

## **Exploring Vaccine Hesitancy Through an Artist–Scientist Collaboration**

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[title] Exploring Vaccine Hesitancy Through an Artist–Scientist Collaboration

[subtitle] Visualizing Vaccine-Critical Parents' Health Beliefs

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### **Abstract**

This project explores vaccine-hesitancy through an artist-scientist collaboration. It aims to create better understanding of vaccine hesitant parents' health beliefs and how these influence their vaccine-critical decisions. The project interviews vaccine-hesitant parents in the Netherlands and Finland, and develops experimental visual-narrative means to analyse the interview data. Vaccine-hesitant parents' health beliefs are, in this study, expressed through stories, and they are paralleled with so-called illness narratives. The study explores the following four main health beliefs originating from the parents' interviews: 1. Perceived benefits of illness, 2. Belief in the body's intelligence and self-healing capacity, 3. Beliefs about the 'inside-outside' flow of substances in the body, 4. View of death as a natural part of life. These beliefs are interpreted through arts-based diagrammatic representations. These diagrams, merging multiple aspects of the parents' narratives, are subsequently used in a collaborative meaning-making dialogue between the artist and the scientist. The resulting dialogue contrasts the health-beliefs behind vaccine hesitancy with scientific knowledge, as well as the authors' personal, and differing, attitudes toward these.

**Keywords** Vaccine hesitancy; Interview; Health belief; Illness Narrative; Arts-based data visualization; Diagram; Artist-Scientist collaboration

## **Introduction**

Vaccination and modern vaccines are generally accepted by populations all over the world as the safest and most effective preventive measure against a number of serious and potentially deadly infectious diseases. However, a small proportion of the population is sceptical regarding vaccines; they want to delay and divide various vaccine combinations or refuse to take them at all. The reasons behind each individual's decision differ and are context specific; they vary from religious convictions to the secular, include political and philosophical concepts, and some are more emotional in nature. These attitudes have existed throughout the history of vaccination. However, there are reasons to believe that new socio-dynamic factors, including the emerging cultural features of "healthism" and the self-empowerment rhetoric conveyed by health promotion (Peretti-Watel et al. 2015), which appeared in the early 21<sup>st</sup> century have made it increasingly urgent to address the phenomenon of vaccine hesitancy (MacDonald et al. 2015).

The current project aims to increase understanding of vaccine hesitant parents' health beliefs and how these influence their vaccine-critical decisions. This is a collaborative project between an artist and a vaccine scientist, and it contributes to an emerging field of arts-based health research (ABHR) (Boydell et al. 2012). Research conducted in the ABHR field combines traditional qualitative strategies such as interviews with methods informed by the arts, and uses them to explore new forms of knowledge translation (Boydell et al. 2016). The study emerges from an on-going multi-disciplinary international project, The Vaccine Project (<http://www.thevaccineproject.com/>), which aims to increase public understanding of vaccines through art and improve global decision making in the field.

Studies that map reasons for vaccine hesitancy often distinguish categories such as "belief system," "philosophical or religious reasons" and "personal beliefs" (Smith et al. 2011; Mckee and Bohannon 2016). However, these are usually not inspected in detail, and the exact beliefs about the body and health that underlie this parental behaviour are not identified. Moreover, the label "personal belief" does not fully represent all beliefs, some of which are developed, for instance, as a result of anthroposophical health-care consultations and are shared by a large group of like-minded people. This study examines four of the most prevalent health beliefs behind late and selective vaccination and vaccine refusal as expressed in interviews by vaccine-hesitant parents. It then aims to form ideas on how to maintain an open dialogue between vaccine hesitant parents, health-care providers, and the government.

In achieving these goals, two distinct voices co-exist, those of the artist and the scientist. The scientist represents the voice of expert knowledge, while the artist's trust in this knowledge is only partial and she, in fact, has reservations about vaccines. In this arts-based project, the two collaborators thus disagree on particular aspects of vaccine acceptance.

The study involves methodological experimentation in its analysis of the interview data. It develops visual-narrative ways to investigate vaccine hesitancy: the artist and the scientist explore forms of visual dialogue in their examination of the vaccine hesitant parents' interview narratives, eliciting and exchanging readings on these through interpretative visualizations. By analysing and publishing the interview data using visual-narrative coding processes, the project explores the role of art in scientific inquiry and simultaneously the role of science in artistic inquiry. The article introduces vaccine hesitant parents' key health beliefs and exposes parts of the collaborators' meaning-making of those beliefs.

The study proceeds in three stages: first, the artist develops diagrammatic drawings to code the data and map the core health beliefs represented in them. Second, these visual narratives are introduced and discussed with the scientist and his colleagues, generating interdisciplinary meaning-making narratives. This process explores various dichotomies in beliefs and knowledge between parents, the artist and the vaccine experts. Third, the collaborators reflect on the meaning-making process.

### **Study Procedure**

The data collected consists of interviews with nine parents who identified themselves as being, to varying degrees, vaccine critical, ranging from selective and late vaccinators (n=6) to total refusal of vaccines (n=3). These parents were between thirty-seven and forty-five years of age, and they all had minor children who ranged in age from zero to fifteen years (n=17). Seven mothers and two fathers were interviewed by Kaisu. The participants represent four different nationalities, all are residents of either the Netherlands or Finland, and they were recruited through Kaisu's social network. The interviews were conducted between October 2015 and April 2016. The open-ended interviews varied from forty-five to ninety-five minutes in duration; they were conducted and audio-recorded at the interviewee's home and subsequently transcribed verbatim. All the participants gave their informed consent, and the study was conducted in accordance with the standards of the Human Sciences Ethics Committee of the University of Tampere.

The parents' arguments were divided into two main categories: 1. Health beliefs and 2. Negative perceptions and experiences with vaccines. Health beliefs refer to the parents' perceptions of the body's immunity, including related aspects of physiology, mental-emotional development, and the life-cycle from birth to death. Sometimes the parents' health beliefs were expressed literally, as in "I just believe all healing is possible", sometimes they were illustrated through stories and metaphors. The belief that "everybody is unique," refers not only to an individual's unique personality but also that this personality is manifested in a unique physical body (including unique immune system responses).

These health beliefs should not be confused with the psychological health belief model (Rosenstock, 1974), in which one of the key elements is the avoidance of negative health consequences. Though connected, the beliefs of the parents interviewed are different from those who perceive vaccine preventable illnesses as being of low-risk. Furthermore, rather than elaborating on arguments based on fear of the vaccine substances, or on negative perceptions of the pharmaceutical industry and the health-care system, this article focuses on the parents' actual health belief narratives, including their origins and the way in which they were expressed. While there is ambiguity over whether the term vaccine hesitancy refers to a set of beliefs, attitudes, or behaviours or to a combination of these (Peretti-Watel et al. 2015), this study holds that particular health beliefs precede negative attitudes towards vaccination, and thus form the foundation on which the parents base their decisions and behaviours.

