undertaking. The story's resonance was personal, contributing to the discovery of my own neurodivergent identity and late-diagnosis.

As a neurodiversity consultant, my responsibilities included sensitively reading the script, advising the creative team on inclusive practices, and ensuring authentic representation of neurodivergent experience. I also advocated for accessible production approaches within a neuromixed team. My dramaturgical role involved triangulating between author, text, and production context, ensuring that the adaptation honoured the source material while meeting the demands of a new form. This required critical attention to stereotypes, language, and ableist

assumptions, ensuring that the adaptation conveyed the rich, often intense, sensory and emotional life described in the book. Aesthetic and ethical values were in constant negotiation – especially given that the podcast might overwhelm some neurodivergent listeners due to its immersive sound design. However, such immersion was essential to reflect the author's vivid sensory world, shaped by acute sensitivities and physical reactions to her environment. A neurodivergent composer and director worked together to ensure that sensory intensity was both accurate and respectful, even as it challenged conventional audience expectations.

Both *Autistic Counterstories* and *The Electricity of Every Living Thing* represent different facets of autistic experience – one child-centred and relational, the other introspective and adult – but each demonstrates the capacity of podcasting to represent neurodivergent life in carefull and inclusive ways. In both projects, podcasting emerged as a powerful, accessible, and affectively rich medium for conveying the complexity of neurodivergent experience when shaped by an ethical dramaturgy grounded in care.

How do we get people to listen to a podcast about autism? (ED)

Who will listen?

“Who will listen?” This question is essential for a broadcaster or production company: a podcast should attract their listener target groups. As a podcast producer with a background in socially engaged and humanitarian advocacy work, that question goes hand in hand with another one: “Who are you making this for?” My main driver for any of my original audio work has been an often-self-generated sense of urgency around a story that had to be told; most of the time someone else's story. In my experience, the owner of that story is my primary listener. Time and again, I realise that it is fairly easy to tell someone else's story. It is much harder to make others listen, let alone trigger a dynamic around a story among listeners, which is what I would define as ‘impact’ as a podcast producer.

A story is only really ‘out there’ when it lives outside the confinement of podcast platforms. “Who will listen?”, is therefore not only the concern of the broadcaster but also a standard question that a producer needs to answer in the planning process for a podcast. Identifying an audience is helpful as it will inform many editorial choices. For others to listen, a story needs to be told in a certain way. One needs to strike the balance right between authenticity and accessibility. Between an individual story told in a first-person voice and a universal message to which any listener can relate.

In that respect, the production process of *Autistic Counterstories* was a real challenge. Throughout the editing process – from the selection of interviewees, topics of conversation, decisions on narration and transitions and the choice of music – I constantly asked myself: Will this alienate the listeners or the podcast participants? In conversation with the interviewees, I realised some of them shared my concern – like Silke (SV) in EP2. (Listen [here](#))

So you asked me to say a few words about myself, and it's funny how this question immediately makes my brain wonder: what does that mean, 'a few'? How many words are that? It's one of the reasons why I've asked you to communicate me the interview structure beforehand; because the simplest questions can become very stressful for an autistic brain to deal with. Or for mine at least.

Who will speak?

The researchers from the Autism Ethics Network at the University of Antwerp who commissioned *Autistic Counterstories*, wanted to make autism research more accessible for a non-academic audience and they wanted to avoid that their podcast would only reach a limited audience of other academics. Indeed, as Persohn & Branson state, podcasting holds the potential to impact public understanding of research by moving beyond the traditional forms of knowledge dissemination to cultivate a more equitable future for research [24].

Broadening the audience is of course not the only condition for more equitable research. It is equally important to invest in a more participatory podcast production process. Therefore, the second question we asked ourselves in the planning process for *Autistic Counterstories*, was: "Who will speak?" As a neurotypical producer with very limited exposure to autistic experiences or research, I did not feel well-placed to be the voice that would introduce or link neurodivergent voices in the podcast. I opted for a non-narrated series instead of a podcast with a voice-over that could add context and introduce people or topics. While this certainly complicated the editing process, I felt it was more respectful towards interviewees and it would allow listeners to experience neurodivergent stories in people's own words.

