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Publication details, including open access policy and instructions for contributors:
http://imaginations.glendon.yorku.ca

## <Immune Nations>

Guest Editor: Natalie Loveless

August 31, 2020

Image Credit:
Kaisu Koski, *Injection Simulator* (2015)

To cite this article:
Koski, Kaisu, and Johan Holst. "Conversations on Art-Science Collaboration and Vaccine Hesitancy." *Imaginations: Journal of Cross-Cultural Image Studies*, vol. 11, no. 2, Aug. 2020, pp. 71–85, doi:10.17742/IMAGE.IN.11.2.5.

To link to this article:
http://dx.doi.org/10.17742/IMAGE.IN.11.2.5

# CONVERSATIONS ON ART-SCIENCE COLLABORATION AND VACCINE HESITANCY

KAISU KOSKI, JOHAN HOLST

*Kaisu Koski, a Finnish artist-researcher based in the UK and the Netherlands, and Johan Holst, a leading vaccinologist in Norway, discuss their collaborative work exploring vaccine hesitancy in parents. The collaboration was initiated as part of Koski's ongoing research in creating films for medical education. Together, the authors developed collaborative exchanges on vaccine-critical parents' health beliefs and visualized them in a multimodal artwork series. Due to the authors' different viewpoints on vaccines, this project raises questions about positionality in interdisciplinary research and the power of visualization in health communication.*

*Kaisu Koski, un artiste-chercheur finlandais basé au Royaume-Uni et aux Pays-Bas, et Johan Holst, un vaccinologue de premier plan en Norvège, discutent de leur travail de collaboration explorant l'hésitation au vaccin chez les parents. La collaboration a été lancée dans le cadre des recherches en cours de Koski en vue de créer des films pour l'enseignement médical. Ensemble, les auteurs ont développé des échanges collaboratifs sur les croyances en matière de santé des parents critiques de la vaccination et les ont visualisés dans une série d'œuvres multimodales. En raison des différents points de vue des auteurs sur les vaccins, ce projet soulève des questions sur la positionnalité dans la recherche interdisciplinaire et le pouvoir de la visualisation dans la communication sur la santé.*

Figure 1: Kaisu Koski, in collaboration with Johan Holst, *Conversations with Vaccine-Critical Parents*, *Theory of Illness #1–4*, and *Syringe Sequence #1–2*, 2015-2017. Installation view, UNAIDS, Geneva, 2017. Photo by Annik Wetter.

## OVERVIEW OF THE COLLABORATION

This collaboration on vaccine hesitancy emerged as part of artist-researcher Kaisu Koski's existing arts-based research project in creating educational films on different clinical topics for medical students.

When vaccine hesitancy was introduced as one of the possible topics to tackle in the <*Immune Nations*> project's first workshop in Ottawa in August 2015, it seemed like an interesting aspect to undertake for Koski, considering her ambivalent feelings regarding vaccines. While she was initially unsure whether collaborating with Holst would be a good idea given the expectation for differences of opinion, she ultimately decided that exploration of tensions between the contrasting viewpoints would be fruitful. Koski approached Johan Holst, a leading vaccine scientist in Norway, in the months following the workshop,

after he distributed publications to the whole project group about the growing challenge to society from vaccine hesitancy. Inspired by these articles and the limited visualizations they provided, Koski suggested that the two work together to respectfully explore the relationship between vaccine hesitancy and vaccine science.