The authors met in August 2015 through an international project on vaccines and art, The Vaccine Project, in which both were invited to participate. After the initial workshop in Ottawa, their collaboration, initiated by Kaisu, began in November 2015 and took place through teleconferences, phone calls, and e-mails. The collaboration before and during the interviews consisted of designing and adapting the interview questions and adding a set of questions Johan and his colleagues thought were missing from Kaisu's preliminary manuscript. After completing the parents' interviews, Kaisu explored the data by creating arts-based diagrammatic interpretations of them in April-May 2016. The interview data and the diagrams were discussed with Johan during four teleconference sessions in May-June 2016. These sessions were recorded and transcribed verbatim.

The study is also connected with medical education, and Kaisu has further developed the interview findings and the dialogue with Johan into an arts-based video to be employed in medical education. This video piece, *Conversations with vaccine-critical parents* (www.xxx.com), was pilot-tested in the “Prevention Study Module” in August 2016 in the University of Tampere medical school, and will be examined in a separate research article with the collaborating medical educators.

### **Health Beliefs, Illness Narratives and Theories of Illness**

Vaccine hesitancy research usually takes place through online surveys, (online) focus groups, or phone interviews (Harmsen et al. 2013; Smith et al. 2011; McKee and Bohannon 2016). In this study, the parents were interviewed in their homes, providing time and privacy for them to share their personal viewpoints. This study considers the health beliefs that manifest through various kinds of narrative, either having been experienced personally or having happened to someone else (for example, as heard from friends or a doctor). Some of the stories represent generalised ideas of how the body functions in both health and illness, which the parents then apply in taking care of their child. Stories are thus the form in which these beliefs are exchanged with other people, including the interviewer. These stories have similarities with so-called illness narratives in that they aim for an understanding of the reasons for and the personal meaning of illness in a child’s life. While the purpose of the interviews was not to focus on particular illnesses, and it was not known beforehand whether the participants’ children had experienced vaccine preventable diseases and, if so, which diseases these were, most parents generated several “micro illness narratives” to illustrate their particular health beliefs.

Two types of illness narrative especially parallel the parents’ health belief narratives. Drawing from Arthur W. Frank’s (1995) typology of three main types of illness narrative, these are: the restitution narrative, the chaos narrative and the quest narrative. Most of the parents’ beliefs were expressed in the form of the quest narrative. In a quest narrative the body, or a person, is allowed to journey through illness in the belief that something is to be gained from the experience. The quest narratives construct not only alternative ways of being ill but also alternative ways of being well (Kilty 2000). For instance, narratives of perceived benefit from illness result in thankfulness and an understanding of why the child is currently healthy. At the same time, the parents also have a firm belief in restorable health, and share the restitution narrative: “Yesterday I was healthy, today I am sick, but tomorrow I will be

healthy again" (Frank 1995). While this is the prevalent narrative in Western medicine as well, the vaccine-hesitant parents' restitution narrative takes place without medical interventions but due to the body's own self-healing capacity and immune responses. In fact, most of the parents interviewed believed in "improvable" health by perceiving an illness as supporting the child's mental-physical development, with the child being "healthier" tomorrow.

In anthropological terms, the parents' beliefs involve features of both "personalistic" and naturalistic theories of illness (Trollope-Kumar 2002). Some of the parents perceive illnesses as having an impact on the child's mental-emotional characteristics and development, while some of them adopt humoral concepts of health in their perceptions of the flow of bodily substances and of the body's temperature. Furthermore, most health beliefs translate directly into parental behaviour, such as avoiding the suppression of a child's cough, or purposefully contacting them with an illness. Other health beliefs, however, are more abstract and are based on and expressed through stories from other contexts. For instance, in contemplating death as part of life, a parent may employ a narrative about the unwanted reanimation of an elderly patient, rather than discussing the possibility of the death of their own child. In this article, we introduce aspects of four main health beliefs that form the foundations of vaccine hesitancy: 1. Perceived benefits of illness, 2. Belief in the body's intelligence and self-healing capacity, 3. Beliefs about the "inside-outside" flow of substances in the body, 4. View of death as a natural part of life.

### **Designing the Diagrams**

The experimental methodology of this study revolves around the translation of the parents' health belief narratives into arts-based diagrammatic interpretations by the artist-researcher. These diagrams represent the main findings of the qualitative interview data, making the selected health beliefs visible and functioning as a vehicle for interdisciplinary conversation about them. In doing so, the project creates a dialogue between the vaccine-critical parents' health beliefs and scientific views on vaccines. The artist is the mediator in this dialogue, facilitating a dialogue with "science" through an arts-based interpretation of the parents' health beliefs. In fact, she varies between representing these health beliefs in parallel with what she considers to be the scientific view, presenting them as though the health beliefs were, in fact, science.

This study explores ways in which the arts-based visual interpretation stimulates and enriches the meaning-making around the health beliefs, as opposed to merely viewing the interview transcriptions together. The process is a form of graphic elicitation, a researcher-led diagrammatic elicitation, where the artist-researcher creates the diagrams during the data collection process for discussion with the scientist (Umoquit et al. 2013). Parallel to exploring the vaccine hesitant parents' health beliefs, the study distinguishes the diagrams' function in the interview analysis in the following ways: first, the diagrams form various relationships between the parents' health beliefs, the stories through which they are expressed, and natural science narratives. Through the collaborative meaning-making, Johan, the scientist, is invited to reflect on the parents' stories from his perspective of scientific expertise, thus interpreting the diagrams in ways different ways from those Kaisu anticipated. Second, some of the diagrams demonstrate two polarities: the parents' belief and what Kaisu thought the scientific equivalent might be, while Johan complements these with both natural science and his personal viewpoint. He, for instance, introduces views that contrast with the parents' beliefs, or blur the borders between the clear-cut distinctions Kaisu had drawn in the diagrams. Third, as a scientist, Johan associates the diagrams with pharmaco-medical narratives, absent from the parents' accounts, and attempts to translate the logic of the parents' beliefs into the logic of science, and into scientific narratives of how the body, illness, or medication function.

In Kaisu's previous research projects (Koski 2013, Koski 2014a, Koski2014b, Koski, Heyning and Zwijnenberg 2016) she analysed and transformed interview data, for instance with medical students, into video and animation works. All these works embraced the ambiguity and multiple interpretations of the interviewees' narratives, aiming to activate the viewer to consider their own personal viewpoint as well. In this study the dialogues with medical and pharmaceutical professionals and familiarization with the conventions of science visualization, contributed to the meaningful data analysis of vaccine hesitancy, in which the artist researcher was able to thematize, deconstruct and transform the interview data into a visual form.

The particular aesthetic choice for the science-inspired diagrammatic expression was determined through an artistic process after completion of the interviews. This means that Kaisu had not decided beforehand what kind of arts-based interpretation she would create, so that the resulting interpretative data visualizations were grounded in the data itself, while also



expressing the artistic style of the artist-researcher. In this study, the diagrams were chosen for their potential in examining spatio-temporal relations. Yet, unlike conventional scientific data visualization, they include aspects such as humour, and present an interplay of clinical and personal dimensions.

All the diagrams operate close to the borderline between evidence and imagination. On the one hand, the parents' beliefs, the actual interview data, may not be evidence-based. From a scientific viewpoint, the data may thus be disinformation about the body and about vaccines. On the other hand, the methods of display preserve the integrity of the beliefs (Tufte 1997, 65) as the narratives are truthfully represented in the pictures. Yet, unlike conventional scientific diagrams, various quantities are absent from these pictures: units such as time, the child's age, and body temperature are not specified as the focus is intentionally drawn into the stories themselves. There are two reasons for this. The specific quantities were absent from the parents' stories to begin with, and exact quantities would also invite the reader to analyse the diagrams based on the evidence only, and thus too easily dismiss the power of a particular underlying belief.

