

# HEALTH POLITICS, SOLIDARITY AND SOCIAL JUSTICE

## An Ethnography of Enunciatory Communities during and after the H1N1 Pandemic in Sweden

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During the H1N1 influenza pandemic 2009–2010 in Sweden, a mass-vaccination intervention was enacted as a precautionary measure. Half a year later, medical authorities reported an increased incidence of the life-long neurological disease narcolepsy, later firmly established as a side effect of the pandemic vaccine. Using interview material together with archived protocols, this article presents an analysis of two communities, the National Pandemic Group and the Narcolepsy Association. The aim is to discuss their respective ways of arguing for solidarity, herd immunity, social justice and claim for culpability of the state. Both communities face dilemmas, doubts and double-bind situations, but also perform politics and ethics for the future in mobilizing notions of solidarity and responsibility in their different narratives.

*Keywords:* H1N1 pandemic, health politics, solidarity, vaccination, narcolepsy

### **Waiting for an influenza pandemic**

In spring and summer of 2009, national and global news media overflowed with stories of a new influenza pandemic. As history has shown, influenza pandemics have had an impact on public health, economy, and societal functions, and since the Spanish flu of 1918–1919, public health authorities regard them as health threats. Furthermore, they are now matters of national and international security, for health, societies, and states. Most high- and middle-income countries prioritize pandemic preparedness, thus strengthening emergency infrastructure and stockpiling antiviral pharmaceuticals and vaccines (Lundgren & Holmberg 2017).

Despite this kind of advanced pandemic preparedness (cf. Lakoff 2008; Barker 2012; MacPhail 2010; Holmberg & Lundgren 2016), the 2009 pandemic brought new challenges to public health governance. It came with an unexpected virus (H1N1 instead of the anticipated H5N1), started from an unexpected place of origin (Mexico and California instead of Southeast Asia), and afflicted mainly young and middle-aged people. Medical risk groups were pregnant women, the morbidly obese, and the chronically ill. Besides the perceived threat to children and young adults, this pandemic was also different from earlier pandemics in other ways. A report from the European Centre for Disease Control states, “it was

the first pandemic with instant communication, so that early impressions ... could be shared ahead of proper scientific analysis.” “Instant communication” implied among other things that the blogosphere and other communications tools needed to be acknowledged (Leung & Nicoll 2010). Charles Briggs and Daniel Hallin have from the perspectives of anthropology and media studies analysed how the news coverage and media logics were incorporated into the processes and practices of different actors during the pandemic in the United States (Briggs & Hallin 2016). As also could be said about Sweden, the pandemic involved “a kind of fusion of science, the state, and media, a largely harmonious collaboration between health officials and mainstream journalists” (Briggs & Hallin 2016: 134; cf. Gherzetti & Odén 2010).

Influenza gives rise to epidemics on a smaller or greater scale each year. An influenza pandemic on the other hand, is caused by a virus strain with a genetic composition and antigenic setup not previously encountered by the global population. Neustadt and Fineberg have referred to influenza as a “slippery disease” because the virus is complex and constantly mutating, making vaccines less effective than for many other diseases. In addition, influenza symptoms are often confused with those caused by other viruses, making it hard to estimate the effects of the virus from year to year (Neustadt & Fineberg 1978).

The H1N1 pandemic (popularly known as swine flu) reached Sweden in the late summer and autumn of 2009. In accordance with the pre-pandemic preparedness, Swedish authorities effectively implemented a strategy for handling the pandemic, including a mass-vaccination intervention as soon as the vaccine Pandemrix would become available in October. At the time, I was working as a Dean of the Faculty of Arts at Umeå University in Sweden. As for most people then, my knowledge about the pandemic was influenced by information from Swedish politicians, health authorities and media debates, including reports from Mexico, California, and the southern hemisphere. During meetings with the Vice-Chancellor and the other Deans, we

discussed what kind of responsibilities we should take as a university, for example, how we should facilitate the vaccination of our employees as soon as possible. Several questions occurred. Was it wise for a group of leaders (myself included) from the university to participate in a planned delegation trip to China, Taiwan, and Australia in September of that year? Moreover, on a personal level, would I be able to persuade my two sons, aged 17 and 21, to take the shot? My concerns were allayed – university employees were vaccinated at their workplaces, my two sons were also vaccinated (as was I), and the delegation trip was completed successfully. My recollections of encounters with the pandemic during the trip are about details such as fever monitoring at some airports, worried or accusatory glances if someone coughed too heavily on the airplane, and our frequent use of hand sanitizers. At that time, I was certainly not thinking of the pandemic as a future object for my own research.