While Holst was enthusiastic about Koski's suggestion for collaboration, acknowledging the need for new and fresh approaches to this issue, he also felt quite outside his comfort zone. Part of his personal motivation and aim was to communicate more effectively with those outside the field of vaccine science and policy. The issue of vaccine hesitancy was not new to him. As a vaccine developer for over 30 years, Holst had experienced the politically and emotionally heated discussion around pertussis (whooping cough) in the 1980s, as well as a number of interactions with critical parents and journalists in connection with an efficacy trial for a Norwegian vaccine against serogroup B meningococcal disease (MenB). Most recently, his employer, the Norwegian Institute of Public Health, had to perform a large epidemiological investigation to study if there was any increased risk of myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS) connected to the use of the MenB vaccine. (The study showed that there was no such negative relationship between being vaccinated and the serious rare disease.) Such incidents led to his conviction that good communication in the area of vaccine hesitancy was crucial. Holst's aim in the collaboration was to increase understanding of vaccine-hesitant parents' health beliefs and how these influence their vaccine-critical decisions.

Koski began the project by interviewing vaccine-hesitant or -critical parents in the Netherlands and Finland. She then identified several health beliefs in the interview data that seemed relevant to parents' vaccine hesitancy, and developed artistic representations of these beliefs with the aim of respectfully communicating these biases. Drafts of the resulting artworks, including diagrammatic prints and a short documentary video, were then shared with Holst and became the basis for a number of phone and Skype conversations between the artist and the scientist from November 2015 to July 2016.[1] By developing novel means of exploring the urgent topic of vaccine hesitancy, this collabo-

ration aimed to provide insights into viewpoints that are often ignored or maligned, to better understand the beliefs of vaccine-hesitant parents, and to improve health communication.

The final work consisted of a documentary called *Conversations with Vaccine-Critical Parents*; a series of four diagrammatic prints, *Theory of Illness #1-4*; and a photo series, *Syringe Sequence #1-2*. The diagrams, which are also included in the documentary as "animations," portray vaccine-critical parents' main health beliefs, borrowing from the conventions of scientific visualizations. The photo series, in turn, includes a range of medicinal plants grown in syringes, displayed in the different stages of their life cycle. This series was developed as a response to the parents' appreciation of the "natural," visualizing the kinds of vaccines they would possibly perceive as beneficial and trustworthy.

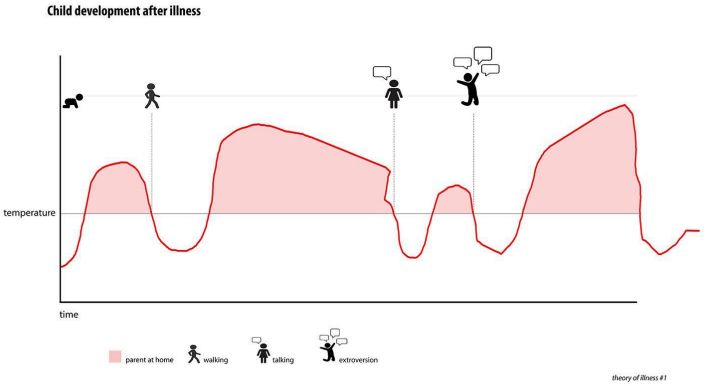



Figure 2: Kaisu Koski, *Theory of Illness #1* (2017), premium fine-art print, Forex mount, 40 x 60 cm. Image courtesy of the artist.

## REFLECTIONS ON *CONVERSATIONS WITH VACCINE-CRITICAL PARENTS*, *THEORY OF ILLNESS #1–4*, AND *SYRINGE SEQUENCE #1–2*

What follows is a dialogue and reflection on the project's genesis, methods, and outcomes.

**Kaisu Koski**: In terms of selecting this topic, though I had experienced certain ambivalence towards vaccines myself, I had not thought of it as my topic for <*Immune Nations*>. It was only at the first workshop in Ottawa, towards the end of the workshop, when it was presented as one of the possible topics we could work with, that I started to really think about it.

**Johan Holst**: Wasn't it when I sent a quite large chunk of material—articles focussing on vaccine hesitancy that really sparked your interest—that you saw the possibility of our collaboration?