The diagrams employ several visual strategies to explore the interview data. In doing so, they are layering information from various aspects of the participants' stories as well as from scientific views on immunization. In fact, all of them represent narratives of time and space by illustrating a temporal course of events (Tufte 1990, 97). Furthermore, several narrative itineraries can be found, such as "time-tables" of fever development and route maps for bacteria and vaccines (Tufte 1990, 101).

Several of the diagrams employ strategies of visual parallelism by locating paired images next to each other, connected by their similar orientation and content (Tufte 1997, 82). In these instances, the diagram contains multiple channels of contrasted information. These channels include beliefs about the role of the body in contracting an illness, different modes of drug administration, as well as an anatomical cross-section narrative with its hand-drawn abstraction. The diagrams employ separation by dividing the layout into two sides. This allows the viewer to consider a comparison, something that is at the heart of quantitative reasoning (Tufte 1990, 67). However, it is seldom that beliefs and scientific views are presented in a visualized comparison as the diagrams here endeavour to do.

## **The Parents' Health Beliefs: Meaning-Making Using the Diagrams**

Before the collaborative meaning-making teleconferences, Kaisu sent Johan a written summary of her interview findings and the diagrams she had created based on those. The diagrams did thus not come as a surprise to Johan, but it was planned beforehand which narrative and diagram would be analysed in each session. During the teleconference conversations, Kaisu and Johan had both the selected diagram and a video image of each other on their computer monitors. The diagrams provided the starting point for the conversation, representing a compression of multiple narratives and layers into one image and serving as a memory aid, as well as a stimulus for discussing complementary themes and interpretations. Through this interdisciplinary meaning-making process, the following four main health beliefs were identified.

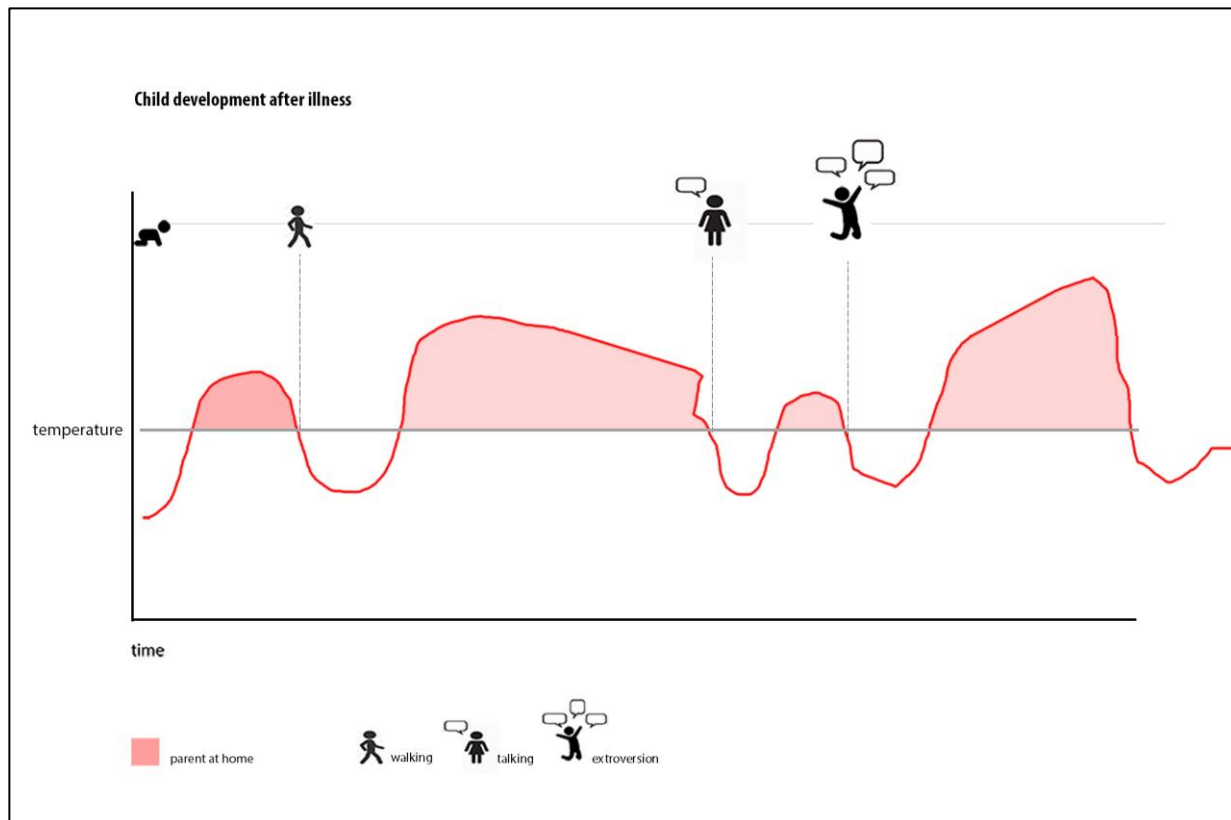
### ***1. Perceived benefits of illness***

*Belief: (vaccine preventable) illnesses are beneficial*

*Story: mumps made a timid child more extroverted (quest narrative)*

One of the most consistent narratives in the parents' interviews was the perceived advantages of going through the disease process. A similar concept emerged in a study by Harmsen et al. (2013), according to which some parents, especially those who were following the anthroposophical lifestyle, believed that physical and mental development would occur through undergoing a disease. We will elaborate on the various advantages perceived and on the perceived role of the parent during a child's illness. This belief strongly influences the parent's behaviour, whether in terms of going to see a doctor, or staying home from work.

Image 1.



**Kaisu:** *Most of the parents identified illness as something positive that contributed to their child's growth. This might be physical such as learning to walk, when, after being ill, the child suddenly started to walk although they had only been crawling before; or it might be that they suddenly started to talk, or even that the child's character changed after an illness. For example, having been very timid, quiet, and shy, suddenly, having had the mumps, a child became more extroverted and dared to voice an opinion. This diagram communicates that the parents feel their primary responsibility is to be at home with a sick child. The societal pressure to go back to work as soon as possible is experienced as unimportant relative to standing by their sick child.*

**Johan:** It's important to remember that many thousands of diseases and infections stimulate your immune system to work in your body. Many of these are not vaccine preventable diseases: you have various diarrheal diseases and the common cold, which you are not vaccinated against, so the child will inevitably get sick, regardless of vaccines. I think it is a common misconception that when you are vaccinated your immune system will not be stimulated by bacteria and viruses. [The parents] seem to be convinced that when their children don't have measles or flu their immune system will not develop.