The pandemic has been my research focus since 2013 with the overarching aim to investigate different cultural and social framings concerning the pandemic and the vaccination measures in Sweden.<sup>1</sup> The project has been intermixed with ongoing efforts to integrate ethnology and humanities into the medical field, and the concept of *medical humanities* into the fields of culture and history (Lundgren 2013, 2015a). My work has resulted in a recursive journey into what would unfold as epistemic labyrinths of the pandemic, oscillating between interviews as the main source, together with observations, media reports, and archived protocols from different authorities. It also meant making excursions into (for me as an ethnologist) unknown territories of knowledge, including infectious diseases, immunology, virology, vaccinology, and epidemiology. Some textbooks in the fields of infectious diseases and epidemiology encouraged the integrated cultural-epidemiological approach to “highlight the creative interdisciplinary ways by which researchers are confronting today’s vexing and complex health challenge” (cf. Trostle 2005: 3). However, more common were the strictly bio-medically informed paradigms governing science, conferences, and funding agencies. The fields

of medical anthropology, applied anthropology and science and technology studies became the academic in-between-landscapes where it was possible to combine the two (cf. Martin 1994; Farmer 1999; Nichter 2008; Singer 2015; Briggs & Hallin 2016).

As Laëtitia Atlani-Duault and Carl Kendall noted in 2009, the responses to the pandemic was overwhelmingly biological and epidemiological in scope. They proposed a research agenda for anthropologists to “play an important and underutilized role in planning and responding to influenza and other global emergencies” (Atlani-Duault & Kendall 2009: 207). Such a research agenda would explore more comprehensive, but perhaps uncomfortable truths, in focusing for example on politics, government, economy, religion and history (2009: 210). In my research project, I have tried to tackle the issue of the pandemic as a broad concept to investigate several subject areas and themes, at times distant from the usual pathways for Swedish ethnological research.

So far, the project has resulted in publications on pandemic preparedness (Lundgren & Holmberg 2015; Holmberg & Lundgren 2016), on lay people’s perceptions of the immune system in relation to the common cold vs. influenza (Lundgren 2015d), and on attitudes towards vaccination (Lundgren 2015c). They have also focused on different aspects of narcolepsy as a side effect (Lundgren 2015b; Lundgren & Holmberg 2015), on issues as solidarity, trust and ethics (Lundgren 2016; Lundgren & Holmberg 2015), and on influenza pandemics and vaccination in history (Holmberg 2016; Lundgren & Holmberg 2017).

In this article, I will concentrate on two main actors in the Swedish narrative of the pandemic: the National Pandemic Group (NPG) and the Narcolepsy Association (NA). With inspiration from Kim Fortun (2001), I will call these actors *enunciatory communities*, both facing emerging doubts and dilemmas throughout the course of the pandemic and its aftermath. My aim is to discuss their respective ways of using concepts such as solidarity, herd immunity, social justice and claims of culpability of the state. The juxtaposing of these two communities enables a discussion about how public health poli-

tics, notions of collectivities, risk and uncertainty intervened into the process of pandemic response in Sweden.

### The Swedish Pandemic Narrative

With the help from evaluations and other official documents, it is easy to construct a broad Swedish narrative about the swine flu. It contains different spatio-temporal ingredients such as the pre-pandemic planning and preparedness starting in 1993, and an advanced purchase agreement in 2007 with a vaccine producer (GlaxoSmithKline) in case there would be a need for a new vaccine. There is the reported outbreak in California and Mexico at the end of April 2009 and the WHO upgrading the epidemic into a pandemic on June 1. It also involves the (almost) consensual and effective decision-makings in the face of this upgrading, and a successful national mass-vaccination campaign with logistics in place and over 60% uptake. Sweden also has the advantage of possessing specialized facilities for treating the most severely ill – the ECMO-ward at the *Karolinska University Hospital* in Stockholm (ECMO = extracorporeal membrane oxygenation). The pandemic eventually turns out to be milder than expected with a very low case of fatality (MSB & Socialstyrelsen 2011).

