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in a global public health challenge**

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“On whose side are you?": Artist-researcher positionality in a global public health challenge

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Abstract

This exposition discusses risks that emerge from the artist-researcher's fluid position within artistic research. The research entails the artistic researcher interviewing vaccine-critical parents and a vaccine scientist about their opposing standpoints toward immunization and vaccination, while remaining ambivalent and sympathetic toward both views. The exposition uses concepts such as positionality, insider-outsider, and sameness to unpack the various risks arising from the stimulation and staging of conflicting voices about vaccines. These risks include upset participants due to unmet expectations raised partially by the artistic researcher's understanding attitude, and the pervasiveness of the "voice" of the documentary film being created throughout the artist-researcher's interactions with the participants.

Introduction

This exposition discusses the risks emerging from an artist-researcher fluid positionality. It introduces an artistic research project where I engage in the urgent global health challenge of vaccine hesitancy. The stakes are high due to an increase in vaccine hesitancy, particularly in developed countries, and outbreaks of previously eradicated infectious diseases have occurred again. Primarily concerning children's health, the issue is emotionally sensitive and difficult to explore without taking sides, given the current polarized pro- and anti-camps. In the project, I purposefully set opposing worldviews in dialogue with each other by interviewing vaccine-critical parents and collaborating with a vaccine researcher. The exposition considers the risks I face as the artist mediating such a dialogue and exploring my own beliefs as part of the project. Such risks involve not only exposing my ignorance or hypocrisy, but also when I simulate either the participants' or the collaborator's worldviews, both may hope for my advocacy of their respective viewpoints, expecting me to side with them.

The vaccine hesitancy project discussed here is conducted within the larger framework of "Immune Nations" (2015–2020), a group of international artists, scientists, and policy makers, invited to collaboratively explore issues related to immunization. I was the only member of this group who decided to tackle the topic of vaccine hesitancy and interview vaccine-hesitant parents for this project. To create a balanced approach to this controversial topic, I invited the vaccine researcher and senior scientist Johan Holst from the Norwegian Institute of Public Health to collaborate with me, knowing that his views would be in contrast with the parents' views (and my own).



My project has proceeded in various stages during which I have acted in different roles and capacities. For the research procedure, I first interviewed vaccine-critical parents in the Netherlands and Finland, aiming to capture the health beliefs that formed the background of their vaccine criticism. Next, I visualized these beliefs and discussed them with Johan (Koski & Holst 2017). Both the parents' interviews and the artist-scientist dialogue are featured in my short documentary entitled *Conversations with vaccine-critical parents* (2017) [view trailer](#). This documentary has been screened in several festivals and exhibitions, but its primary audience comprises medical students. I designed a writing exercise, together with the film screening and related discussions, as an educational intervention and conducted a pilot study on this intervention with my clinical teacher collaborators (Koski, Lehto & Hakkarainen 2018). The intention of this phase of the project was to prepare medical students to respond to different health beliefs and non-compliance in a respectful manner. This exposition discusses the kinds of shifts that occur in my orientation toward the participants, the collaborator, medical students, and the topic of vaccine hesitancy during the project.

Over the past decade, my art-research practice has emerged largely from an outsider's perspective. I have conducted fellowships and work periods in scientific laboratories and medical schools, while my identity and methods are those of an artist. Perceived from another angle, it is increasingly acknowledged that such perspectives are evolving constructions. In fact, there emerges an understanding that researchers may experience moments of being insiders and outsiders during the course of a study and that both these perspectives are legitimate (Sharan et al. 2001).

It is tempting to polarize approaches to vaccines into two camps, for instance, as a dichotomy between medicalization and healthism. However, from a central perspective, both the pro- and the anti-vaccine groups share the same fundamental goal. Interestingly, both groups even use similar strategies of power in their communication, claiming to possess real knowledge and to be more trustworthy (Heis 2011). Setting the differences aside, most of us (and them) are fixated on achieving a better state of health. For the pro-vaccine side, the main threats to attaining this goal are illness and death, whereas for the anti-vaccine side, the main danger is a disturbed course of nature.



Managing risks for participants, maintaining artistic integrity

I begin by providing a background on the concept of risk in artistic research from the standpoint of institutional ethics protocols. I focus on situations where an artist-researcher involves human participants and collaborators from different contexts and disciplines, and the project is formulated to comply with institutional research ethics. The primary purpose of the protocols of institutional research ethics is to minimize the harm and maximize the benefit of a given project, as well as protect the research participants' autonomy and privacy. Risks related to research participants are generally understood as forms of harm and should be avoided. In this project, the parents' identities have been kept anonymous, and I do not discuss the risks related to their privacy in this exposition. Instead, I

refer to them as both parents and participants. I call my scientist collaborator by his first name Johan, as this is also how he is introduced in the documentary.