**Kaisu:** *I think this is an important point because it seems to me that the parents don't make a distinction between a common cold and measles, for example. So if this diagram could say "a child's development after the common cold", it would be a different story. If it says "after a vaccine preventable illness" it would again be read differently.*

**Johan:** Yeah absolutely, if the parents don't distinguish between measles and the common cold it is a problem. When they have measles most people are definitely very sick, they do need to stay at home, and most children are completely healthy afterwards. However, if you look at a whole population, some individuals who contract measles become really ill and can even die. That is not the case with the common cold. Your immune system is actually very "low" after measles. A lot of things can happen after you have had measles. So, it's not as some people believe, that you are stronger after measles, actually, you are much weaker. That's a fact, so you need to be careful because additional diseases, secondary infections, are very common after measles.

**Kaisu:** *Many parents consider the illness as being merely the active expression of the illness. They think of it as the time when you have a fever and a rash on your skin, things like that. Parents don't consider the incubation period or the lowered immune system afterwards.*

**Johan:** It's quite surprising to hear that because we all should be sufficiently educated to know about this. But it also indicates how we relate to what we can directly sense and feel, and we forget our knowledge and forget the complexity of what we don't see. There's more to the picture than meets the eye.... The iceberg is much bigger than what you see. Even though we as a society are sophisticated, and our education system is sophisticated, we tend to go back to rather unsophisticated world-views, and sometimes we end up acting like we were from the middle ages.

**Kaisu:** *Well I have a few theories about this, and why it is like that, especially for this group of parents. I sense their enormous longing for something they label "natural." So it is not a longing for the middle ages, but to go back to something far more intuitive, where they respond to the cycles of nature rather than to the cycles of medical intervention, for example.*

*Reflection*

This conversation introduces two aspects underlying the parents' health beliefs. First, the parents typically bundle many illnesses under the same umbrella, and fail to make a distinction between a common cold and vaccine-preventable illnesses. However, from a natural science viewpoint, there are enough infections to stimulate the immune system even if one does not contract a vaccine preventable disease. Furthermore, from a scientific perspective, our continuous contact with microbes stimulates our immune systems without necessarily causing disease at all. The second aspect is that natural science recognises that the immune system is lowered after a vaccine-preventable illness, such as measles, while many parents consider the illness to be only the active expression of symptoms and not the periods before or after. In the course of an interdisciplinary meaning-making dialogue, these aspects were able to emerge organically, instead of Kaisu merely introducing the parents' viewpoints and Johan responding to them. Johan equally introduced the views of natural science, initiating a theme, which Kaisu attempted to relate to the parents' narratives.

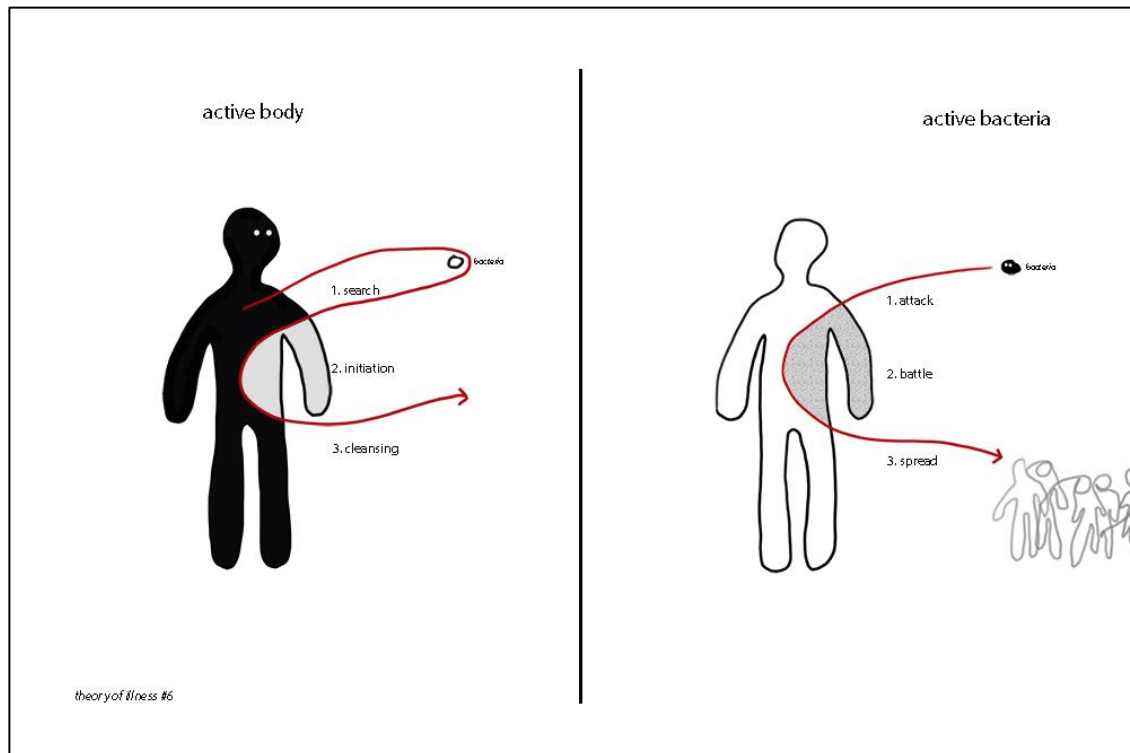
## **2. *The body knows best***

*Beliefs: the body's intelligence and self-healing capacity, improvable health*

*Stories: a boy "searching" for illness, a boy "developing" illness (quest narratives)*

This diagram emerged from a narrative in which a parent tells about a friend's son whose body is "searching for an illness" that would enable him to become thoroughly sick. He has been continuously just a little bit sick, and the anthroposophical doctor has introduced the idea that he may be looking for a more serious illness to clear out his system thoroughly. This story is told by reporting what the friend and a doctor have said. Underlying it is the belief that the body is an intelligent agent or entity, which knows best what it needs and may be actively looking for an illness for cleansing purposes. This belief considers illness as productive both physically and emotionally, as portrayed in the image 2 narrative. This opposes the scientific view in which bacteria and viruses are always active, and the body should be prepared to prevent their attacks. In the first narrative, the needs of the individual were seen as paramount, but the second narrative contains a double risk where not only is the body attacked, but the virus can spread uncontrollably to other bodies.

Image 2.



**Kaisu:** Here I've shown three steps in the first view where the active body plays the active role in the narrative, searching for an illness, and then through the illness experiencing some kind of mental-emotional initiation. After that, it is cleansed from whatever it needs to be cleansed from. This is opposed to the scientific view, which presents a narrative about active bacteria. Typically these are looking for a host to attack, a human body, and a battle follows. In this scene, the illness is a battle against the bacteria and, at best, you will survive the battle, but you may spread it to all the other bodies around you.

**Johan:** Bear in mind that you might have other scenarios too. For example, in natural science we often have the situation where bacteria live in a symbiotic or passive state with the host. But then, all of a sudden, a few individuals will get the disease, while the rest of the population continue to carry the bacteria as a commensal. This is often the case with meningococci, where ten per cent of humans have it in their throats at any given time, but very few get the disease from it. Regarding the anthroposophical understanding, there are elements to that story that also fit with natural science. When you really stimulate the cytokines and other kinds of biologically active substances with an infection or, for instance, with the tuberculosis vaccine (BCG), the body reacts strongly and can also eliminate other

things. In the Netherlands and in other places too, they have used the BCG vaccine as a cure or a treatment for bladder cancer. Because the body reacts with a lot of immune cells they “clean out the cancer”. So, there are elements of this narrative that also relate to conventional medicine. However, the “bodily intelligence” mentioned in the story, which is “searching for an agent that will initiate the cleansing,” sounds a little bit far-fetched to me.