The mass-vaccination intervention was debated and authorities were questioned whether they had exaggerated the threat from the pandemic (cf. Gherzetti & Odén 2010). There were also criticisms and worries about the economic costs of the vaccination. Overall, there was initial public confidence and trust regarding how the authorities handled the situation. However, in the unfolding of the consequences of the mass-vaccination, the narrative also carried its peripety – an abrupt turn of events and reversal of circumstances. This materialized in reports, starting in the summer of 2010 and continuing during 2011 about children and young people who were diagnosed with the unusual and life-long neurological disease narcolepsy as a side effect of the vaccine (Läkemedelsverket [Medical Products Agency] 2011). For these, now estimated more than 300 young people and their families, the authorities’

precautionary measures have turned into personal catastrophes and to alternative pandemic narratives.

## Methods

My research project (Epidemics, Vaccination, and the Power of Narratives) started in 2013. That meant, “arriving after the fact” (Fortun 2001: 2), since the pandemic was already over. I began my work in the post-pandemic phase, when the pandemic was officially declared over by the World Health Organization.<sup>2</sup> The Swedish mass-vaccination had passed and the side effects were known. This had of course implications for my study and it is important to remember the different positions of the people involved. For authorities and health professionals the interviews provided situations to look back and reflect on processes and decisions regarding the already past event. The narcolepsy families still faced their problems in the present and in the future.

I carried out my interviews through parallel sessions mostly during 2013 and 2014, with individuals from three groups comprising different formations of the pandemic: 1) authorities, policymakers, and decision-makers, 2) narcolepsy patients and their families, and, 3) health care workers and medical researchers. I have conducted 14 interviews with different officials from authorities, most of them in one way or another connected to the NPG. I have also made 10 interviews with parents of narcoleptic children, and 2 interviews with young adults with narcolepsy. Furthermore, I have made 12 interviews with health care workers and medical researchers. In the citations, the informants are anonymous (as much as it is possible because people in the authorities are often public persons). In the case of the parents, I have used pseudonyms. During the interviews, I have used a person-centered approach (Linger 2005). I started asking the interviewees questions about their childhood, their education and working life. Then the interviews continued with dialogues about experiences of infectious diseases, personal memories of epidemics or pandemics and specific positions during the swine flu pandemic.

In interpreting the interviews my basic tools come from cultural analysis as developed by Ehn and Löf-

gren (2001) – a critical ethnological approach based on the social and cultural present, but far from leaving history aside. Cultural analysis shows the societal and individual past as part of contemporary ways of living. One of the most important advantages for cultural analysis is its way of creating new forms of understanding and its critical potential for scrutinizing and questioning predominant opinions and dissecting stereotypes and prejudices. Arthur Frank and his method of dialogical narrative analysis also inspired me. Narrative analysis is broadly defined as a method of qualitative research in which the researcher listens to the stories of the research subjects, attempting to understand their experiences, cultural and social framework and the situation at hand (Arvidsson 1998; Riessman 2008). One important element in Arthur Frank’s method is the mutual (dialogical) relationship between stories and humans. Stories make life social and connect people into groups and collectivities (Frank 2010: 15). Stories have capacities in many ways – they have the capacity to display characters and to make one particular perspective not only plausible but compelling (Frank 2010: 3). Stories and storytelling also carry inherent morality about what counts as good or bad. Stories are resonant, that is, they echo other stories and sometimes summon up whole cultures (Frank 2010: 37).

In this article, I will focus on two of the interviewee groups. First, my interviews with authorities and policymakers connected to the National Pandemic Group and my interviews with some professionals who in their daily capacities were dependent on the positions taken by the NPG. Interviewing state officials from different authorities implies specific challenges. Legislations, special assignments, specific rationales and organizational limitations frame authorities and their actions. Nevertheless, it is important to note what Didier Fassin has defined as central for an “ethnography of the state”, that “the state is a concrete and situated reality ... simultaneously embodied in the individuals and inscribed in a temporality” (Fassin 2013: 4). It is the “agents themselves who make the policy of the state, by feeling more or less constrained by the scope of their job

and resources, by taking more or less initiative with respect to the regulations imposed on them” (Fassin 2013: 5).