**Koski:** Yes, you are right! It was especially one of the diagrams in a particular article where the "Acceptance Continuum" created special reactions in you and some of your colleagues.[2] At the time, I had just interviewed one parent who was quite radical in her beliefs, and I thought, there's a huge contrast here between this diagram and this person's beliefs. I asked myself, how would she situate herself on this diagram? To my mind, it felt like the diagram was lacking something, something to make it more personal, which led me to thinking that I needed to try and revisualize the diagram in a way that she might actually be able to place herself on it. But honestly, in the first workshop, my concern was how I could even contribute to this main project given my partial vaccine hesitancy. So that became a key factor for why I chose this topic: Why not start with what I'm already experiencing?

**Holst:** I also think I tried to start in that way. I have been very concerned with the difficulty and the challenges of communicating with vaccine-skeptical parents, since I'm a strong believer in the powerful benefits of vaccines. If you want to communicate with people who hold different beliefs, I know you can't just use pure logic and strong arguments; you can't just use your own belief. You need to understand the other person's belief and perception of the world. That's what mo-

tivated me. You, in a way, offered a sort of training dialogue. That's how I remember it starting; and, of course, I was fascinated by your interpretation of the dialogue you had with the parents, and then how you transformed it into those very powerful graphics.

I also liked the communication we had, and I think you have had that very strong and clear drive to it. In a way—even though I was occupied with many other things—we found ways to stay in contact and keep the project going for the two years we were actively developing the works. It was very inspiring. This is something rather unique and multidisciplinary, a collaboration between very different skills that made this possible and interesting.

**Koski:** Were you skeptical about anything in the beginning?

**Holst:** Yes, of course, a little bit. This kind of project is not a typical thing that would become important in my career or that I would be recognized for. So, I was skeptical if it was really worthwhile for me in the start.

**Koski:** In terms of your career.

**Holst:** Yeah, a rather narrow-minded thought, but through the process I also learned that there are so many other things that really count: shared dialogue, contribution, and even pleasure. The project was not only informative, it was fun!

**Koski:** For me, because I didn't know you at all, I was wondering how you would respond when you actually found out that we think quite differently. I wondered how far our dialogue would be able to go, because with some people disagreement is the end of the story. There were moments when, for instance, your colleagues saw the diagrams and you said they found them disturbing. I think it was the parent's reflections over "Death as a Natural Part of Life" that were taken as very provocative. And then I thought, "Okay, does this mean you don't want to be associated anymore with this project?"

**Holst:** So that was your skepticism? That I would not be able to play ball and follow the whole project through?

**Koski:** Partly, because I had initiated the project and I guess I felt responsibility for its continuation. But I also doubted myself, because I made up the concept of first interviewing, and then translating the findings into diagrams. It's not like I do that all the time. It was a new idea. Then, when the time came and I had done the interviews, I was like, "Okay, now I need to come up with those diagrams, right?"

**Holst:** I think you did a good job with those, even though they are not always scientifically accurate. My intention was not to try to "trick" or convince people to change their belief. Our project was not about that at all.

**Koski:** No, it's not. But it's actually quite hard to pinpoint or explain to other people what it is about, because people assume we have a message. It's either "you're *for* or *against*." That is "war rhetorics" actually. It's hard to explain the importance of having a dialogue somewhere in between, to meet somewhere halfway and work to mirror each other's opinions. For example, the film leaves things in the middle. It doesn't take sides, but presents both sides in some way. Though one parent started to doubt me later, after seeing the film. "Whose side are you on?," literally.

**Holst:** Oh dear, I understand.

**Koski:** I was shocked at first. Nobody else had said that. I had told each parent that I would represent their message and the vaccine researcher's message equally. But this shows how difficult it is to be on nobody's side, especially in a "polyphonic" film like *Conversations with Vaccine-Critical Parents*. While I associate with their side because I share some of their concerns, in retrospect perhaps it was confusing for the parents that my dialogue with a vaccine researcher was conducted in such a positive atmosphere. Making the quasi-scientific diagrams in collaboration with you, a scientist, also presented an interesting dilemma because maybe you were hoping for the diagrams to actually communicate something pro-vaccine to people, whereas they actually are quite scary if you take the time to really read them. But it was really more about the meaning of the diagrams than about changing someone's mind. The purpose was never that I would create pro-

or anti-vaccine diagrams. It was to visualize the health beliefs and, through that, aim for better understanding.