When listening back to interviews to select the most insightful or emotionally powerful sections of people's stories, I realised that so much of the neurodivergent experiences we wanted to share with listeners, was 'hidden' in the interaction between the interviewer and interviewee. Therefore, parts of those 'meta conversations' were added to the podcast, for instance apologetic comments from interviewees about unstructured answers or a lack of

focus – even before starting the interview, questions about the interview set-up or interruptions because of discomfort linked to certain sounds or light.

It's hard for me sometimes to...to talk into words. I'm better in writing. (Maysa in EP3 – [listen here](#)).

From the outset, we decided that the podcast production team had to include neurodivergent people. We left it entirely up to them to decide whether or not they wanted to be interviewed at some point during the process. There is one particularly powerful moment in the third episode of *Autistic Counterstories* where Assistant Producer Louis suddenly shifts from his role as an interviewer to one of an interviewee with lived experiences. That segment illustrates the potential of a non-narrated podcast where the conversation itself – rather than the chosen podcast structure – can steer the story in certain (often unexpected) directions ([listen here](#)):

[Maysa] I don't need a drug to tone me down because I'm too much...

[Louis] I really resonate with what you are saying. Like... ever since I first got diagnosed when I was six, I remember just wondering, just out of the blue, I wondered if I could have a day where I just woke up and I didn't have it so I could just see what it was like for a day to be neurotypical. (...) I've always wondered how it would change me. So, to hear that from you (...) I guess that is how it would work, like taking the good times as well as the bad times. I personally wouldn't want to give any of it up at all. (...) I've always said that autism is just like... it's just another way of being human.

Finally, in answering the question "Who will speak?", I also wanted to be transparent about who was speaking on behalf of others. In the second episode of *Autistic Counterstories*, for example, I included a section of an interview with Christiane where she refers to a conversation she has had with her autistic son about the podcast process ([listen here](#)):

By the way, could I just quickly say a little bit about my son, because I talked to him after we had the interview and I promised to ask him. So he said we're allowed to say Christoph, his name. When I told him about the podcast, his first question was "Can't I take part at all in this interview?" and then I said "Would you be interested?". He said "Yes" and I said "Well, you're obviously not going to be able to do this because you won't be here at that time and you don't speak English, but I can ask you some of the questions they asked me in the interview."

I remember feeling puzzled by Christiane's choice of words. While I understood the logistical constraints, it was not 'obvious' to me that her son could not take part in the interview. We could have found ways to accommodate an online conversation in which he could participate directly

and perhaps more meaningfully. As this also prompted conversations between myself and the co-producer of the series DD on informed consent and doing justice to the stories of other people (see below), we decided to add Christiane's reflection in the second episode. As this episode revolves around perspectives from autistic people who communicate in different ways, it was our way of acknowledging the limitations of our participatory podcast production approach.

How to stage encounters of care across difference? (DD)

As co-producer and lead editor, I held all the stories of *Autistic Counterstories* 'in my hands' – cutting, pasting and merging interview sections through the interface of the editing software. I did so with the privilege of someone who has not faced disablement by a neuronormative society, and who has not experienced the sharp end of social injustice [25]. One of my motivations for participating in this project has been my personal relationships with autistic people, which clearly dismiss the classical (and neurotypical) conception of autism as an unreachable other [18]. Yet, autistic and non-autistic people do experience the world differently, which often results in a breakdown of reciprocity and mutual understanding [26]. Sometimes, discourses in certain activist spaces seemingly frame this Difference as an unbridgeable divide, paradoxically reinforcing a sense of othering inherent in the classical framing of autism.

