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# What's at Stake with Biomusic? Ethical Reflections on an Emerging Technology

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### **Abstract**

Biomusic is an emerging technology that translates signals emotionally salient physiological sound/musical output. It has been proposed to have utility as an assistive technology in many contexts, including for people with autism. This article engages with a variety of perspectives in the humanities and social sciences—notably science and technology studies (STS), dialogism, and meaning-centered anthropology of autism—to reflect on the ethical dimensions of this emerging technology in the context of autism. These reflections are grounded with reference to a three-day event-Interfacing Biomusic and Autism: What Are the Everyday Ethics of Representing the Physiology of What Moves Us?—which brought together individuals who identify as autistic, their family members, developers of the biomusic technology, scholars from the humanities and social sciences, and students in rehabilitation and engineering to learn about, experience, and reflect on the potential uses (and misuses) of biomusic. In this article, the authors

discuss the potential of, and ethical concerns about, biomusic using three interpretive concepts: translation, voice, and aesthetic representation. In conclusion, we describe the utility of engaging citizen stakeholders in innovative technology and in the multiple theoretical perspectives to consider. We encourage stakeholders to address ethical concerns early and throughout the process of designing emerging technologies with applications in rehabilitation.

### Introduction

The development of technologies in the context of disability raises important ethical issues, particularly where the introduction of technologies is framed as "assistive." Users of such technologies have expressed concerns about the power imbalances that arise between designer and user, and of the association of disability with assistive technologies. The contributions of user perspectives for the design of biomusic specifically, and engineering and design of assistive technologies generally, have already been discussed in

Grond et al,<sup>1</sup> by detailing how three complementary perspectives (technical, ecological, and human-centered) support the integration of ethical concerns into technological development. This article explores these issues in the context of biomusic and autism from a humanities perspective.

### What is Biomusic?

Biomusic is an innovative technology that translates emotionally salient physiological signals sound/musical output. By enabling others to "tune in" to meaningful changes in an individual's physiological state, biomusic has been shown to increase the recognition of the presence and personhood of individuals whose communicative modes fall outside of normative social expectations.2 As an affective technology (ie, a technology related to affect and emotion), biomusic is likely to have profound implications for people with autism,3 as it offers a new mode of understanding others, particularly those with neurodivergent sensory sensitivities.<sup>4</sup> Biomusic blurs the boundaries placed around whose expressions of subjectivity are considered valid and how those expressions are interpreted, by both conceptually and literally joining physiological signals with a cultural form of representation that is audible to others. The inclusion of both bodily and discursive (or social and symbolic) dimensions<sup>5</sup> of an interaction could counteract (mis)interpretations of others' intentions based solely on expressions, gestures, or actions.

This article's authors—representing the humanities, social sciences, and natural sciences and working at the intersection of technologies, ethics, and disability/rehabilitation—are linked by a shared interest in understanding the possibilities of biomusic to shape, and be shaped by, social relations as it moves into the public sphere. This framing, informed by

science and technology studies (STS) as well as the social science of medicine, shifts our focus away from views of biomusic as merely a technological tool to be used or acted on by humans, toward that of an understanding of biomusic from a humanities perspective.

The purpose of this article is to draw from different theoretical backgrounds to reflect on questions such as:

- What's at stake in biomusic?
- What does biomusic do?
- What are its effects?
- How is it affected by the social?

What ethical issues should be considered as biomusic is mobilized in disability communities?

This article addresses these and other questions raised in response to prospective applications of biomusic in the context of autism explored during a three-day knowledge-mobilization initiative, *Interfacing Biomusic and Autism: What Are the Everyday Ethics of Representing the Physiology of What Moves Us?*, held in Montreal, Canada in April 2016. It provides a reflective examination of biomusic from multiple disciplinary angles (especially STS, dialogism, and the anthropology of autism), foregrounding key theoretical constructs (boundary object, utterance, meaning) that focus attention on three interpretive concepts—ways of understanding biomusic (as translation, as voice, and as aesthetic representation)—that help identify potential ethical issues associated with biomusic.