The institutional ethics protocols typically consider the presence of emotions a risk as it may cause participant distress. Participant distress may refer to any negative emotions, such as embarrassment or being upset, as well as fear and other forms of discomfort. However, this issue challenges many art-research practices because various forms of distress can be artistically intriguing, much more so than perfect harmony. Furthermore, a researcher could ask why emotions are often considered dangerous in the first place, thus questioning the link between emotions and harm. In certain ways, the lack of emotions could be considered harmful as well. I have previously considered humor one of the powerful tools to manage distress, either the participants' or my own. However, the use of humor, especially the incorporation of laughter in a film, has appeared to be particularly risky in terms of avoiding negative responses. For instance, while it was evident to me that I was laughing with someone or at myself, the audience might perceive my mirth differently (see Koski, Heyning & Zwijnenberg 2016).

In my ethics approval application to the Ethics Committee of the human sciences in the University of Tampere, I state, "My assessment is that participation in this project will result in no long-term discomfort or risk and very minimal (if any) short-term discomfort." However, I do not mention that risk is often an inherent component of an artistic vision and practice. In fact, not taking artistic risks poses a threat to artists, in terms of the integrity of their work, as well as legitimation by their critics, peers, and various audiences. Accordingly, artists do not wish to create 'harmless' work merely to satisfy the ethics boards. Traditionally, the institutional research ethics guidelines have not addressed art's particular relationships with risk, sometimes causing dilemmas at (too) late stages of artistic research projects. However, there increasingly arises the understanding about the necessity for a discussion on ethics guidelines in research involving art practices. For instance, the Canadian Interagency Advisory Panel on Research Ethics has acknowledged one of the core challenges in research involving creative practices:

[...] risk [...] carries very different connotations in arts than it does in areas like medicine. In arts-based research the description of a creative project as "risky" or an artist as "taking risks" is a coveted compliment. [...] Describing a project as "minimal risk" in the arts is a dismissive criticism (Blackstone et al. 2008:6-7).

How may this issue manifest itself when the artist-researcher invites human participants and collaborators to join one's research project? Obviously, artistic risks should not be taken at the participants' expense (without a clear agreement at least), but the risk may lie in putting the wellbeing or reputation of the artists themselves at stake. Nonetheless, there is often a conflicting sense of loyalty, as well as expectation, that the artist-researcher empathizes with the research participants and cares about the integrity of one's work. Participants are not (paid professional) performers. The setting is even more complex if there are research collaborators with their own agendas as well. Briefly stated, being neurotic about protecting and pleasing everyone risks producing unconvincing work, whereas too much friction and tension with the participants and the collaborators could lead to unpleasant and unproductive conflicts, which might even have legal consequences.

One of the key instruments of managing risks is the participants' informed consent. However, informed consent is not necessarily a strong instrument to guarantee participant protection, not to mention the risks it presents to the artist-researcher. According to many artists, including Graig-Martin (2015:12), artists expose their true position through their work; the artwork typically tells the truth about their views and lets the audience know the artists. While this view is challenged in the academic research context in many ways, it especially fails to address the participants' informed consent. In other words, an absent, yet-to-be-created artwork is mute. Thus, next to jeopardizing the integrity and the spontaneity of their work (if describing a riskless project), the artists may also risk making the participants feel upset and withdraw from the project and the collaborators' disagreements with the artistic decisions. The major question is how and what to communicate to prospective participants, in the absence of the artwork, when recruiting them and requesting their informed consent.

The various challenges that institutionalized ethics pose in academic-(bio)artistic practices are currently being explored through a multitude of individual art-science projects, as well as international ventures, such as the “Trust Me I’m an Artist” project (2012-2017) initiated by bioartist Anna Dumitriu. Events within this framework address the ethical dilemmas faced by artists when entering the environments and employing the techniques of science, collaborating with scientists, and relating their practice to the protocols of institutional research ethics. As the project title implies, trust is essential in such transdisciplinary undertakings. However, the project expands beyond considering what constitutes trust and trustworthiness in art-science projects. The artists participating in this project (Willet & O’Reilly 2017) also ask whether they can trust themselves regarding their perceptions of others’ viewpoints and experiences.