As a researcher, I became interested in how we can stage encounters of care across Difference (especially Difference bound up in social injustice and structural inequality). Coming together as a production team of autistic and non-autistic people, we selected podcasting as our method of encountering. To frame the opportunities and challenges of this method here, I introduce the framework of Narrative Medicine. Narrative Medicine is a form of clinical practice which applies narrative competence to the delivery of healthcare [27] and we can productively expand its principles to podcast production. While clinicians can certainly use podcasting as a method for Narrative Medicine, I focus on the narrativity of the clinical encounter and how it provides orientation for engaging with podcasting as "encounters of care" [28].

Narrative Medicine frames the work of clinicians in a clinical encounter as "entering into a suffering which necessarily resides outside [their] own physical and emotional being" [29]. According to physician and author Sayantani DasGupta, "[t]his entering into the suffering of another is akin to the work of the novelist" [29]. In shaping the interviews with our contributors into a narrative whole, we avoided the connection of "suffering to autism" (as Silke (SK)

puts it in EP2 – listen here). Instead, *Autistic Counterstories* set out to "celebrate and affirm the diverse perspectives of autistic people" (in the words written by M. for episode introductions read by their friend Ada – listen here, here and here). Nonetheless, the disabling impact of a neuronormative society on autistic people was evident in all the stories that contributors shared during our encounters.

Although our podcasting is not clinical work, it was nonetheless orientated around a notion of restorative care. We drew on Hilde Lindemann's concept of 'counterstories' [3], i.e. liberating stories that reframe societal master narratives which support oppressive power structures that deny the agency of autistic people. Paradoxically, medical interpretations which frame autism as a disorder are central to the oppressive master narratives we set out to challenge in *Autistic Counterstories*. The medical model of autism, which defines autism as a deficit that needs curing, is a paradigm of medicine practiced without 'narrative humility', i.e. medicine which forgets that "we cannot ever claim to comprehend the totality of another's story" [29]. As podcast producers, we too experienced something of the "hierarchical imbalance of the clinical relationship" in the power we had to select, mix and ignore parts of contributors' stories in interviews, which we invariably had to edit down to fit the narrative structure of a three-part podcast mini-series.

Narrative Medicine provides a threefold framework to navigate these challenges in encountering [27] – whether in clinical or podcasting practice. The first stage of an encounter involves the bestowing of attention; in the case of podcasting, to the stories of contributors in emails, meetings and interviews as part of the pre-production process. This process requires time and multiple moments of connection to establish trust between producers and contributors. Producers should proceed with narrative humility and acknowledge that "each story [they] hear holds elements that are unfamiliar – be they cultural, socioeconomic, sexual, religious, or idiosyncratically personal" [29]. As a cis, white and male producer, who does not identify as autistic, I cannot claim familiarity with the experiences of "multiplying misfit[s]" (a concept introduced by Maysa in EP3 – listen here), including experiences of contributors at the intersection of autism and transness (Terre and Sym in EP3) or Arab diasporic identity (Leila and Imane in EP1).

The second stage involves representation through narrative writing, a process where clinicians narratively represent the stories they have attended to, in order to achieve a true sense of 'attention'. In our production process, we transcribed our interviews with contributors, so we

could ‘emplot’ them into scripts for podcast episodes by selecting certain perspectives and organise them alongside each other, as well as selected music and voiceover choices, to bestow evaluative and emotional import. For example, in EP2, we went through some effort to fit in a somewhat tangential remark by Silke on unhelpful discourses about autism and “savant talent”, to signal that the piano music we hear throughout the episode from Gabriel, who uses few words to communicate, should not be interpreted in this way (listen [here](#)). In this process, podcast producers – like clinicians – should remember that “stories are not objects that we can comprehend or master, but rather dynamic entities that we can approach and engage with” [29]. The producers themselves should also engage in “constant self-evaluation and self-critique”, including awareness of what they bring to the stories they engage with and their own desires in shaping the narrative of the podcast [29]. As producers, there were definitely stories we wanted to tell for ourselves, and we also held assumptions about stories we imagined our intended audiences wanted to hear or expected to be told in certain ways. Undoubtedly, when making a podcast, there is a tension between the narrative interests of contributors, producers and listeners that can never be fully resolved.