### An Emerging Technology

From a technical perspective, biomusic can be considered a system that collects emotionally-salient physiological signals and translates them into sonic output. Biomusic records signals often found to be related to emotions (skin conductance, temperature, and heart rate) through a sensor worn on the finger, which are sent via Bluetooth to an application on a mobile phone. From these raw signals, emotion-related changes are detected in real-time and are rendered audible in various sounds and musical styles, such as classical music or nature soundscapes.<sup>2</sup> Variations in physiological signals are mapped to the variations in sound. For example, heart rate may link to flowing water sounds, or the crackling sounds of burning logs. Peaks of skin conductance in turn translate into short birdsongs or chords on strings. Skin temperature variations may control the overall atmosphere of the sound scene through, for instance, reverberation. A further description of biomusic, including related images and media clips, is available online.

Early prototypes of biomusic were used with non-communicative individuals with extremely limited behavioral repertoires in complex continuing-care settings. Pilot studies have indicated that biomusic can contribute to increased feelings of interpersonal connection, and to generate (self)awareness of the emotional state of the user. <sup>2,6</sup> In its current version, biomusic is a wearable and mobile technology, with potential use in everyday situations with individuals on the autism spectrum. This potential has been further encouraged by pilot studies that provide evidence that caregivers listening to their child's biomusic can accurately differentiate states of anxiety from states of calm. <sup>6</sup> From a therapeutic point of view, providing caregivers with the opportunity to perceive a negative

internal state—which may not be accompanied by any other external manifestation—opens the possibility for early intervention, and appropriate responses. These research avenues are in line with general trends in the field of affective computing, aiming at, for example, making others aware of actions that provoke discomfort, such as eye contact.<sup>3</sup> The designers of biomusic believed that the technology's ability to engender awareness of the emotional states of the self and others was well-suited to address the needs of individuals with autism, who often have mild to major affective swings that may arise from sensory and other challenges.

From a conceptual perspective, biomusic blurs distinctions between human and technology, emotion and expression, private and public. Translating physiological signals into music could potentially humanize how people and social institutions attune to and recognize the presence of persons who are marginalized due to diverse communicative capacities. Increasing the potential for communication in where situations there are likely be misunderstandings is one of biomusic's advantages. However, tuning in to an individual's electrophysiological states and translating emotional correlates also creates potential risks such as misrepresentation, or invasion of privacy. Thus, the interface between biomusic and neurodiverse conditions such as autism-spectrum conditions raises ethical concerns, both pragmatic (or practical) and aesthetic (or representational), that must be addressed before moving to integrate biomusic into everyday life.

### Knowledge Exchange

These concerns sparked the creation in 2016 of a knowledge-exchange event, Interfacing Biomusic And Autism: What Are the Everyday Ethics of Representing the

Physiology of What Moves Us? This interdisciplinary and inter-sectoral initiative was structured to disrupt power imbalances in technology design by encouraging people on all sides of the biomusic design process to explore the technology together. Individuals who identify as autistic, their family members, and persons who administer educational and cultural programs designed for persons on the spectrum brought experiential knowledge to the event. Developers of technology; biomusic technology industry representatives; engineers; rehabilitation scientists; social scientists; scholars from the humanities; and graduate students from art history, engineering, and occupational therapy brought their technical and practical knowledge to the event. Workshop attendees came together to learn from each other (a citizen-led panel, academic presentations) and with each other (by experiencing biomusic technology while touring a fine arts museum) to reflect on the potential uses (and misuses) of biomusic. Workshop attendees had the opportunity to engage with biomusic in multiple roles, including listening to their own biomusic as they walked through an art gallery as a group, observing the real-time biomusic of a dancer, designing potential future iterations of the technology, and critiquing the technology through various disciplinary lenses. This process explicitly moved away from a medicalized perspective on the emerging technology, adding a humanities lens to its application for rehabilitation.

This article reports on the reflections of the four emerging scholars, with expertise in:

- Science and technology studies (RMO);
- Sound design (FG);
- Critical disability studies/dialogism (GT); and

• Anthropology of autism (MAC).

They were invited to provide reflections of their experience of biomusic during the three-day symposium. At the time of the event, the four were all postdoctoral fellows, affiliated with research programs focused on ethics in the fields of psychiatric rehabilitation (RMO), assistive technology design (FG), childhood disability (GT), and neuroethics (MAC). The convergence of their different theoretical and disciplinary languages around three interpretive concepts (translation, voice, aesthetic representation) raised the questions central to this article. Their combined reflections suggest initial steps toward a multi-disciplinary conceptual framework integrates social and critical with technical perspectives.