I had initially thought one aspect of being able to be vaccine hesitant would come down to one's tolerance of ambiguity in life in general. I thought maybe scientists wouldn't tolerate ambiguity very well because they try to understand everything. But in the vaccine-hesitant parents' interviews, it appeared that while they want to live naturally and let things take their own course, they still have a very strong need to understand why things are happening. So they construct narratives about the reasons for illness, for instance. And actually, who am I to say that these narratives are not true?

**Holst:** It is very human and understandable to have or create an overarching logic to life or particular events. Scientists have their way of trying to over-rationalize and explain all things, in a way to try to have control over things happening. Another element is that scientists try to dissect and look at just one factor at a time. "Reductionistic," I think this approach is called in English. Sometimes, this way to order or control the world and your life is very understandable. But, in reality, it's artificial or oversimplified because a lot of things, events, and factors intermix. The reality is much, much more complex than the artificial situation when you study just one parameter at a time. You can, in such a way, end up with a much skewed or very strange picture of reality. This is in fact a limitation in many experiments and often in the ways a number of scientists are thinking. I see this project, <*Immune Nations*>, as an implicit criticism of this approach.

**Koski:** Well, on a certain metaphorical level that scientific approach is not so different from the parents who also try to make isolated decisions: "Okay, I'm taking this vaccine but not the other one," based on considering risks and benefits, and also thinking of themselves as individuals that are not very actively connected to the other bodies. (This, the issue of herd immunity, or, rather, herd protection, is something that one of the other projects in <*Immune Nations*>, *Shadowpox*, addressed really well.) It seems that nobody has an overview of everything—of course not—so we just deal with the areas we feel we can

handle, areas we can somehow monitor and control. But that is partly an illusion.

**Holst:** Regarding the visual aspects of your diagrams, throughout the process I have wondered about and questioned some of your stylistic decisions. We have talked about this quite a bit—actually every time you have introduced a new diagram! For instance, in *Theory of Illness #2*, the "active body" is mostly green. Then you have a grey area marking the initiation. Can you explain why you have chosen that colour scheme? Because for me, logically, it would be that the darkest part would be the initiation.

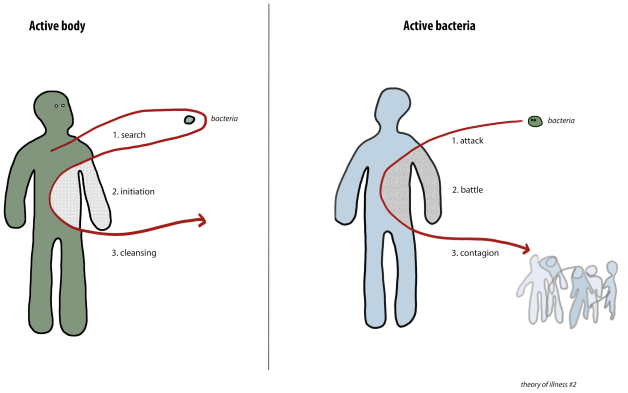



Figure 3: Kaisu Koski, *Theory of Illness #2* (2017), premium fine-art print, Forex mount, 40 x 60 cm. Image courtesy of the artist.

**Koski:** Well, firstly the initiation in this perspective is not something bad, but an initiation in becoming a wholesome person. That's not the same as the battle on the right side of the diagram. But, I see what you mean.

**Holst:** Then you have no eyes on the body on the right-hand side.

**Koski:** But that has a reason: this body on the left side is actively searching. The eyes are a metaphor for searching for the bacteria, and on the right side of the diagram the blue body is happily unaware and facing in the other direction.