The third stage of encountering in Narrative Medicine offers a strategy to navigate this tension through the “affiliation” generated by ongoing “spirals of attention and representation” [27]. A conscientious podcasting process involves going back to contributors and ensure they see themselves faithfully represented in the final mix, before it is released. Yet, this necessary process for establishing consent should not be confused with fully capturing someone else’s stories. Our contributors may have signed off on the representations in *Autistic Counterstories*, but they no doubt wanted us to attend more fully to some parts of their stories than we felt we could, including sometimes to the way they told them. The story we represent in a podcast can never fully coincide with the story of the other. This distance was clearly pronounced in some of our encounters.

While Gabriel assented to us joining him and his family for a piano class in EP2, and has engaged with us and the podcast episode since, we had to rely on his parents as guardians for consent to release the final mix. Similarly, when the parents of the poet Birger Sellin told us he was unable to contribute to the podcast, Silke provided her interpretation of his poems in EP2; while Christiane, a friend of the Sellin family, told us about her relationship with her son Christophe, who was not available to join us himself. These encounters are not fundamentally different from those with the contributors who did join us and sign off on the final mix. In every podcasting encounter, we must always take a leap of faith and hope that we got it right enough to do justice to the stories of others.

Narrative Medicine is a method which claims to promote empathy as narrative competence to improve the delivery of care in clinical encounters [27]. Empathy has become a suspicious concept [30] and popular discourses have indeed too readily assumed that media like video games can let you ‘walk a mile in the shoes’ of a trans person or a parent who has lost a child to cancer [31]. We certainly do not pretend that *Autistic Counterstories* can make listeners understand someone else’s autistic way of being in the world – and actively refuse such an interpretation of our work. Instead, I personally started from the acknowledgement that there are certain “relentless divides” [27], perpetuated by systems that in some ways structurally privilege me, but cause suffering for contributors to the podcast and listening events we have hosted as part of its dissemination. Following Narrative Medicine, I believe that these divides are “bridgeable by virtue of the narrative powers of telling, listening, gathering around any kind of campfire to hear one another out” [27]. Podcasting can serve as such a meeting space, which resists the totalisation of the other’s story and refutes a full understanding of their experiences but nonetheless achieves enough connection for a meaningful encounter. This process, which we pursued through our action research project of producing a podcast, strikes me as a realistic and productive interpretation of empathy and its virtues.

Discussion

DD and ED: These individual perspectives demonstrate a range of engagement with *Autistic Counterstories* that we, as producers, were not fully aware of before writing this article together with contributors and listeners. Three issues, in particular, merit further discussion, i.e. how *Autistic Counterstories* is a mediated encounter, and therefore has its limitations we need to be critically aware of as part of a practice of care; that this practice requires a specific kind of care that differs from working with 'human participants' in a standard research project; and that the success of podcasting lies in ongoing process of encountering with care.

DD: Some of the perspectives in the individual contributions clearly articulate worries I have felt as a co-producer and editor. SV describes a process which sounds like the audio equivalent of 'masking' so that autistic speech passes as neurotypical. In the editing process, I surely contributed to creating a normative sound aesthetic, cutting out pauses, re-starts, filler words and tangents where ED and I assumed it would facilitate engagement for an imagined (neuro)typical listener. FS reminds us helpfully of the limitations of the spoken word to fully capture lived experiences, while LM warns for a pursuit of empathy that erases difference and fails to take into account difference. Is there a circle here that's very difficult to square, i.e. trying to capture something truthful and meaningful about autistic experiences – which disrupt normativity – while adhering to generic expectations of what a podcast should sound like?