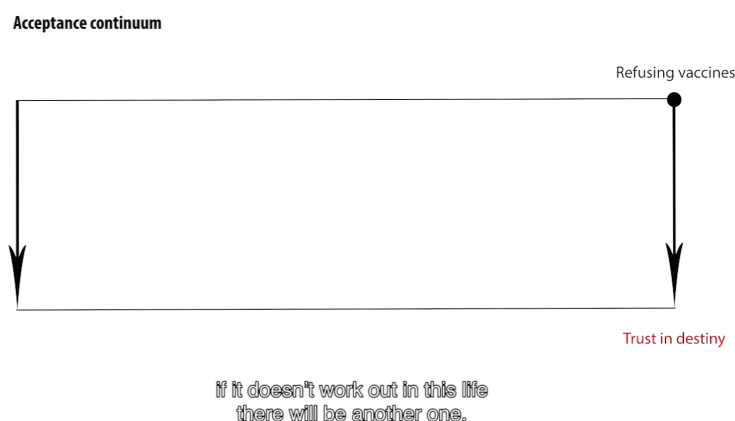


Positionality regarding vaccine hesitancy

Positionality is an often-used term in several fields, such as feminist research, migration research, and minority research. Essentially, positionality refers to the notion that personal values, views, and location in time and space influence how a researcher understands the world (Sanchez 2010). In this regard, neutral or apolitical research does not exist because the researcher’s opinions, beliefs, and social background shape one’s methodological and analytical decisions (Vanner 2015). Need for explication of the researcher positionality in the continuum between insider-outsider positions is widely acknowledged in ethnographic (Eppley 2006) and action research projects (Herr and Anderson 2005). So far, however, positionality has rarely been examined in artistic research literature. One reason may be that until recently, artistic research (unlike arts-based research) has typically not involved research participants and other cultural settings or the associated university research ethics protocols. Especially when the artist-researcher has focused on aspects of his or her own (professional) self and/or practice, the sole position taken has been that of insider, alternating between making and reflecting. This exposition focuses on how my role as an artist and my “natural habitat” in my art practice adds to the complexity and risks of a research project involving participants and settings beyond my practice. Positioning in this project takes place by asking who I am in relation to my research participants and collaborator (Herr and Anderson 2005) in crossing border to vaccine critical parents’ subculture and the fields of natural science and public health. This includes reflection of the ways in which my beliefs and artistic methods have influenced the participants and the process outcomes (Savin-Baden and Howell Major 2013). My fluid positionality manifests in variations in my roles and attitudes depending on with whom I am interacting and in which foreign setting. Even though I can sympathize with, and have firsthand experience of, both of the participant-collaborators’ worlds, I consider myself an outsider in terms of their settings and views, as opposed to an insider of my own art practice.

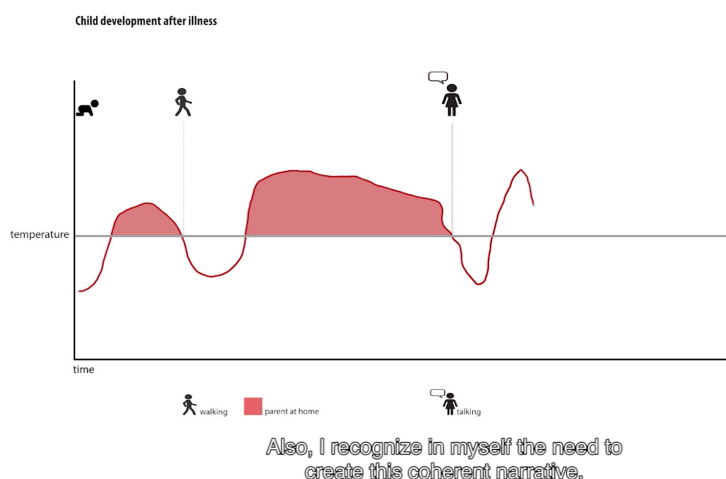
How do I then relate to the research participants and the topic of vaccine hesitancy? Similar to the parents whom I have interviewed, I am a privileged Westerner who has not witnessed severe infectious disease outbreaks. However, on a personal level, many of the parents (and I myself) have contracted milder infectious diseases, such as chicken pox, without further complications, hence associating a sense of harmlessness with them. Several of my participants are my friends or colleagues, and the rest