Over the course of the project, we not only talked about the diagrams' visual appearance, but also the terminology I used in them. For example, *Theory of Illness #4* is about different modes of vaccine administration, and initially I didn't know what to call these modes. I just called them oral administration and muscle administration, and I also used topical administration for skin. You then introduced the word "parenteral."

**Holst:** Parenteral is outside the oral route: actually, from Greek; "para-" meaning "next to" or "outside," and "entero," meaning "inside" or "gut"—literally, "through the intestines." So that's through the blood, through the muscle, or directly in your veins; all kinds of administration that are not through the oral and rectal route; or over the mucosa, that is, via the nose. For some substances, it's not good to use the muscle. For a number of vaccines, however, it is good. You then get a "deposit" for the vaccine components. In the muscle, there are a lot of immune-competent cells, like dendritic cells (which are even more abundant in the deeper parts of our skin), and the macrophages can then find the antigen and process it so the body can make an immune response. While the word "parenteral" is very common in medical jargon, people who see this diagram don't understand it. When you say muscle administration, it's much more straightforward and easier to understand. One thing is that—maybe it was intentional—but the figure of the muscle administration looks ominous—maybe that is intentional?

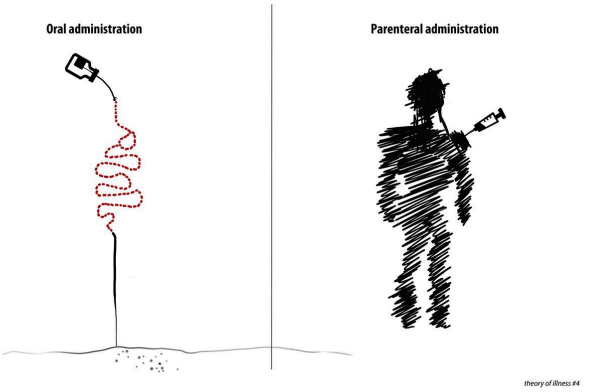



Figure 4: Kaisu Koski, *Theory of Illness #4* (2017), premium fine-art print, Forex mount, 40 x 60 cm. Image courtesy of the artist.

**Koski:** Well, yes, because according to this parent's theory something bad is happening, and so I used the hand-drawing movement in a very intense way, following its pathway through the body. And if you look, the drawing shows the vaccine messing up your brain, which was part of a few parents' narratives. The vaccine is kind of stuck in the container of your body, because it can't be released from a muscle, you know. That was the reason I made it look like that.

This reminds me, in terms of our findings in the actual interview data, that we noticed that the definition of "natural" is very important, because the parents communicated a very strong wish to live a natural life. To raise their children "naturally." One of the important things that we talked about was "What if vaccines were understood as natural?"

**Holst:** As vaccine providers—giving lectures to students, communicating with parents, or with relatives in a coffee party—we should emphasize better some of the key principles in vaccinology. How vaccines work is actually by stimulating a very natural process. We use

a triggering or starting signal that the body interprets as danger (from an intruder), and then the defence mechanisms start. Also, then the body's (immune) memory gets built up and you are protected against the actual disease the next time you encounter it. I think one should emphasize the fact that vaccines actually work in a very *natural way*. Following stimulation by a specific microbe, the body is triggered to develop its natural mechanisms of protection in order to get rid of the infection and later to avoid becoming susceptible to the actual disease. Vaccines can truly be regarded as collaborating with humans and the body itself. I think we—scientists—haven't done well enough in this area. People often have the perception that vaccines and vaccination are unnatural and harmful. Many of these perceptions and claims are not true. Or, at best, just a little "pin shot" of truth that has been exaggerated. We need to be better and more respectful in the way we deal with this type of communication than we have been. Art and artists can certainly help us with this.