SV: What is sometimes overlooked when we discuss 'masking' is the usefulness of this strategy. This is the reason I'm quite ambivalent about the topic. It felt necessary to bring it up after acknowledging the normative speech patterns I subjected myself to while preparing for the interview and during the interview. Masking demands a lot of energy and the efforts behind it are, arguably, not very emancipatory, to say the least. At the same time, to me, the primary function of masking in this way is to maximise my chances of being understood. Such an elementary function cannot be simply dismissed as harmful. For autistic speech to be truly liberated, I think there's a task at hand to collectively and critically examine interabled speech dynamics. A widely cited theory by autistic autism researcher Damian Milton comes to mind [26]. With the "double empathy problem", Milton laid bare the mutual nature of communication problems between autistic people on the one hand and neurotypicals on the other. Previously, these communication hurdles were, and they still often are considered a problem caused by autism, residing in the autistic individual. I'm afraid that, as long as allistics are not inclined to make the same effort as is continuously expected from autistic folk – translating their "autistic mother tongue" in the words of autistic researcher Hanna Bertilsdotter Rosqvist, to "neurotypical speech" – masking in this way will continue to be a most necessary survival skill. But perhaps podcasting can play a role in, as DD suggests, willfully disrupting normative expectations around speech and sound.

DD: I think it's really important to appreciate podcasting as a mediated process, as you highlight, SV – and this awareness and appreciation is part of the necessary process of care in producing, contributing and listening. *Autistic Counterstories*, in particular, is a mediated encounter between autistic and allistic people at every step of the process. And what it provides is access to that mediated encounter; not to some sense of people's unmediated autistic experiences.

I am interested to ask a bit more about podcasting as a medium that facilitates access to these encounters. I've felt that it was easier for people to engage with the podcast as a form of scholarly activity than writing this article. For a variety of reasons, many people who had been able to contribute to the podcast as form of scholarly activity, were unable to contribute to (or continue engaging with) writing this article. This signals to me the importance of cultivating scholarly podcasting as a space for encounters of care that are more difficult to achieve in other academic formats. But I might be at risk of romanticising the medium here.

ED: A scholarly podcast is not by definition a more inclusive space than an academic article, just because its format is more 'dynamic'. Even if the intention of the producer is to create a podcast with individual stories told in the first-person voice, the final product is a new story altogether. This can, in some cases, alienate the interviewees who participated. They may feel they were not represented accurately or that they were expected to talk about their lived autistic experiences in a way that a neurotypical audience would understand. On the other hand, a podcast can also unintentionally push listeners away. Certain story structures simply work better than others, especially if the topic of conversation – and how it presented, for example, without voiceover narrating in *Autistic Counterstories* – is demanding.

DD: Again, insofar as podcasting constitutes a process of care, it should come with the critical reflection of producers, contributors and listeners about the limitations involved in the mediation process. I don't think the point is to strive to overcome these limitations – they will always be there – but appreciate podcasting as a process through which we can critically reflect on such limitations, which are also involved in our everyday encountering.

But, without romanticising the podcast, does it have different affordances than, say, the academic article (acknowledging that we are playing with the form and style of the article here, inspired by our engagement with podcasting).

NS: As someone with a performance background, particularly contemporary and socially engaged performance, I'm interested in multimodal forms of creative practice as embodied aesthetic knowledge; this generates a level of engagement and understanding that moves beyond the academic article, deepening understanding through an experiential and immersive encounter with the subject being researched. Academic writing has an important purpose contextually, conceptually and can also be creative but the podcast can contribute to an interdisciplinary or transdisciplinary approach as a fusion of different modes of knowledge and perspectives on a topic or problem. In terms of autism, we are engaging with a 'condition' that has been medicalised through diagnostic criteria but which lacks a phenomenology as autism has historically been defined through observational accounts [17]. With the rise of the neurodiversity movement, there is increasingly recognition of the plurality of autistic voices, the complexity

and intersectionality of what is referred to as neurodivergence and an urgent need to challenge the stereotypes through representations of lived experience. The challenge is how to develop new models of scientific and aesthetic understanding that encompass richness and rigour and which are inclusive of the diversity of autistic experience.