### **Disciplinary Backgrounds**

To consider the multiple meanings that different actors assign to biomusic, as well as the potential risks and ethical tensions that this technology could pose with respect to misrepresentation and invasion of privacy, we briefly present the theoretical lenses that informed the reflections of the four contributors, followed by three interpretive concepts that we identified as most useful to illustrate the pragmatic and aesthetic ethical issues related to biomusic. Rather than seeking to reconcile or merge the different epistemological foundations of the theoretical lenses, our aim is to highlight what is foregrounded in experiences of biomusic. These multiple lenses also allow scholars, designers, and users to better understand the potential of biomusic as an evolving technology that is currently under development. Meanings of biomusic are fluid on many levels, as the technology moves in the world through different contexts. These contexts in turn actively influence how biomusic is conceptualized in its

current developing stage. In this way, both the social contexts and the social technology are fluid and mutually inform one another.

## Viewpoints and Foregrounding

Science and technology studies (STS) foregrounds how biomusic functions as a boundary object. According to Susan Leigh Star and James R. Griesemer,8 boundary objects are objects that are at the same time flexible enough to adapt to local needs and constraints of the actors who use them and strong enough to preserve a common identity across sites. As an example, recordings with two microphones placed close to the ears of the recordist (binaural recording) have been discussed by Grond and Devos<sup>7</sup> as a sonic boundary object in the context of translating experiences between blind and sighted collaborators. Boundary objects are weakly structured in everyday use, and become strongly structured in individual-site use. In addition, such objects have different meanings in different social worlds, but their structure is common enough to be recognizable in more than one world as means of translation. The creation and management of boundary objects is key in developing and maintaining coherence across intersecting social worlds.8

A sound design perspective. As pointed out by Grond and Devos,<sup>7</sup> biomusic emerges as a type of "sonic boundary object" because, despite the possible different meanings sound may evoke, the common structure of this system could facilitate interaction between all parties involved. Individuals with autism have worked together with the biomusic design team to create sounds for the technology that link emotion-related physiological changes in sonic output that they

find effective and aesthetic.<sup>9</sup> In addition, we will use *Actor-Network-Theory (ANT)*. ANT is a methodological and theoretical approach that treats everything in the social and natural worlds as a continuously generated effect of the webs of relations within which they are located.<sup>10</sup> This approach will enable us to situate biomusic as both the translation of emotionally salient physiological signals into music and a means of translation among different worlds.

A critical studies viewpoint concerning the question, "What is at stake with biomusic?" can be addressed by taking up a dialogical lens, specifically Mikhail Bahktin's 11,12 theory of dialogism, which argues all modes of communication (verbal as well as a wide-range of non-verbal modes) can be viewed as "utterances" and that meanings are always situated and interpreted in the space between two or more persons. Since biomusic involves the translation of a person's physiological signals into musical sounds, biomusic can be regarded as an emergent communication mode, composed of synthesized utterances, which opens new possibilities for forming social connections. Biomusic understood through a dialogical lens extends the notion of voice beyond concrete instances of voice synthesizers as assistive technologies for people who cannot speak<sup>13</sup> by asking us to reconsider normative assumptions about how voice is constituted, where it is located, and whether any one of us possesses their own "authentic" voice.14

A cultural anthropology viewpoint, particularly related to the *anthropology of autism*,<sup>15</sup> can also further an understanding of the experiences of biomusic. The anthropology of autism is characterized by: (1) a holistic view that considers the place of autism in the larger sociocultural context; (2) attention to the local and historical particularity of the concept of autism; and (3) attention to the lived experience of people with

autism, including sensory experiences,<sup>4</sup> drawing on interpretive<sup>16</sup> and meaning-centered traditions in medical anthropology.<sup>17,18</sup>

### **Interpretive Concepts**

In response to the question, "What is at stake with biomusic?" each of our disciplinary backgrounds foregrounded different aspects of the experience of biomusic as well as related ethical reflections. In what follows, we describe the interpretive concepts that emerged from our reflections and experiences of biomusic and the ethical issues they bring to the foreground.

We examine what's at stake with biomusic in terms of:

- Biomusic as translation;
- Biomusic as voice; and
- Biomusic as aesthetic representation.