of the participants were recruited through them. I sympathize with them more than with the field of vaccine research, let alone the pharmaceutical industry, and respect their courage to make choices against the authorities' recommendations. From this position, I also enjoy far greater trust than an unfamiliar artist-researcher would or a person single-mindedly promoting vaccines. There seems to be the mutual sense that I could be one of them and likely would if I had children. This familiarity, leading to an illusion of sameness (Pitman 2002), originates from sharing personal experiences, such as being hesitant about many kinds of pharmaceutical interventions, using alternative healthcare services, and eating organic food. My attitudes toward vaccine hesitancy are also related to positionality as a physical location, influenced by my encounters with the parents. Meeting the parents in their homes, in the presence of their children, spouses, and pets, has affected me. I am charmed by the warmth and seeming simplicity of their lifestyles. Their generosity and authentic concern about their children's wellbeing touch me. However, none of these points detracts from the fact that I also experience respect and warmth toward my scientist and clinical collaborators. The project partly thrives through an ideal that if these groups would only meet each other, they would also realize how wonderful (the other) people are.



Meanwhile, I have openly communicated to the participants and the collaborator my somewhat hesitant attitude toward vaccines, and that my primary intention in this project is to expand medical students' horizon of how to respectfully communicate with vaccine-critical parents. Yet, misunderstandings may arise from showing only selected parts of the discussions in my documentary film. When I was with the parents, for instance, my tone of voice was primarily sympathetic. However, I later tried to present their views to Johan in a neutral manner. Since only the latter segments are included in the film, where the parents' answers are narrated in my "neutral" or detached voice, the parents may perceive a dissonance between my presence in the interviews and the film.

The entire process—visiting a subculture of vaccine hesitancy, collecting its beliefs, and subsequently creating visual representations of these—simulates a cartographer's work. I drew maps as they emerged from the parents' stories and my visits to their homes. I subsequently showed these maps to Johan and invited him to reflect on them. He was familiar with some parts of the landscape; other areas were new to him. It also appeared that here and there, I had drawn the border between the land of vaccine criticism and the land of science as artificially clear-cut, whereas there might be overlapping gray areas. Sometimes, Johan thought that the field of science was not correctly pictured.



Power-relations between artist-researcher, participants and collaborator

Though the vaccine-critical parents I interviewed are in many ways privileged, they are also subject to societal power struggles involving risks beyond infectious diseases. In fact, in the Foucauldian sense, vaccination can be perceived as a form of governmental biopower; the bodies are being controlled and manipulated by the disciplinary technology of vaccination (Foucault 1978, Dew 1999, Engels 2015). From this perspective, the parents' striving for bodily sovereignty seems justified. In fact, refusal to follow the (tradition of the) vaccination program entails an inordinate social risk for the parents (Sobo 2016), hence the need to preserve their anonymity in this project as well.

One risk originating from fluid positionality relates to the power that an artist-researcher holds over the participants and the collaborators. This power may be camouflaged as artistic freedom, but it includes a justification for a role-play that purposefully takes sides, among others. This is a spontaneous performative approach (inherent in much of my art-research practice) to feeling what it would mean to embody a particular viewpoint, to be "the other." I have also taken a position as a devil's advocate in both ways, often mentioning this point to distance my personal opinions from provocative criticism. Such blurring of positions, roles, and tones of voice during the interviews is risky. It may raise expectations among the participants and the collaborator, thus leading to disappointment when these are unmet. As both pro- and anti-vaccine groups currently feel misrepresented and misunderstood, it is natural for them to have expectations of the researcher's advocacy of their viewpoints. Significantly, instead of a felt sense of power, the authority to make decisions can be experienced primarily as pressure; the artist-researcher's loyalties are inevitably conflicted between the human participants and an artwork creation.

Some risks emerge when trying to avoid others. For instance, throughout the whole project, I have been hyperaware that my limited knowledge of science, particularly microbiology, is insufficient to make informed decisions about vaccines. Moreover, I do not believe that I have the right to critique anyone's immunization decisions. Thus, in the hope of avoiding the risk of hypocognition, not realizing what I do not know, I have empathized with both groups' worldviews, potentially appearing as a turncoat at times. Nevertheless, this fluid positionality is not only an artistic strategy but a personal experience as well; I did not know whose side I was on initially, and I remain uncertain now. I experience this personal in-betweenness as artistically stimulating.