The podcast is a medium in which this is possible because it moves beyond words to an experiential encounter which involves audiences in thinking and feeling. In writing about this, post-production, I'm aware of a different positionality to an academic article as it fuses creative and critical thinking and writing. It's quite liberating to be able to do this. There's so much to think about in terms of ethics, voice, integrity, inclusion but also a sense that this is a non-linear process of iterative practice research in which we can shift and be dialogic in our sense making. My concerns about delivering the knowledge needed for the podcast need to be realigned with the podcast delivering a new knowledge through a process that is unpredictable, potentially messy but deeply meaningful.

DD: Speaking of experiential encounters – and here's a question I didn't expect I was going to ask – can we dance to *Autistic Counterstories*?

There is something interesting hidden in this question, something strange. At first glance the answer seems more than obvious.

FS: No, one cannot dance to a speech heavy podcast, which primarily consists of people talking. It's not rhythmic in the way that, for e.g. drum n bass and metal songs are, nor is it melodically satisfying as a good pop or jazz track.

If the answer is so obvious, why do I think that it is an interesting question? Well, to keep it short, it's the fact that the question of whether or not someone can dance to a podcast should obviously be answered with a no, yet that many autistic people do it nonetheless on a daily basis. We dance to a podcast everyday when we listen to it while decluttering, folding laundry, doing dishes, going out for groceries, biking to a meeting, working out, showering and even falling asleep. You can see us make minute movements, stimming, as we gain and lose interest, shake in excitement as we follow a resonant idea and stop dead when we realise something important. A performance where we embody the story told, where its energy intertwines with ours in order and leaves behind a spotless living room.

To be autistic is to be embodiment, that much is obvious. What is less obvious is the way this embodiment is mediated by media, guided by the stories we immerse ourselves in so that the overflow of data gathered in boredom does not fry our system. It is this mediated existence, this living-with and living-by the content that consumes us as much as we consume it, that I must insist in calling a dance. For what else is dance if not the reversible back and forth of energy shared by a guide and guided.

DD: FS, in your generous interpretation of my prompt to see *Autistic Counterstories* as something we can dance to, you're hitting on what I feel are some interesting differences with articles or books I have contributed to as a scholar, which do not afford embodied experiences in the same way. This gets me to the scholarly status of a podcast like *Autistic Counterstories*.

Before starting production, we secured Ethics approval for *Autistic Counterstories*. We did so because we were engaging with contributors beyond academia, most of whom were autistic people – so we wanted to ensure we took the greatest care in this encounter. The Ethics review process was fraught. For one, it was set up to evaluate 'research' with (or perhaps more accurately: about) human participants. This framework did not capture the work we set out to do, i.e. we were not collecting data for analysis. FS, I feel your analysis gets at this fundamentally different status of a podcasting project like *Autistic Counterstories*. Ironically, the Ethics process made it more difficult to ensure that we included perspectives from people who often do get excluded from sharing their stories.

NS: The question of whose stories are included has particular significance for my personal involvement. EP2 features a piano lesson with Gabriel, my autistic son who has complex communication needs and – what is sometimes referred to as – a spiky profile. What this means is that speaking using voice words is not his preferred means of communication; he communicates in other ways, expressing emotions through his embodied engagement with the environment (e.g. jumping, stimming, sitting, gesturing) and he also uses music and sound, singing, humming and piano playing.

Autistic Counterstories aimed to include the perspectives of autistic people who have been marginalised in research due to complex communication differences and the challenges of what counts as seeking informed consent. The ethical imperative towards voice-driven data and research informed by lived experience can also present barriers. The central issue is the tension between the need to protect vulnerable individuals and the principle of including neurodivergent voices in research that concerns them. Traditional Ethics protocols emphasise the necessity of informed consent as a precondition for participation. However, for some autistic young adults – particularly those with high support needs or limited verbal communication – this model of consent may not be accessible or meaningful. As a result, there is a risk that such individuals may be excluded from research entirely, leading to a silencing of their perspectives and the perpetuation of epistemic injustice.