Some of those I interviewed in the first group were also formal members of the NPG. Their meetings before and during the pandemic have been documented in archived protocols. Maybe due to the ongoing threat from the pandemic together with the Swedish official legislation regarding authorities’ documentation (protocols are public and open to any citizen to read), these protocols are quite brief and contain no transcriptions of the discussions or indications of possible disagreements. I studied the protocols after I had made the interviews. Since the interviews provided many nuances regarding the different conditions for taking a stand or making decisions, I read the protocols with curious eyes, to find expressions of doubt and dilemmas.

Second, I will use my findings from interviews with parents of children with narcolepsy and from my participatory observations during some meetings with the NA. These interviews focused on how the side effect had disrupted individual and family lives, but also how patients and parents played an active role in the production of knowledge about narcolepsy and how their ways of forming a collective action has made them create a reflexive organization using collaborative mechanisms, collective action and mutual learning (Rabeharisoa & Callon 2004: 145). In analysing these interview sessions, I had a similar experience as with the NPG interviews. Talking to parents one by one, when they were representing their families or children, provided another kind of information than when asking specifically about the association as the advocating or acting entity. For the association to be able to gain trust both among their members and among medical and governmental authorities it was important for them to navigate strategically between the individual and the organizational levels.

Following Kim Fortun, I define these two constellations (the NPG and the NA) *enunciatory communities*. In Fortun’s definition, enunciatory communities make new subject positions emerge as a response to profound change (Fortun 2001: 13). The NPG,

although existing since 2005, met a situation of a new and unexpected pandemic that challenged the pre-pandemic preparedness. The families that created the NA had faced a disease that hardly anybody had heard of, and where collective action was necessary. These unexpected realities also involved *double bind* situations – fields of force and contradiction (Fortun 2001: 11), emerging both from the pre-pandemic preparedness and from handling the adverse effect from the mass-vaccination. Double bind situations imply not only difficult choices but also that individuals confront more than one obligation, that could be equally valued, but inconsistent (Fortun 2001: 13). In some cases, the double bind situations could become corroding factors for the chosen strategies.

### **Advocating Solidarity and Herd Immunity – Strategies, Doubts, and Dilemmas in the National Pandemic Group**

The NPG started in 2005 in accordance with WHO proclamations regarding national pandemic preparedness. It played an important role in the Swedish pandemic preparedness and as an actor in European and global networks. The National Board of Health and Welfare (NBHW) was the convening actor, and their Director-General served as the chair of the NPG meetings. Other members in the NPG were the Swedish Institute for Communicable Disease and Control, the Swedish Civil Contingencies Agency, the Swedish Association of Local Authorities and Regions, the Medical Products Agency, the Swedish Work Environment Authority, the National Veterinary Institute, the Swedish Board of Agriculture, and the National Food Agency. During the course of the pandemic, the first four organizations were the most involved with the NPG. The group held their meetings once every week from April to November 2009, after which meetings were less frequent and mostly by teleconferences. The function of the NPG was to support collaboration between all the stakeholders and other actors involved in dealing with the pandemic. Citing Haas (1992: 3), Paul Forster has pointed out both the allure of such collaborative models comprising “epistemic communi-

ties” and “communities of shared knowledge” and the simultaneous risk that they might only provide solutions that “support a technical, scientific viewpoint, and exclude others” (Forster 2012: 23).

The specific swine flu accounts in the NPG protocols date back to the spring of 2009. These intensified through September of 2009, and the last protocol concerning the swine flu was on August 11, 2010, the day after the WHO announced that the pandemic was over. Using a person-centred ethnography approach to people in the NPG, broader and sometimes differentiated accounts prevail than can be found in the official protocols. Personalized narratives for analysing the work of the NPG constitute ways of illuminating “how different pathways of responses are created, shaped and justified” (Forster 2012: 4).