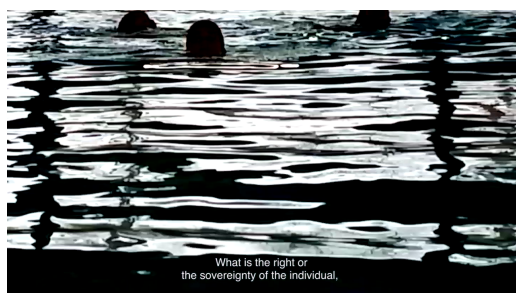
While my interviews reveal that most parents have faced judgment and irritation from healthcare providers, this project neither intends to specifically empower them nor to give them a voice. It does not need to do so. Here, the parents are neither considered oppressed (at least as long as vaccination remains voluntary) nor powerless or in actual danger when expressing their opinions. However, they may be discouraged from speaking due to misunderstandings and negative feedback. Instead, the

project aims to stimulate known and unknown voices in two different contexts and position them in an imaginary yet potential dialogue with each other. Empowerment and giving people a voice are in fact not synonymous; voice, as well as silence, can be empowering, but there may also be a negative side to giving people a voice (Bhavnani 1988). For example, a voice and empowerment can be granted at different instances in the same project. By giving a voice to the parents, have I not empowered (future) healthcare providers to more effectively try to change the parents' minds?

While a certain power inequality exists between the vaccine-hesitant parents and the healthcare providers, the relationship between an (a vaccine-hesitant) artist-researcher and a parent is also disproportional. In fact, on some level, this relationship always remains authoritarian, while it can momentarily create an illusion of equality or even sameness. The power hierarchies in artistic research are not diminished by a documentary or a participatory approach, either. In fact, there exists inequality between the visiting filmmaker and the participant in her own environment. One parent, for instance, explicitly mentioned being intimidated by the shotgun microphone pointed at her. On the other hand, I did not visit a scientific location for this film. Due to him and I being situated in different countries, the dialogue with Johan took place through the internet and over the phone. Even though I had met him in person previously, the mediated mode of our dialogue may have influenced its content by providing privacy for both of us and by rendering the act of recording invisible (another ethical challenge).

Each artistic medium introduces a specific set of risks. In terms of documentary film-making there is a reciprocal relationship between ethics and aesthetics: aesthetic assumptions have ethical consequences and ethical assumptions have aesthetical consequences (Pryluck 1976). My entire production was shaped by the tension between the parents' views and the voice of science, represented by vaccine researcher Johan Holst. The pivotal moment in the early process was a decision to invite Johan into a dialogue, knowing that differences of opinion would surface, leading to unforeseen risks. I experienced the tension and risks artistically (and aesthetically) exciting, even though I knew it would make my position more uncomfortable. Simultaneously, however, the research composition felt more balanced ethically as opposed to involving parents only. I felt a sense of responsibility toward my future audiences and toward "science" to provide a comprehensive view on the topic of vaccine hesitancy. From this perspective, the artistic risk seemed necessary not only for an intriguing documentary and its educational relevance but also to maintain an ethical balance in representing different worldviews.

Yet another set of power-relational risks originate from the artist-researcher's position as an author; in the case of a film-based study, this is manifested through the process of editing in particular. As the creator of this film, I eventually decide which voices and images should be included and even have the possibility to re-record my own voice in case I would be dissatisfied with my spontaneous formulations. The participants and the collaborators typically lack access to this process. Furthermore, while their informed consent offers them an opportunity to withdraw from the project after seeing a rough cut of the film, they may be prohibited from doing so due to their knowledge that this would create difficulties for the artist-researcher. Thus, they may be inclined to accept the rough cut even if they are not completely pleased with how they have been portrayed. Seen from another angle, while my initial motivation behind inviting the parents' home video footage was a quest for authenticity and anonymity, the footage also appears as modes of representation and dissemination of how the parents see their children and environment (see Mitchell and Sommer 2016). However, there is no guarantee that these representations work in favor of the parents, such as reducing the judgment they face in the health care system.



Artistic mediation as positional

ity
Despite my friendly affiliations with the vaccine-critical parents and warm long-term collaboration with scientists, this project does not advocate for either group. Instead, I set out to initiate and mediate a dialogue, which previously ended in either conflicts or withdrawal. Furthermore, the mediation does not only occur between the vaccine-critical parents and a scientist but also between the vaccine-critical parents and medical students. Mediating a dialogue in a conflict zone may sound like an admirable goal, but it is challenging to pinpoint the actual goal of such a conversation. Is the purpose perhaps to unveil previously unknown reasons for these groups' current polarization? Is the aim to achieve a respectful agree-to-disagree stance between the vaccine-critical parents and (future) healthcare providers? In the grand scheme, the intention is to contribute to the education of open-minded physicians who can manage to restrain themselves from expressing judgments about people who represent different worldviews. However, from the perspective of positionality, I have made a film about insiders for outsiders who wish to change the insiders' views. This approach in itself involves risks.