The power imbalance between researcher and participant is particularly pronounced in this context, where institutional authority intersects with the participant's potential dependence on caregivers or support systems. Moreover, the use of proxies such as parents or guardians can introduce further ethical concerns around misrepresentation or the erasure of the individual's own experience and agency. This is the situation we encountered with Gabriel, requiring an extended exchange with our institutional Ethics Committee, a letter from Gabriel's parents and a process informed by the principles of relational consent Van Goidsenhoven and De Schauwer [32] whereby consent is reconceptualised not as a one-off, procedural checkbox but as a relational, communicative, and ongoing process, shaped by interaction, responsiveness, and mutual understanding.

DD: Understanding podcasting as a process of care in this way strikes me as crucial to appreciating what it offers us as a practice of care. Which brings me to my final Discussion question: when can we consider such a podcasting process 'successful'?

FS:	I think it depends a lot on what we measure success by. Will this podcast start the revolution that will liberate us all? No, I don't think so. But I do think that as part of a broader push to explore the experiences of different types of autistic people, to push back against and counter flattening ableist stories, it works quite well. I had a good time listening to it as an autistic person. I felt seen, had a few moments of out loud saying "Oooh that's well said" and overall just felt like a new slice of this onion was shined on.
SV:	I would like to suggest that the podcast was successful for the simple reason all of us are engaged in a meaningful discussion because of it right now. Without an audience survey, it is hard to say anything about the impact beyond the circle of podcast producers, participants, and others involved. But the mere fact a dialogue has been started on podcasting as a medium to promote autistic perspectives, and autism as a subject is brought closer to a wider audience, to me personally feels like a win.
ED:	The post-production process is as important as the creation phase. Collective listening events and collaborative writing efforts like this article, are useful spaces to critically examine the impact of a scholarly podcast or any academic work for that matter.

Conclusions

These final reflections on the importance of framing podcasting as an ongoing process represent our key takeaway about podcasting as a process of care. In this respect, we can refer to careful podcasting as a series of 'continuing conversations' (a concept that has emerged from exchanges between some of the co-authors here, alongside Stella Bolaki, Élaina Gauthier-Mamaril and Ian Sabroe). This article, we hope, constitutes such a 'continuing conversation' in action. One particular value of the encounter we have staged in this article is that it provides space to critically reflect on limitations, imperfections and tensions in the podcasting process – in a way that they could not be addressed during the production process. Here, there is a clear synergy between the spaces of the scholarly podcast and academic article. This article itself serves to demonstrate that we should not aim for podcasting to deliver a final 'perfect' product, but rather that it should prompt continuing conversations, where we take care to navigate the complexities of the podcasting process.

Acknowledgments: We thank the Autism Research Network at The University of Antwerp, who commissioned and supported the development of the podcast Autistic Counter-stories. We thank everyone who contributed to the development of the podcast, but wasn't able to contribute to this article. Thank you to Stella Bolaki, Élaina Gauthier-Mamaril, Chris Millard and Ian Sabroe for ongoing reflection and discussion about these and other topics related to scholarly podcasting.

Research ethics: Ethical approval for the project was granted by the Central Research Ethics Advisory Group at The University of Kent (Ref. CREAG124-7-23).

Informed consent: Informed consent was obtained from all individuals included in this study, or their legal guardians or wards.

Author contributions: All authors have accepted responsibility for the entire content of this manuscript and approved its submission.

Use of Large Language Models, AI and Machine Learning Tools:

None declared.

Conflict of interest: The authors state no conflict of interest.

Research funding: None declared.

Data availability: Not applicable.