It is important to note that even as the different theoretical constructs we reference (eg, boundary object, utterance, meaning) highlight different aspects of biomusic, they and their relationship to academic disciplines are themselves more plural than our division of them may imply and are, at times, contested (see the above discussion on STS<sup>19</sup>). We intentionally resist dividing the theoretical concepts neatly onto our disciplinary backgrounds; instead, we take an interdisciplinary approach to the ethical questions that emerged during this project. Thus, how these interpretive concepts or theoretical constructs converged in the reflections and discussions that emerged in writing this article potentially constitutes the initial steps toward a theoretical framework for exploring the interface between humans and biotechnological innovations, including biomusic.

Biomusic as Translation. Biomusic has been used, among other things, to reveal the internal reactions of non-communicative children<sup>2</sup>, and to make parents aware of states of anxiety in autistic children.<sup>6</sup> The biomusic design team has conceived of these use-cases of the technology from the perspective of the fields of affective and assistive technology, leaving more applications to be discovered as we consider the technology through different disciplinary lenses. The process of creating biomusic (ie, recording physiological states, translating them into audible output, interpreting the output as emotions) touches upon a central question: can one person access and understand the experiences of another? As assistive technology seen from an anthropology of autism lens, biomusic can be understood as a tool speaking persons use in an attempt to communicate with non-speaking persons. However, this attempt may reveal more about the speakers than the non-speakers, particularly if it is directed by and interpreted within normative speaking frameworks. If biomusic is a tool for communication between speaking and non-speaking persons, it is a technological mediator and facilitator of such communication, similar to, but expanding beyond, modes such as images or texts that are used in augmentative and alternative communication (AAC) technologies such as communication boards or speech-generating devices.

Drawing from the anthropology of autism, biomusic can be understood as a form of "radical translation," which Brendan Hart<sup>20</sup> defines in the context of autism as the way that "parents translate and frame their child's behaviors and utterances in ways that index a complex—if difficult-to-access and radically different—inner world" (see also Chew<sup>21</sup>). Biomusic can be seen as technological mediator for this radical

translation, particularly if end- users contribute to shaping the forms of their communications. However, the underlying assumption that persons would want to contribute to shaping their own output also raises ethical questions. Not everyone may want what biomusic reads (eg, their physiological signals) to be translated to or by everyone else. Biomusic renders audible aspects of experience that generally remain private from others, and that could be regarded as personally and culturally quite intimate. The opposite side of biomusic as translation could be biomusic read as an invasion of privacy. What is at stake when biomusic is understood in this way includes issues of communication and control. If translation is technologically-mediated, then whoever designs and controls that technology has an important impact on how it works. This also raises the question: Who can decide who gets to hear biomusic, especially when the people whose biomusic is being recorded do not communicate in ways that are translate-able to the speaking world?

STS provides a lens that allows us to examine the processes of translation that biomusic makes possible. Building from the work of proponents of ANT, <sup>22,23</sup> translation constitutes the movement of an actor's goals, knowledges, technologies, etc., across different medico-scientific topologies, <sup>24</sup> settings, <sup>25</sup> and/or worlds. <sup>26</sup>

From this approach, we could see that in biomusic there are multiple processes of translation in various directions among physiological signals, emotions, and sounds/music. In this sense, translation, far from being "literal,"23 is transformative: the emotionally salient physiological signals become music. This transformative movement attempts to create relations salient equivalence between emotionally physiological which signals and music,

incommensurable. However, this STS lens does not provide a response to the ethical question raised previously about translating between radically different worlds so much as it highlights additional ethical issues. What is at stake is the fidelity of translation, including questions such as: How are equivalences between emotionally salient physiological signals and sounds built? Are there meanings that get "lost in translation"? An Italian saying, "tradduttore, traditore" ("translator, traitor"), holds that translation is always an act of betrayal, which is highlighted in the translation of emotionally salient physiological signals. meanings may remain incommensurable. incommensurability raises the question: What are the risks of misrepresenting or mistranslating individual emotional states? If we also consider that translations are endless, we can bring into the discussion design perspectives that underline that no technology is ever "finished," or that user feedback (often through networked devices) constantly translates improvements of existing and deployed technologies after their conception (ie, "design after use" versus "use after design").27

Although ANT has an emergent approach regarding how power comes into being,<sup>28</sup> and has been criticized for neglecting uneven relations of power,<sup>29</sup> we would like to highlight that it is important to acknowledge the unequal relations often involved in knowledge and technology translations. In the case of biomusic as translation, people living with autism, caregivers, and researchers in charge of creating and implementing biomusic systems are situated in power-differentiated positions where people without autism are typically afforded more power than autistic people, and researchers accorded more power than non-researchers.