The work in the NPG was largely dependent on the previous pandemic preparedness efforts. The preparedness plan before and the evaluations after the swine-flu pandemic and the protocols from the NPG showed that the preparedness was framed by biosecurity together with evidence-based policymaking (see also Holmberg & Lundgren 2016). Biosecurity refers here to the “various technical and political interventions – efforts to ‘secure health’ – that have been formulated in response to new or newly perceived pathogenic threats” (Lakoff & Collier 2008: 8). Sweden, with its relatively high awareness of biosafety and biosecurity, has implemented a robust and concrete governance, steered by the National Veterinary Institute and the Public Health Agency. One example is the implementation of an internal bio-risk programme, including the high-containment laboratory (BSL-4) at the Public Health Agency of Sweden. This facility is the most advanced in the Nordic countries and one of few in Europe. Other examples are biosecurity and surveillance in animal husbandry and response to effects of so-called invasive species. A third example of Swedish biosecurity is the stockpiling of antivirals in case of influenza pandemics. This area of biosecurity also includes preparedness for mass-vaccination against pandemic spread. All of these examples are related to what Hinchliffe and Bingham have defined as areas of biosecurity (2008: 1535–1536).

Influenza positioned as part of global health security and developed into processes of securitization, have made pandemic declarations matters of national or international security (Buzan 1998). Kezia Barker has argued that this securitization by itself caused a “bureaucratic reflex” when measures were taken during the pandemic (Barker 2012). One example was the Swedish advance purchase agreement with a vaccine supplier and the logistics plans that were in place for distributing the vaccine. When the WHO declared phase 6 of the pandemic, the purchase agreement was enacted and the vaccine was produced and distributed (MSB & Socialstyrelsen 2011).

Thus, the swine flu experience represented the first “real-life test” of pandemic preparedness after the NPG started in 2005. Briggs and Hallin (2016: 120) also accentuate the pandemic as a primary real-life test in their analysis of how previous communication exercises came back as realities in 2009. Reading the protocols from the NPG is a way to recognize how each statement, although shortened by bureaucratic language, iterates “nested worlds” that implicate each other in specific ways. The protocols form a chain of arguments combining health security and evidence-based practice with certain core categories and strategies. These include the special characteristics of the H1N1 pandemic, the assessment of who was at risk, the concept of herd immunity, trust in the evidence for vaccination, the mass-vaccination intervention, the strategic use of the solidarity argument, and the importance of consensus regarding measures and information. As we will see, the interviews provide important nuances to this picture.

The risk assessment was based on experiences from previous pandemics and seasonal influenza outbreaks as well as the reported pandemic outcome during the summer of 2009 from Mexico, the United States, and the southern hemisphere. The reports stated that children and young people were especially afflicted (MSB & Socialstyrelsen 2011: 9). The facts about afflicted children would eventually lead to somewhat confusing information from the authorities. Although young people were not considered a medical risk groups, the NBHW designed



a special Facebook-campaign to reach the young adults for vaccination.

The social, cultural, and historical context – Sweden as a modern Scandinavian welfare society with a historically high degree of institutional trust and several experiences with successful medical and public health interventions – is important to have in mind. The formal structure with a division between the governmental level and the self-government by counties and municipalities is another essential condition. The county councils made the formally operative decisions concerning for example the mass-vaccination. As a part of the Swedish constitution, this principle of local self-government (*kommunala självstyret*) gives the county councils the right to design and structure their activities concerning public health. However, in practice, there were strong limitations regarding the possibilities to act in other ways than the pandemic plans had proposed.

Sweden has had a long history of vaccination practices and a very high coverage in the national child vaccination programme. Even voluntary seasonal flu vaccinations had a relatively high uptake during the years prior to the swine flu pandemic (<http://www.socialstyrelsen.se/publikationer2013/2013-6-37>). The ways officials talk about child vaccination as a success story in medical history, resemble what Rabinow and Rose define as a hybridized truth, mixing biology, susceptibility, and demography (Rabinow & Rose 2006: 197). This perception also characterized pandemic vaccination interventions. Although there were reports indicating that there was no conclusive evidence for the effectiveness of previous seasonal influenza vaccines for the elderly<sup>3</sup>, pandemic mass-vaccination was considered the best preventive measure. There was no evidence for the efficacy of the new vaccine, or for the risks of severe side effects. A special fast-track procedure was established for the new pandemic vaccine, with the European Medical Agency as responsible main actor.