References

1. Declercq D, Sabroe I, Brown D. Conversations about Arts, Humanities and Health. *The Polyphony* 2022. <https://thepolyphony.org/2022/01/14/conversations-about-arts-humanities-and-health/>.
2. Gefen A. Literature as a form of care? From therapeutic narratives to the literature of care. In: Elsner AM, Pietrzak-Franger M, editors. *Literature and medicine*. Cambridge; 2024.
3. Lindemann Nelson H. *Damaged identities, narrative repair*. Ithica: Cornell UP; 2001.
4. Walker N. *Neuroqueer heresies: notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Fort Worth: Autonomous Press; 2021:60–1 pp.
5. Yergeau M. *Authoring autism: on rhetoric and neurological queerness*. North Carolina: Duke UP; 2018.
6. Kafer A. *Feminist, queer, crip*. Indiana: Indiana UP; 2013, vol 24.
7. Piepzna-Samarasinha LL. *The future is disabled: prophecy's, love notes and mourning songs*. Vancouver: Arsenal Pulp Press; 2022.
8. Manning E. *Always more than one: individuation's dance*. North Carolina: Duke UP; 2013:162 p.
9. Lipari L. *Listening, thinking, being. Toward an ethics of attunement*. State College: Penn State University Press; 2014.
10. Van Goidsenhoven L, De Schauwer E. *Listening beyond words: swinging together*. *Scand J Disabil Res* 2020;22:330–9.
11. Playfulness LM. 'world'-travelling, and loving perception. *Hypatia* 1987;2:3–19.
12. Sontag S. *Against interpretation*. In: *Against interpretation and other essays*. London: Penguin Random House; 2009.
13. Preciado PB. *Testojunkie*. New York: Feminist Press; 2021.
14. Faye S. *The transgender issue*. London: Penguin Random House; 2022.
15. Bataille G. *Eroticism*. London: Penguin Random House; 2001, vol 15:24 p.
16. Nall J. Nietzsche didn't say that... but he would've agreed. [Online]. <https://jeffreynall.substack.com/p/nietzsche-didnt-say-that-but-he-wouldve> [Accessed 15 Jul 2025].

17. Shaughnessy N, Green J, Williams E, Smith JA, Tzovaras BG, Aitkenhead G, et al. Developing a phenomenology of autism. In: Bertilsdotter Rosqvist H, Jackson-Perry D, editors. *The palgrave handbook of research methods and ethics in neurodiversity studies*. London: Palgrave Macmillan; 2024.
18. Green J, Shaughnessy N. Autistic phenomenology: past, present, and potential futures. *Front Psychol* 2023;14.
19. Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future together: shaping autism research through meaningful participation. *Autism* 2019;23:943–53.
20. Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol* 2017;8:438.
21. Milton D. Autistic expertise: a critical reflection on the production of knowledge in autism studies. *Auton Crit J Interdiscip Autism Stud* 2014;1:1–14.
22. Pellicano E. Whose voices count? Neurodiversity, epistemic injustice and the ethics of autism research. *Lancet Psychiatry* 2022;9:465–8.
23. Thompson J. Care aesthetics: for artful encounters in everyday life. London: Routledge; 2023.
24. Persohn L, Branson S. Scholarly podcasting for research dissemination: a scoping review. *Sage Open* 2025;15:21582440241311694.
25. Jones EK, Orchard V. Neurodiversity and disability: what is at stake? *Med Humanit* 2024;50:456–65.
26. Milton D. On the ontological status of autism: the ‘double empathy problem’. *Disabil Soc* 2012;27:883–7.
27. Charon R. *Narrative medicine: honoring the stories of illness*. Oxford: Oxford UP; 2006.
28. Charon R, DasGupta S, Hermann N, Irvine C, Marcus ER, Rivera Colsn E, et al. The principles and practice of narrative medicine. Oxford: Oxford UP; 2016.
29. Dasgupta S. Narrative humility. *Lancet* 2008;371:980–1.
30. Bloom P. *Against empathy: the case for rational compassion*. New York: Ecco Press; 2016.
31. Ruberg B. Empathy and its alternatives: deconstructing the rhetoric of “empathy” in video games. *Commun Cult Crit* 2020;1:54–71.
32. Van Goidsenhoven L, De Schauwer E. Relational ethics, informed consent, and informed assent in participatory research with children with complex communication needs. *Dev Med Child Neurol* 2022;64:1323–9.