**Kaisu:** *For me, the implication that people who get severely ill have somehow searched intentionally for that illness, is challenging. So if we take the [story of the] child who frequently develops a fever because it allows him to withdraw from the world for a period, there appears to be an ambiguity about whether illnesses are actually self-created. That is interesting, but it places a lot of responsibility on the individual. However, I also recognize in myself the need to create a coherent narrative, a meaning for certain events in my life. Why do these events happen? This question seems to be very central to many of the parents’ arguments. The narrative of illness and its meaning feels important to them. It appears that even if you want to live naturally and you let things take their own course, you will still have a strong need to understand why things happen. But one can easily create different stories from the same situation.*

**Johan:** I think, in what you have just said, you are capturing something very important. Maybe this is a strong feature of this group of parents that you have been interviewing and of their environment. However, I think it is also universal human behaviour to try to find the “logic behind” our life events. We humans try to create a sort of logic, to find some reasoning behind what’s happening in our lives. However, as I said earlier, very often, to me at least, many things just happen by chance and there is no real logic behind them, but it’s chance and that’s actually life itself.

**Kaisu:** *Yeah, I wish I could have the same attitude, honestly.* [both laugh]

### *Reflection*

Two main aspects are developed in this dialogue that relate to the belief and to the diagram under consideration. First, Kaisu has paralleled the parents’ belief in a self-initiated illness with what she considered the scientific view, the attacking bacteria. However, Johan expands on this by introducing a third scenario from natural science, which deserves a diagram in its own right, according to which our bodies live in symbiosis with many microorganisms (the

microbiota). Relating this situation to the parents' beliefs, the body would not need to search for illness, but rather select or allow space for one or more of the already embedded microorganisms to take over. While the self-healing capacity of the body is widely acknowledged, believing in "self-inflicted illness actions" of the body represents a radical expansion of this view. Johan considers this view too "far-fetched," while Kaisu also finds it challenging to accept, as it would falsely blame people who happened to be ill. By relating the logic of science to the parents' logic, Johan draws a parallel, a medical intervention that uses increased immunity to cleanse the body from cancer cells, which correlates with the parents' belief in cleansing the body through illness. While these perspectives actually represent two opposing views, this "translation of logic" is considered as an exercise in relating to the parents' line of thinking.

The second aspect contemplated in this dialogue situates Kaisu closer to the parents' world. The interviews indicated that the narrative of illness and the meaning of it are important to the parents, and Kaisu recognizes the same need for a coherent narrative in her own life, while also acknowledging that it may be simpler to adopt Johan's belief in chance. The authors here include some of their personal life views in their reflections on the parents' narratives, especially when it comes to aspects that are not primary concerns of science. In addition to reflections that relate to professional knowledge, the meaning-making dialogue thus allows the authors to personally agree or disagree, as well as to wonder, speculate and freely associate with the parents' narratives.

### ***3. The body's physiology: substance drainage in the body***

*Belief: body as a container or pressure-cooker*

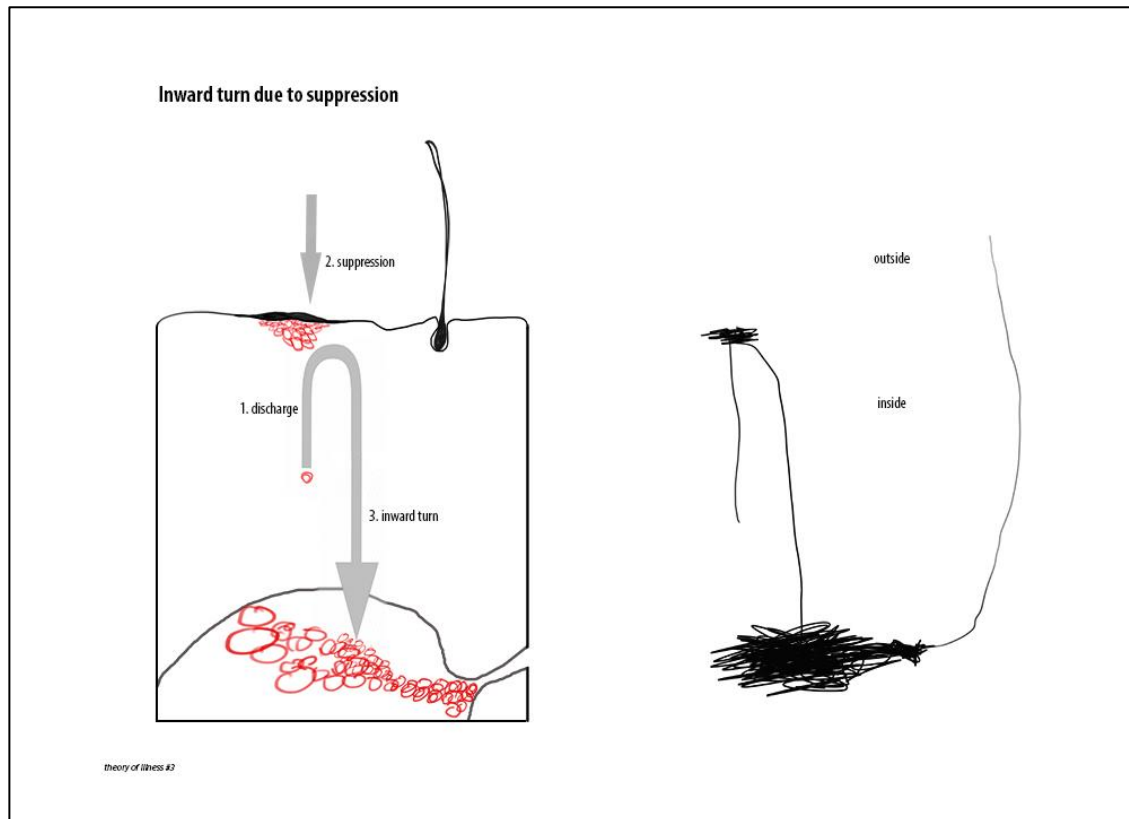
*Story: suppress eczema, get asthma*

According to this health belief, the body has the intelligence to release unwanted substances. However, when this process is interrupted or suppressed by a medical intervention, such as a topical medication, the flow of the body's natural discharge from inside to outside may turn inwards, causing even more challenging conditions. There is a perceived border between the inside and outside of the body, and in illness the body naturally directs unwanted substances towards the outside. This story was told by a parent holding a coughing two-year old in her arms, and using the child as an example: "the reason she is coughing right now is...". The story was conveyed with an "expert" voice: "what you often see is that when you



suppress....” The child’s presence in the interview, initially considered as a challenge by Kaisu, thus prompted the emergence of this narrative.

Image 3.