From a design perspective, we now need to ask how

these endless and continued translations reaching beyond the participatory phase of conception affect the power relation between the designers and the users of biomusic. Is this constant feedback a type of translation that is beneficial, or does it rather promote user surveillance? To answer this question in context, we must consider if this translation serves the individual's own ends or those of the caregivers or health providers. Thus, in considering biomusic as translation, what is at stake includes ethical issues associated with privacy and control, interpretation, self-monitoring. (mis)representation and Understanding biomusic as translation raises many exciting possibilities, but ethical issues must be considered.

Biomusic as Voice. Bahktin's 11,12 theory of dialogism informs the perspective of biomusic as voice. Since biomusic involves the translation of a person's emotion-based physiological signals into musical sounds, the use of biomusic has communicative potentialities. When biomusic is regarded as a form of utterance, new opportunities are opened reconsidering normative assumptions about how voice is constituted, where it is located, and whether any one of us possesses their own authentic voice. 14 Dialogism asks us to reconsider who and/or what is engaged in the production of the utterance as a shared experience, and expands and makes visible the shared space of interaction through the experience of making and listening to biomusic. In this framework, persons speaking and/or communicating primarily in ways other than speech, interact using multiple modes to jointly form meanings and connections through those interactions.

This perspective contrasts with the consideration that "voice" as a concept is socially constructed as an individual possession, an autonomous expression of

one's inner self, and an independently-produced utterance. Even further, a dialogical perspective contrasts with dominant conceptualizations of voice, which frame oral speech as natural and preferred. Speech differences, such as those experienced by some people labelled autistic, are identified in biomedical terms as pathologies to be corrected. This pathologization has the effect of devaluing the communicative acts of persons who communicate primarily in ways other than speech, ultimately minimizing their sense of personhood.<sup>30</sup> Even autistic persons who speak are often constructed (biomedically and otherwise) as lacking in "rhetoric."<sup>31</sup>

Bakhtin argued that taken-for-granted assumptions about the "individual, autonomous speaker" are illusions and that "voice" is constituted in the space—or interface—between persons. Thus, meanings are actualized through interrelation. As we have noted earlier, biomusic also introduces possibilities for meanings to be actualized through the interrelation of persons and *technologies*. Thus, communication in the context of biomusic—indeed *all* communication—is an interdependent and mediated co-production. A dialogical view of biomusic suggests it is a communication mode with the potential to enable new forms of dialogue, interaction, and connection between persons.

Bakhtin asserted: "To be means to communicate. ...A person has no sovereign territory, he is wholly and always on the boundary; looking inside himself, he looks into the eyes of another or with the eyes of another."<sup>32</sup> Here, Bakhtin is blurring the boundaries of personhood and suggesting that notions of personhood might also be dialogical.

From this perspective, what's at stake in biomusic are issues of personhood, inclusion, and respect. We might

ask: Is personhood realized not within individual bodies but at the interface—the in-between space between persons, places, and technologies? considering broader conceptualizations of communication and personhood, we suggest it is necessary to transcend dominant conceptualization of voice that act to discount, mute, or silence some persons. Such conceptualizations perpetuate moral hierarchies, judgments, and beliefs about whose voices matter. Consideration of the ethics involved in recognizing the communicative potential of biomusic requires attention to the social relations in which meanings are co-constructed, and increased acknowledgment of the moral agency of the persons within those relations. What are the implications if we fail to recognize the communicative potential of biomusic? We leave this as an open ethical question.

Biomusic as Aesthetic Representation. Even though biomusic was first developed in a clinical care with context and tried individuals without communication interactions<sup>33</sup> and with profound disabilities, 2,6 the term "biomusic" evokes something that could be appreciated aesthetically. Aesthetic considerations (such as the choice of sounds, timbre, etc., used in the sonification) strongly inform the biomusic design process, and the ultimate musical form it takes. These important aesthetic issues draw attention to the ethical issues at play during the process of selecting what sounds will be used and how the physiological signals affect and manipulate those sounds.