While there are multiple risks caused by the fluid positionality of an artist-researcher in interaction with (any) research participants, several risks also emerge from the controversial topic of vaccine hesitancy in particular. These include the following: 1) risk of misrepresenting either the parents' or the scientist's views; 2) risk of promoting vaccine hesitancy by making the vaccine-critical parents exotic and romanticizing the "purity" of their lifestyle; 3) risk of promoting vaccines, with the project being used to limit their voluntariness, eventually setting up the participants for an even more difficult situation; 4) risk of drawing an artificially solid border between pro- and anti-vaccine views, while several aspects of it may be blurred (about behavior but especially on the level of ideas); and 5) the lack of a single-sided opinion and agenda, which may leave the artist-researcher vulnerable to psychological manipulation by the participants.

While my art practice often involves participatory methods, rendering my presence in various roles as a filmmaker transparent, I still remain an outsider to most roles I play. I can pack up my film gear and go home, whereas the vaccine-critical parents continue to defend their stance against doctors and other pro-vaccine parties (Pryluck 1976). Moreover, I am not only an outsider to the lives of others but also inevitably inside the sphere of my artistic practice. I may change my opinion about vaccines during the process, but I can't afford to step outside my identity as an artist and artistic practice. In a way, these form a magic circle, a mode of aesthetic assumption, which moves with me from place to place. It is within this invisible sphere that I encounter the participants and collaborators and in which their polyphony and my ambiguous relation to it is embraced. Participants, however, may not be aware they are within the circle of artistic practice from the beginning of the process. Furthermore, no single participant witnesses all the voices that I (spontaneously) perform in that circle, and they end up inevitably having only a partial perception of my (fluid) positionality.



Discussion

This project's resulting artwork—a documentary film—exposes some aspects of my fluid positions as an artist-researcher, manifested in the differences in my tone of voice and nuances of expression addressed to the participants in particular. In the first half of the film, I allow the parents to talk, and I do not ask questions as an interviewer. My voice is present only in the dialogue with the scientist, therefore obscuring the nature of my dialogue with the parents from the audience. In a couple of film scenes, I agree with the scientist, such as when pondering that the acceptance of death as a fact of life differs from accepting the death of one's own child. Such mutual agreements might come across as taking (more) the scientist's side than the parents'. In fact, when thanking the parents after showing them a preview of the rough cut of my film, one parent, though not wanting to withdraw from the film, responded (in a mildly disappointed way) wondering, "On whose side are you?" This comment implies that either I have given the parents the impression (at some point) that I would be on their side, or it seems that in the film, I am taking Johan's side. In retrospect, I cannot claim that on a performative level, I would not be guilty of both of positions. Even though I feel uneasy for upsetting any participant of the project, it is difficult to think that I could have proceeded significantly differently in the film-making process. Specifically, the filmmaking has been guided by the exploration of my ambivalence toward vaccines, as well as the integrity of my artistic strategies of fluid positionality. Perceived from the artist's position only, if wanting to avoid creating harmless art, the primary goal should not be ensuring that nobody becomes upset. In this instance, the participant's distress is left to my conscience (instead of further repercussions). I can accept it (and learn from it) because I feel authentic respect toward the parents, knowing my intention was to portray them accordingly. Perhaps the uncomfortable feeling that I am left with is more challenging. Despite my best intentions, I might have revealed some of the parents' "secrets" (genuine health beliefs), potentially causing vaccine-hesitant parents even greater struggles in the healthcare system. The potential negative emotions, such as distress or guilt, often surface at later stages of a project or even after it. There is thus a gap in time and space between the risk management strategies (mentioned in the institutional ethics application) and the reality of how the encounters with the participants and art practice have emerged.

When considering the impact of the documentary, its main aim was to expose medical students to real-life parents and their noncompliance to medical advice. The film has thus far been employed in two medical schools' curriculum, and the students' responses have been studied through qualitative analysis (Koski, Lehto, and Hakkarainen 2018). Other audiences' responses have not been recorded or further examined; however, the film reaches out to a variety of different scientific and artistic contexts internationally. These include invited screenings at an epidemiologists training event, multiple curated expositions, film festival selections, and medical educational conference presentations. The documentary, among my series of other vaccine-hesitancy related artworks, has also been purchased by the Canadian Public Health Agency.

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