**Kaisu:** This [diagram] communicates an understanding of the body, really the material side of it. The flow of things from the inside towards the outside, in the form of a narrative, was pretty surprising to me. One parent gave me an illustrative story: that everything is fine as long as you allow the body to discharge, or to drain, or to push out the unwanted or unneeded substances, such as bacteria and viruses. But if you medically interfere with this process, as is happening in this diagram, suppressing it through topical medicine like a cream, what needs to be released will turn inwards. In the parent’s example, eczema is a way in which the body releases through the skin, if this is suppressed, it will turn inwards to the lungs and cause asthma.

**Johan:** When I saw the diagram, and especially after hearing you tell the narrative, I saw the situation very much from the perspective of psychiatry or human behaviour. If you don’t speak up and don’t manage to express what you are feeling, then something bad can happen

to your self-esteem; or you develop bodily pains and stomach-ache and things like that. To me, this view or narrative appears far more similar to concepts and terminology from our mental state than to those used in somatic medicine. However, there are some elements of similarity between my universe and the universe reflected in this narrative. For instance, if you treat an infection with antibiotics, you certainly interfere. If you interfere in an incomplete way, the bacteria remain in your body, but you are now selecting those bacteria that can survive that antibiotic. If you stop the treatment too early, or if you use a suboptimal antibiotic, you are likely to create another problem, resistant bacteria. These organisms can then cause far more severe diseases. So that, in short, is why we have this huge problem with antibiotic resistance. But the way that woman thought about eczema and letting it blow itself out rather than getting asthma—that's a completely different set of thoughts and beliefs, which I am not convinced about, or really I don't understand it very well.

**Kaisu:** *I'm thinking about what you said about psychiatry. To me, it sounds as though there are all these metaphors for the body implying that it is some kind of container, or that the body is a kind of pressure cooker. The flow of what should go inside and what should stay outside, that is the kind of negotiation that you do in psychotherapy. So, maybe this is a physiological manifestation of the same narrative.*

### *Reflection*

This diagram, a cross-section, which perhaps comes the closest to an actual scientific diagram, generates two different readings. First, Johan connects the narrative about suppression and “inward turning” with psychiatry, leading Kaisu to considering that here the mental metaphor of a pressure-cooker is translated into an understanding of the physiology. Second, Johan draws from his own field, by introducing a pharmaceutical “suppression-turns inward narrative” in the form of the development of antibiotic resistance. He is thus not only reading the diagram from the logic and language of science by labelling the diagram differently, but he is also introducing an important theme that is indirectly related to vaccine-hesitancy, the ever increasing use of antibiotics.

#### ***4. Death as a natural part of life***

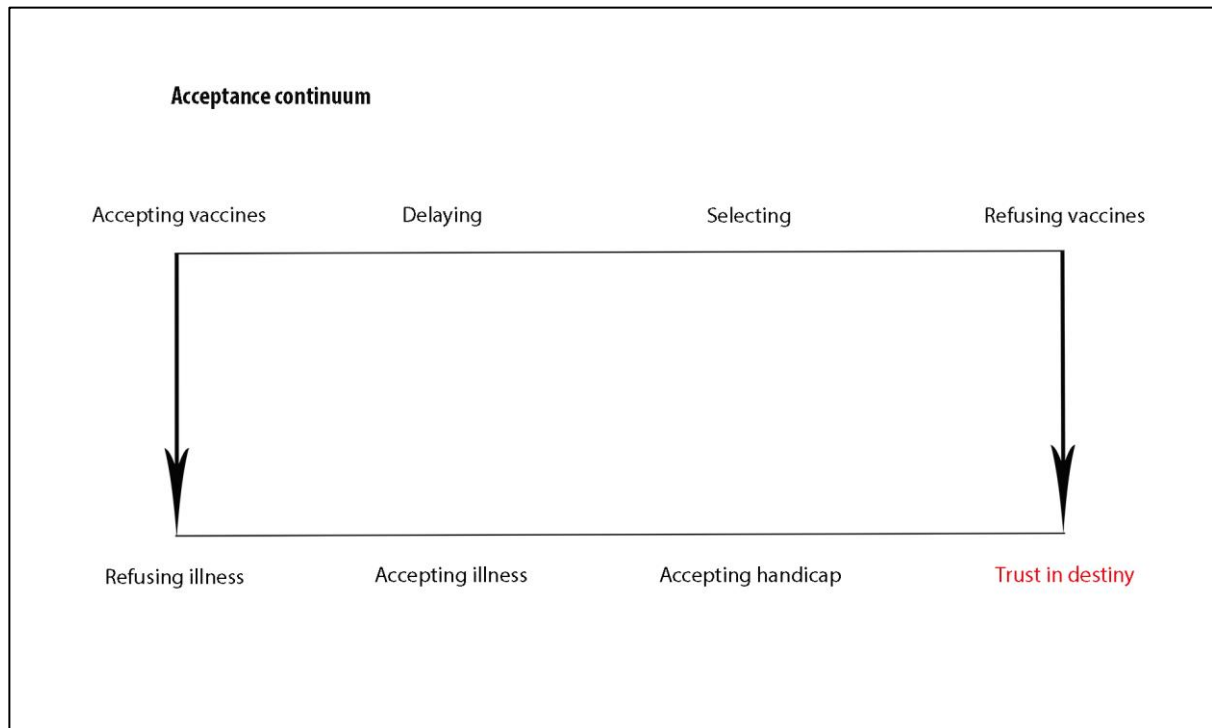
*Beliefs: we are part of nature, death is natural, and everybody has their time to die (destiny)*

*Story: elderly family member, reincarnation*

This belief and its diagram are more controversial than the previous ones. Not only did some of the participants introduce contradictory beliefs but the stories that were used to demonstrate this belief were either borrowed from other contexts (such as artificially prolonged life in elderly care), or kept abstract, like the concept of reincarnation. In neither case was the belief expressed in relation to the participants' own children, nor was it connected directly to their vaccine-hesitancy.

In the first interview, the participant explained that she understood death as a natural aspect of life, and that a long life for her was not an obvious goal, to be aimed for at any cost. On the contrary, she referred to an experience in which the health-care system did not allow a person to die but kept them alive artificially. While this narrative was only indirectly linked to the parent's concerns about vaccines, Kaisu began to explore this viewpoint of accepting death by adapting an existing diagram about vaccine hesitancy, introduced by MacDonald and the SAGE working group of Vaccine Hesitancy (2015: 4162). In the subsequent interviews, two other parents introduced the view "if it's your time, it's your time", seeing death as something pre-determined, a destiny. However, after Kaisu showed her initial sketch of the diagram to Johan, he showed the diagram to his colleagues, and they found the diagram disturbing for several reasons. Johan told Kaisu that while he accepts vaccines, he also accepts that his life will at some point come to an end. From his perspective this is obvious. To him, it seemed insulting to sketch that parents who do vaccinate their children do so due to their non-acceptance of death as a normal part of life. Furthermore, some participants, in an apparent contradiction with Kaisu's initial assumption, stated that they could not accept it if something happened to their child as a result of their not vaccinating. In fact, there was a prevalent concern for the possibility of death when separated from a child. Yet, as a vehicle for conversation, the diagram stimulated examination of the relationship between fear, life and vaccine related decisions.

Image 4.