Biomusic is a form of representation, in that the sounds specifically stand in for something—in this case representing something particular about an individual's physiological signals. This form of representation therefore has ethical ramifications in terms of how the music is rendered. What's at stake are

questions of authenticity and identification. Whose musical traditions are drawn upon? Different musical traditions use different instruments, rhythms, melodies, and so on. Do these sounds or traditions resonate with the users, or, at base, do users like them? These are some of the issues being taken up in related participatory approaches<sup>34</sup> working with persons on the autism spectrum to design sounds that could be included in the biomusic application to provide musical options informed by a diversity of aesthetic preferences.

**Individual biomusic experiences.** In addition to the aesthetic considerations proper to the creation of the biomusic medium, we also had the opportunity during the workshop to experience the representational aesthetics of our own or other's biomusic (in small dyads and triads) while observing works in an art museum. Commenting on this experience, several participants raised the possibility of jointly listening to biomusic, for shared enjoyment, as a potential best usescenario for this technology. At the same time, some individuals commented on their own added awareness of others listening to them. Their response—trying to then control their own physiological reactions to certain artworks—raises questions about the potential mis-use of biomusic as a tool for self-surveillance. If biomusic makes individuals aware of their negative emotions, would individuals wearing the technology be responsible for the constant control of these emotions, as opposed to being allowed to express them freely?<sup>35</sup> In contrast, another participant was quite taken with hearing their own biomusic in the context of a museum, which they experienced as empowering. This joint listening experience can be framed as "musicking together" and has potentially a two-fold function: (1) to reduce the aspect of an asymmetric power dynamic of one person listening to the other, <sup>36</sup> and (2) to initiate multiple positive effects that joint music-making has

on the development of mutual understanding and judgment (informed through music therapy).<sup>37</sup>

A dancer's biomusic. After touring the art museum listening to our biomusic, we watched a dancer perform a structured improvisation while hearing the live sonification of her biomusic that evolved along with her movements. A video of this performance is available online.

During the performance, an art historian/curator and researcher (TT) drew our attention to the many layers of representation we were partaking in as an audience: observing the artworks, listening to each other's biomusic, observing the dancer and listening to her biomusic, and throughout, observing each other experiencing these activities together in a public space. We were invited to consider the relationship between what we saw (i.e., the moving dancer) and what we heard (her live biomusic): did it appear to be a causal or linear relationship, or were there any surprises or contradictions? The researcher's commentary alerted us to the fact that the connection between what appears to be the dancer's inner state and what we could hear as the manifestation of her physiological signals was an evolving and unstable one, and that it was not necessarily predictable. The translation of her physiological signals into biomusic was but one layer of representation among the several that she, as a trained dancer, and that music, an art form, already carry as distinct aesthetic mediums.

### Discussion

The reflective examination of the experience of biomusic from multiple theoretical lenses foregrounded theoretical constructs (boundary object, utterance, meaning) that focused attention on three interpretive concepts (translation, voice, aesthetic representation) that identify potential ethical issues that could be associated with the use of this technology in the future. We framed these ethical issues around the question, "What's at stake in biomusic?" and highlighted different answers informed by considering biomusic through these interpretive concepts. Our diverse disciplinary backgrounds provide the possibility to look at biomusic from multiple angles, benefiting from productive comparisons and contrasts in different ways of looking at the interpretive concepts of translation, voice, and aesthetic representation.

### A THEORETICAL DESIGN FRAMEWORK

Here in the discussion, we sketch out the beginnings of what could be a useful theoretical framework for understanding the design of emerging technologies in rehabilitation, by tentatively combining these interpretive concepts.

Ethical issues of translation are particularly evident when we look at biomusic using notions from STS, dialogism, and the anthropology of autism. The ethical issues that emerge put into question the actual possibility of translating between radically different worlds (the worlds of autistic people and of neurotypical people). The issues raised include the ways in which equivalences between physiological signals, emotions, and sound/music are built; the meanings that are not translated or remain incommensurable; the risks of misrepresenting or mistranslating emotions of people with autism; the power differences involved in the process of translation (whose emotions will be translated and for the ends of whom); and the potential for invading the personal privacy of people with autism and reducing them to stereotypes about autism.