## ACKNOWLEDGMENTS

**Johan Holst** would like to thank Drs. Lisbeth Meyer Næss and Hanne Nøkleby, colleagues at Norwegian Institute of Public Health for fruitful and constructive discussions of artworks and viewpoints during the active collaborative exchange-phase with Kaisu Koski.

**Kaisu Koski** would like to thank all those parents who generously volunteered to be interviewed for this study. She is also grateful to Professor Kati Hakkarainen for her feedback during the interview process from microbiological, clinical, and educational perspectives. Koski's participation in the <Immune Nations> project was financially supported by the Academy of Finland and Tampere University.

## IMAGE NOTES

Figure 1: Kaisu Koski, in collaboration with Johan Holst, *Conversations with Vaccine-Critical Parents*, *Theory of Illness #1–4*, and *Syringe Sequence #1–2*, 2015-2017. Installation view, UNAIDS, Geneva, 2017. Photo by Annik Wetter.

Figure 2: Kaisu Koski, *Theory of Illness #1* (2017), premium fine-art print, Forex mount, 40 x 60 cm. Image courtesy of the artist.

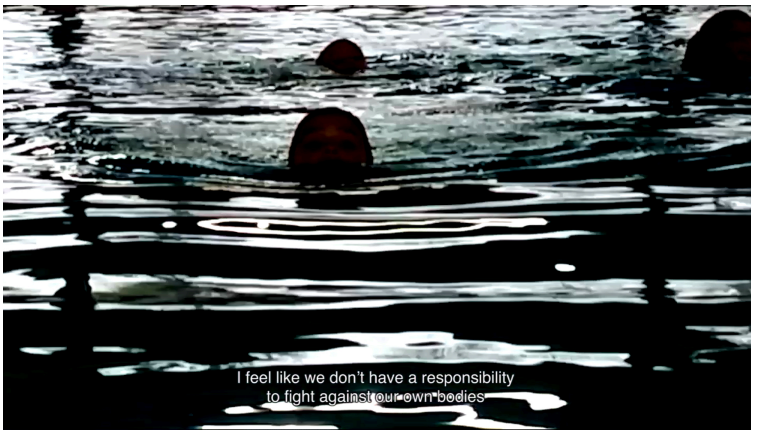
Figure 3: Kaisu Koski, *Theory of Illness #2* (2017), premium fine-art print, Forex mount, 40 x 60 cm. Image courtesy of the artist.

Figure 4: Kaisu Koski, *Theory of Illness #4* (2017), premium fine-art print, Forex mount, 40 x 60 cm. Image courtesy of the artist.

## NOTES

1. A detailed description of their process of collaboration is available in Kaisu Koski and Johan Holst, "Exploring Vaccine Hesitancy through an Artist-Scientist Collaboration: Visualizing Vaccine-Critical Parents' Health Beliefs," *Journal of Bioethical Inquiry*, vol. 14, no. 3, 2017, pp. 1–16.

2. The article Holst provided Koski was Noni E. MacDonald, "Vaccine Hesitancy: Definition, Scope and Determinants," *Vaccine*, vol. 33, no. 34, 2015, pp. 4161–64, https://doi.org/10.1016/j.vaccine.2015.04.036.




Kaisu Koski, with Johan Holst, *Conversation with Vaccine-Critical Parents*, 2016-17. Single channel HD video. Image courtesy of the artist.


Kaisu Koski, with Johan Holst, *Conversation with Vaccine-Critical Parents*, 2016-2017. Single channel HD video. Image courtesy of the artist.


Kaisu Koski, with Johan Holst, *Conversation with Vaccine-Critical Parents*, *Theory of Illness #1-4*, *Syringe Sequence #1-2*, UNAIDS, Geneva, 2017. Single channel HD video, Fine art print, forex mount, digital C-print, wood frame. Photo by Annik Wetter.

Kaisu Koski speaking at the opening Reception, Immune Nations, UNAIDS, Geneva, 2017. Photo by Mkrtich Tonoyan.