**Kaisu:** *This [diagram] can be seen as a rather radical scale; the reality is not a choice between accepting or refusing, there are grey areas between. There are people who accept illness as part of life, people who accept the risk of illness as part of life, and so forth. It follows that the people who refuse death would do all the vaccinations possible.*

**Johan:** It's certainly a way of thinking. However, I can add that even though I believe in vaccination and use all the vaccines I think are sensible and necessary, I also accept death as a very real possibility: tomorrow, today, or sometime in the not too distant future.

**Kaisu:** *You know, my illusions about it were quickly removed by you and even by the second interview where the participant, even though she is very selective about vaccines, thinks about death all the time, she is afraid of car accidents...*

**Johan:** She uses a safety belt?

**Kaisu:** *Yes, exactly. But someone else who completely refuses vaccines can see that the death of those who are evolutionally weaker can actually help counteract overpopulation.*

**Johan:** Did she say that?

***Kaisu:** Yes. But I have to admit that it's not that black and white: the two people who said that immediately made a comment that this should not be taken out of context.*

**Johan:** So, they are not pro-eugenics? Deleting those individuals with substantial handicaps or weaknesses, who could not survive in nature or an unregulated society?

***Kaisu:** No. The argument "everybody has their time to die" leads back to this longing for the natural, back to nature, seeing humans as animals. Part of me wishes to believe it is so, because it would be a lovely natural life, living in harmony with nature. It's a scenario that I find very attractive as a life view. Then the idea of reincarnation, if it doesn't work out in this life, there will be another one. I can imagine that it brings some kind of comfort if you believe that.*

**Johan:** It's a continuum, but they are approaching a very, very difficult path. One thing you haven't mentioned is the consequences and outcomes of disease other than death. Not everybody dies, but some get paralysis, and they can have sequelae [medical conditions as a consequence of disease] of various kinds. Through not vaccinating, you can create dysfunctional or handicapped children. So, that's also one dimension that needs to be considered.

***Kaisu:** Most parents didn't really seem to think about the possibility of injury or handicap as a consequence, the decisions are made on the basis of how likely it is that you will die from this or not. And it's also a different thing to accept death as part of life than to accept the death of your own child.*

**Johan:** Exactly.

### *Reflection*

In this dialogue, Johan reflects on the participants' beliefs in death as being a natural part of life from two distinct perspectives. First, he draws from his personal view of life by saying that his acceptance of vaccines does not exclude him from accepting death as well, which was initially Kaisu's interpretation of a particular parent's belief. However, after completing

all interviews, it appeared that the parents related to death in dramatically different ways. What they seemed to share was the aim of a “natural life” in harmony with nature. Kaisu identifies with the participants in this regard, while Johan reminds her that “natural” meant something different in the middle ages than in our times. Second, Johan drew attention to the risk of handicap as a consequence of not vaccinating, while Kaisu’s impression is that most parents don’t seem to think about the possibility of injury or handicap as a consequence of disease.

### **Negotiating the Motivations and Aims of the Project**

**Johan:** [the diagrams] bring me to a more general comment or to a concern that we should think about. These various stories of the narratives are very strong and you have tried to capture them in a few diagrams. However, what would you like the readers to think about and to associate with them?

***Kaisu:** Are you afraid that by doing this I will convert more people to be vaccine hesitant because the diagrams make the vaccines sound too scary?*

**Johan:** I haven’t thought about being scared, but how it should be “framed” so to speak, in order to make an understandable story. There are all these different beliefs, all the different narratives. However, what do we want to be “the take home message”? How do we want the readers to absorb this text and then continue? What are the intentions and the purpose of the whole thing?

***Kaisu:** I would say that the overall aim is to create a better understanding of vaccine critical parents’ views on health, the body and illness; especially among medical students, doctors, nurses and other medical professionals. My personal starting point is an ambivalence towards vaccines. At first I thought I would operate as a kind of devil’s advocate in both directions. So, when I’m interviewing people, and this has happened in an interview, I have introduced something I’ve heard you saying, or I’ve heard clinicians saying, to challenge the participants. But I started to wonder if my overall aim became the ability to change their minds? I would feel a little bit as though I was betraying the parents if I was sharing in the aim of manipulating them out of their “fictitious” narratives.*

**Johan:** If that were even possible. [laugh]

**Kaisu:** *If you (the vaccine professionals) try to adapt strategies on how better to communicate with this group of people, that is fine with me.*

**Johan:** I'm definitely very positive about working on vaccines as a pharmacist and using vaccination as a preventive tool. There is too little that you can do with antibiotics, or other drugs, once the damage has happened. We have heard many of the arguments you have presented before, and my type of argument is also well known. But I think it is invaluable to understand what lies behind people's decisions, especially when it comes to the reasoning of these parents. Why do they do as they do, and why is it so very important to them to be against vaccines? These things I need to learn about in greater depth, and perhaps we can thereby make some contribution and "lower the barriers," creating better communication and a more generous understanding. If we can contribute a little in this area, then I'll be very happy.

**Kaisu:** *You have previously suggested that it is very much a question of identity, but I have to say, I have my reservations about that, the suggestion that these parents would refuse vaccination just to feel that they belong to a special group. My impression is that they are longing for a natural and clean kind of life; they perceive vaccines to be harmful, dirty, infectious, chemical, and artificial, and that totally opposes their striving to be as natural as possible. So then, we need to ask, what is the definition of natural? Afterthought: maybe we could consider the "natural parent" as an identity?*

**Johan:** That's maybe my own take on the overall message: that their perception of vaccines and vaccination as being very unnatural doesn't really hold up. So maybe we, the vaccine providers, should emphasise this and explain more about how these vaccines are manufactured, how they are controlled, and what they contain and do not contain. Vaccines are, in many ways, far more natural than antibiotics. The principle behind a vaccine is to stimulate the natural defence mechanisms of the human body. I think that the vaccine hesitant parents should reflect a little bit more about that, and perhaps we, as vaccine providers, could do better in presenting the fact that vaccines are actually stimulating the natural protective mechanisms of your own body. Thus, my learning and inspiration from our exercise is that one could communicate with the public more positively about vaccines and emphasize the natural, biological processes behind vaccination.

## Discussion

This project has explored vaccine-hesitancy through visual-narrative means in an artist-scientist collaboration. It had a dual purpose in understanding the vaccine-hesitant parents' health beliefs and in developing an interdisciplinary arts-based method for exploring these. The study parallels the parents' health beliefs with a scientific understanding of immunity and vaccines, and considers the parents' beliefs as expressed through narratives comparable with so-called illness narratives.

The collaboration in this study is not only professionally interdisciplinary, but the authors represent different attitudes towards vaccines as well. This raises several questions: how do collaborators negotiate their different goals within the same project? While Kaisu's goal and expectancy for this project may have been better understanding and improved communication with the vaccine-hesitant parents (and medical students), she does not share the ultimate goal of changing the parents' minds. Her goal is rather to open the medical students' minds to be more tolerant of different worldviews without frustration. Furthermore, and equally important, was Kaisu's purpose in exploring the topic as an artist, with an end goal (and expectancy) of creating compelling artworks, thus making the methodological development central to this project.