Biomusic as Communication. Viewing biomusic as translation and viewing biomusic as voice are both ways of considering biomusic as communication. However, while translation might imply speaking, the concept of voice transcends speaking. Therefore, considering biomusic as voice necessitates considering what forms of communication are valued, as well as communication and personhood are cointeraction. constructed through interpersonal Biomusic technology has the potential to challenge notions about what constitutes an authentic voice and, instead, foregrounds the personhood of its users—but only if its communicative potential is recognized. For these reasons, there is an ethical risk in understanding biomusic only as a translational tool, and not as an alternative mode of communication.

Understanding biomusic as an aesthetic representation also interfaces with understanding biomusic as translation. Aesthetic choices are a factor in translation, and we argue that translation only works if we also pay attention to the aesthetic decisions involved. While focusing on biomusic as translation allows us to consider content and social context, focusing on biomusic as aesthetic representation allows us to consider form.

Aesthetics and Ethics. We can attend, therefore, not only to translation, voice, and aesthetic representation, but to the aesthetics of translation and voices, the translation of aesthetic representations, and so on. A focus on aesthetics also asks us to attend to the ethical considerations in terms of the form of biomusic (pitch, timbre, and so on). Given the nature of the biomusic technology—that it provides users with sounds that are linked to physiological signals—those who use biomusic make important aesthetic judgments about what sounds to develop and make available to users. These aesthetic judgments have ethical dimensions, as

aesthetic judgments are culturally constructed and might exclude listeners or users whose aesthetic preferences are not reflected in the technology. Aesthetic representation also asks us to consider the ethical implications related to its functional potential, as either surveillance, as something beautiful to be appreciated, or both, or neither.

Issues of Power. All of these approaches ask us to reflect on issues of power embedded in the aesthetic choices made during the construction of biomusic as well as in the contexts in which it will be heard. Does biomusic faithfully represent its users, either communicationally (in terms of translation and voice) or aesthetically? Both concerns can be captured through sonic metaphors: does biomusic have an appropriate tone, does it hit the right note? These are active issues the design team is addressing

Participatory Design. One way to address ethical issues in the development of technology is through a participatory design process. Participatory design is based in participatory research, an approach in which researchers "work in equitable partnerships with those affected by the research and/or those who must ultimately act on its results." In participatory research, subjects are not only participants of a study but also co-researchers (they have an active participation in shaping the research). The 3-day workshop described here was an attempt to explore the intentions and concerns of potential stakeholders in biomusic design and to incorporate them into the future design of the technology.

**User Engagement.** During the workshop, we saw that biomusic has the potential to bring the participatory approach even further: to a situation in which researchers engaged with technology as users. For example, to demonstrate how the technology

works, researchers often try the technology with their own bodies, use their physiological signals to show how biomusic works, and discuss with potential users their emotional states. We see using the participatory approach as a first step toward balancing power differences between the designer and the user in the development of technologies that may be used in (but not limited to) rehabilitation.

### Conclusion

Biomusic technology is being developed with an eye toward rehabilitation. Ethical considerations are key in the development of any new technology, which is necessarily embedded in social context. Inter-sectoral and interdisciplinary reflection on ethical issues from both potential users and scholars representing a range of humanities and social sciences helps us to understand the ethical issues at stake with biomusic.

In this article, we have focused particularly on the different ways biomusic can be understood in humanities frameworks, and the ethical insights derived from considering biomusic in these ways.

#### What's at stake with biomusic includes:

- Control (Who designs and controls the technology, who can decide who gets to hear biomusic?)
- Fidelity of translation (What is lost in translation, and what are the risks of mistranslation?)
- Respect (How is personhood understood and realized?)
- Authenticity (Whose musical traditions are

drawn upon, and how do sounds resonate with users?)

These questions do not yet (and may never) have answers, but they serve to guide designers in addressing ethical issues raised by new technology. These insights were developed during a three-day knowledge-exchange event, which underlines how inter-sectoral engagement among the community, industry, and academia is a promising avenue not only for addressing ethical issues in the development of technology, but broadly for integrating the important insights of the humanities into the field of rehabilitation technology design.

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#### CONTRIBUTIONS

MP, SB-M, and TT designed the biomusic workshop. FG contributed also to its execution. MAC, GT, and RMO contributed ethical reflection during the workshop. Based on this reflection, MAC, GT, and RMO outlined this paper. All authors revised the outline. All authors drafted and revised the paper, and all authors approved the final version.