One of the project's methodological aims was to experiment with the role of arts-based diagrams in data analysis and knowledge transfer. In the collaborative meaning-making, the diagrams were presented simultaneously with the parents' arguments. Johan was invited to respond to either the argument itself or to the diagrammatic interpretation. Most of the authors' dialogue is a merger of these. However, the diagrams stimulated discussion on themes that were not present in the parents' narratives, but that are indirectly related to vaccine-hesitancy, for instance, the topic of antibiotic resistant bacteria. In a later stage of the project, the diagrams could be adapted or expanded as a result of the scientific reflections. Recurring questions in the authors' talks were: what is the relationship between scientific facts and artistic ambiguity, and is an illustration of a "false" belief dangerous? From Kaisu's viewpoint, the ambiguity of arts-based research outputs, such as the diagrams and the short film, allow space for the audience to create their own interpretations, and to activate them.



Recruiting vaccine-hesitant parents' through Kaisu's social network, and her sympathizing with some of their views, raises several ethical questions. It could be considered that the researcher being so close to the participants (several of them she knew personally) would prevent her from creating the necessary distance, and reduce her critical assessment of their views; however, this project considers trust to be foundational for the participants who share their personal narratives. This trust greatly benefitted from the fact that Kaisu was not a scientist with the interests of pharmaceutical research or the industry in mind, but that "she was one of us." The role of mediator that Kaisu plays between the participants and Johan (and the medical students) seems to be meaningful because it allows for a richer variety of voices to be present in the meaning-making, as opposed to Johan communicating with the parents directly. Furthermore, Kaisu's familiarity with the parents' worlds allows her to step into their shoes and represent them in the dialogue with Johan, using role-play as a way to speculate on aspects of and reasons for their narratives. In fact, both authors' personal and imaginary viewpoints are welcome, together with their professional knowledge, as well as their humour, upset, doubt, or any range of emotions raised by the topic. Seen from another viewpoint, when evaluating the dialogues afterwards, Johan felt that certain spontaneous comments did not fully capture the range of his professional knowledge, which he wished to have better reflected. This implies that the dialogic meaning-making requires cycles of iteration, and that speaking about a particular theme only once is insufficient.

Among the major challenges of Kaisu's mediator position, and the polarizing research topic, were the contrasting expectations of advocacy: some of the parents feel very strongly about their anti-vaccine opinions and may wish that this project expresses those messages as well. Simultaneously, Johan and his colleagues hope to increase vaccine acceptance, and wish that this project supports that aim. Due to Kaisu mediating the interview findings, Johan did not communicate directly with the parents. However, he was introduced to the parents' worlds, including their voices and images of their homes through audio-visual means. Johan also viewed the many versions of the short film intended for medical education, in which parts of the authors' dialogue is also represented. Additionally, as Kaisu consulted with Johan during the interview cycle, she introduced many of Johan's ideas during the interviews as well.

In terms of a take-home message for the pharmaco-medical community, all the four main health beliefs discussed in this project can be connected to one underlying aim: "a natural way of living." One of the major hurdles in understanding and working with vaccine-

hesitancy is communication with the parents. While it has been suggested that public health institutes should continue to communicate about the severity and susceptibility of vaccine-preventable diseases (Harmsen et al. 2013), the interviews here however indicate that fear-inducing communication may not cause the desired response in this particular group of vaccine hesitant parents. While the parents do lack elaborate and balanced information about the pros and cons of vaccines, the perceived natural way of living and conducting their own health-care is paramount to most of these parents. This study suggests that it may be useful to consider whether vaccines could be discussed further in this particular context, as well.

## References

- Boydell, K.M., B.M. Gladstone, T. Volpe, B. Allemang, and E. Stasiulis. 2012. The production and dissemination of knowledge: A scoping review of arts-based health research. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 13(1), Available at: <http://www.qualitative-research.net/index.php/fqs/article/view/1711>. Date accessed: 08 Oct. 2016.
- Boydell, K.M., M. Hodgins, B.M. Gladstone, et al. 2016. Arts-based health research and academic legitimacy: Transcending hegemonic conventions. *Qualitative Research*, 1468794116630040.
- Frank, A.W. 1995. *The wounded storyteller*, Chicago/London, The University of Chicago Press.
- Harmsen, I.A., L. Mollema, R.A. Ruiter, T.G. Paulussen, H.E. de Melker, and G. Kok. 2013. Why parents refuse childhood vaccination: A qualitative study using online focus groups. *BMC Public Health*.13:1183. doi: 10.1186/1471-2458-13-1183.
- Kilty, S. 2000. Telling the illness story. *The Patient's Network* 5(3).
- Koski, K., F. Heyning, and R. Zwijnenberg. 2016. Collaborative meaning-making in arts-based research: Data interpretation with an artist, a physician, and an art historian. *Art/Research International: A Transdisciplinary Journal*, 1(1): 234-257. Available

online: <https://ejournals.library.ualberta.ca/index.php/ari/article/view/24838>

Koski, K. 2014a. Anatomical self-portraits: Observations, improvisations and elicitations in the medical school. *Journal of Artistic Research* (6) Available online: <http://www.researchcatalogue.net/view/56534/56735>

Koski, K. 2014b. Mapping the female reproductive system: Arts-based inquiry of medical students' anatomy drawings. *Studies in Material Thinking* 10.

Koski, K. 2013. As-if the patient were in the classroom: Video-based enquiry into the absent body in medical education. *Journal of Applied Arts & Health* 4(2): 207–222, doi: 10.1386/jaah.4.2.207\_1

MacDonald N.E., SAGE Working Group on Vaccine Hesitancy. 2015. Vaccine hesitancy: Definition, scope and determinants. *Vaccine*. 14;33(34):4161-4. doi: 10.1016/j.vaccine.2015.04.036.

McKee C. and K. Bohannon. 2016. Exploring the reasons behind parental refusal of vaccines. *Journal of Pediatric Pharmacology Therapy*. 21(2): 104-109.

Peretti-Watel P., H.J. Larson, J.K. Ward, W.S. Schulz, and P. Verger. 2015. Vaccine hesitancy: Clarifying a theoretical framework for an ambiguous notion. *PLOS Currents Outbreaks*. doi: 10.1371/currents.outbreaks.6844c80ff9f5b273f34c91f71b7fc289.

Rosenstock, I. 1974. Historical origins of the Health Belief Model. *Health Education Monographs*. 2(4).

Smith P.J., S.G. Humiston, E.K. Marcuse, et al. 2011. Parental delay or refusal of vaccine doses, childhood vaccination coverage at 24 months of age, and the Health Belief Model. *Public Health Rep*. 126 Suppl 2:135-46.

Trollope-Kumar, K. 2002. "Theories of Health and Illness" *Encyclopedia of Public Health*. Retrieved September 02, 2016 from Encyclopedia.com: <http://www.encyclopedia.com/doc/1G2-3404000840.html>

Tufte, E.R. 1997. *Visual explanations: Images and quantities, evidence and narrative*. Graphics press, Cheshire, Connecticut.

Tufte, E.R. 1990. *Envisioning information*. Graphics press, Cheshire, Connecticut

Umoquit, M., P. Tso, T. Varga-Atkins, M. O'Brien, and J. Wheeldon. 2013. Diagrammatic elicitation: Defining the use of diagrams in data collection. *The Qualitative Report*, 18(60), 1-12. Retrieved from <http://www.nova.edu/ssss/QR/QR18/umoquit60.pdf>

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