#### CONFLICTS OF INTEREST

All authors report that they have no conflict of interest to declare.

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#### About the Authors



Ariel Cascio, PhD is an Assistant Professor at the Central Michigan University College of Medicine, teaching the Art of Medicine, and Society & Community Medicine to first- and second-year medical students. Dr. Cascio received a PhD in Anthropology from Case Western Reserve University and conducted postdoctoral research in health ethics at the Institut de recherches cliniques de Montréal (with an affiliation also at McGill University, Montreal, Canada). Dr. Cascio's research focuses on social issues around autism including cross-cultural autism studies, social movements, and lived experience. This research has been funded by the US-Italy Fulbright Commission and the Social Sciences and Humanities Research Council of Canada Banting Postdoctoral Fellowship Program. As the adage goes, anthropology is the most humanistic of the sciences and the most scientific of the humanities. The humanities are important to Dr. Cascio's research projects because they draw on humanities methods through interpretive analyses of qualitative data.



Rossio Motta-Ochoa, PhD completed her doctorate in cultural anthropology at the University of California, Davis. Her fields of specialization are Science and Technology Studies, medical anthropology, and person-centered anthropology. Her areas of interest are Assistive Technologies, artificial intelligence, and human-computer interaction. Currently, Dr. Motta-Ochoa is a postdoctoral fellow at the Biosignal Interaction and Personhood Technology Lab (BIAPT), under the supervision of Stefanie Blain-Moraes. Dr. Motta-Ochoa conducts ethnographic fieldwork about the effects of biomusic on the lives of those who can potentially benefit from it, such as individuals with dementia and their caregivers. She provides their viewpoints to inform decisions regarding the design of this technology.



**Gail Teachman, PhD** is an Assistant Professor in the School of Occupational Therapy, Western University, Canada. Using a range of qualitative methodologies and informed by social theory, occupational science, childhood ethics, and critical disability studies perspectives, Dr. Teachman's research advances understanding of how disabled children's experiences of inclusion, exclusion, and inequities are shaped by social, cultural, and political contexts.



Florian Grond, PhD received his PhD from Bielefeld University, Germany, where he conducted his doctoral research on auditory display in the Excellence Cluster for Cognitive Interaction Technology. Prior to receiving his doctorate, he worked several years at the Centre for Art and Media (ZKM) in Karlsruhe, Germany. He held postdoctoral appointments with Concordia University and McGill University in Montreal, Canada, and is currently a postdoctoral fellow with the School of Physical and Occupational Therapy at McGill University. In addition to his research in auditory display and spatial audio, he has a special interest in disability, technology, art, and design.



**Tamar Tembeck, PhD** is an art historian whose research engages with medical humanities and critical disability studies. She has a professional background in the performing arts, develops projects as an independent curator, and is currently General and Artistic Director of the artist-run centre OBORO in Montreal, Canada. She is an Affiliate Member of the School of Physical and Occupational Therapy at McGill University, Canada, and an Adjunct Professor with the *Université du Québec à Montréal s* research chair for innovative practices in art, culture, and well-being.



Stefanie Blain-Moraes, PhD received her doctoral degree in Biomedical Engineering and Rehabilitation Sciences from the University of Toronto, Canada. She completed two postdoctoral fellowships at the University of Michigan; the first focused on the development of brain-computer interfaces for individuals with severe disabilities, and the second studied the neural correlates of consciousness through anesthetic-induced unconsciousness. In 2016, she became an assistant professor in the School of Physical and Occupational Therapy at McGill University, Canada, where she leads the Biosignal Interaction and Personhood Technology (BIAPT) Lab. Her research focuses on developing assistive technologies to enhance the assessment of and interaction with individuals who are behaviorally unresponsive.



Melissa Park, PhD is an Associate Professor in the School of Physical and Occupational Therapy, Faculty of Medicine, at McGill University, Canada. She is a core member of Participatory Research at McGill University, and a full member of *Centre de recerche interdisciplinaire en réadaptation du Montréal métropolitain*. As an occupational therapist with a background in History of Art, Occupational Science, and Medical Anthropology, she uses the terms of humanities and rehabilitation to

understand healing, transformative, and relational processes. Her funded ethnographic and participatory research has focused on working with, and understanding the priority concerns of, neurodiverse persons with invisible disabilities, family members, and healthcare professionals.