In hindsight, commenting on the mass-vaccination and the serious side effect of narcolepsy, one official at the NBHW recalled:

Vaccination is fundamentally the best intervention to prevent a disease ... the tragic outcome of the pandemic with narcolepsy is very tragic and deeply sad. Nevertheless, all the critics, they are now looking at this *a posteriori*, in hindsight, and of course then it is easy to have an answer. Nevertheless, when you are to judge a situation where people, young people, children, died in the southern hemisphere, where the intensive care units were inundated by influenza patients... That's what is interesting now in the global world, the rest of the world can sit on the balcony and plan what to do because we know it will come to us. (Interview with official at the NBHW, February 27, 2013)

The concept of “herd immunity” was articulated together with “solidarity” in the communication about the mass-vaccination and was emphasized as an important constituent part in the argumentation in favour of the vaccine intervention. The arguments aimed to persuade people to accept vaccination as an altruistic way to protect those who for different reasons could not take the vaccine. The argumentations turned out to be a mixture of a political strategy and of epidemiological evidence.

While proclaiming vaccination as a rational and reasonable decision for all, there were no arguments regarding categories such as ethnicity, gender, or religion. Also, there were no special arguments regarding specific ways of communicating with different hard-to-reach groups, for example, homeless people, refugees or ethnic minorities. However, the official recommendation for vaccination was translated into 18 different languages. In the informal group “Pandemic analysis” at the National Board of Health and Welfare, specific discussions were held about the risk of forgetting some groups in society. Were there enough efforts made to get sufficient knowledge and reach all minority groups in Sweden? My impression is that these discussions did not become part of the agenda of the NPG, although the issues were brought to their attention (personal communication with formal official at NBHW). One official of the NPG explained to me some of the reasons for claiming the solidarity argument:

Yes, in this case, there was a very strong solidarity argument because the experiences from the southern hemisphere indicated that this was a very serious disease. ... And it was the fact that you do it for yourself, but just as much for your family and friends and the weakest in society. Actually, this is the first time, as far as I can remember, that we have had a solidarity argument, that it became such a foundational argument for this. ... I think it is really interesting that solidarity could be such a foundation... I think it was correct. Because most of those who would have been afflicted, the children, had no say in the matter... (Interview with official at the NBHW, February 27, 2013)

This quote emphasizes solidarity as an important argument for the mass-vaccination, although it does not confirm its use generally in public health. As I will argue later, there are different interpretations of whether solidarity has its base in public health work or in national state politics, or in both.

#### *Consensus vs. Doubts and Dilemmas*

The NPG protocols of 2009 and 2010 are rather brief and describe no contradictions, no questionings, and no inner conflicts. When reading them after I had made the interviews, I was somewhat surprised to learn about the outspoken consensus. The first protocol in 2009 (April 28) explicitly stated the need for consensus with “to agree upon”, “to co-ordinate”, “to voice in common”, “to having press conferences in common”, etc. It is repeatedly expressed in the protocol that the NPG shared the WHO’s judgments and recommendations. The Ministry of Health and Social Affairs also communicated to the NPG that “all information needs to be unanimous” and “that the experts must follow those agreements about messages that the information officers have been involved in bringing forward” (quote from NPG protocol May 5, 2009). This indicates how restricted this epistemic community was, and actually was designed to be.

One official commented on the consensus in the interview:

Obviously, you can never have a one hundred percent consensus for a measure as large as this one [*the mass-vaccination*]. However, in the NPG, we had full consensus. (Interview with official at the NBHW, February 27, 2013)

Still, the official talks of at least one person, who afterwards has claimed an opposing opinion regarding the mass-vaccination, but never voiced during the meetings:

And that was really the fact, and that is interesting, that he afterwards spoke in a way that I don’t think anyone should: “I regret I did not oppose it.” Because he never opposed it in the NPG. What he said at the time in the NPG was all about frustration in not getting the vaccine quickly enough. Therefore, his change of heart has come very conveniently afterwards. He had every opportunity to question this during every weekly meeting. (Interview with official at the NBHW, February 27, 2013)

Later, I interviewed the particular official who was criticized. I asked him how he felt about the vaccination intervention, and he told me he had doubts during the pandemic. His opinion was that medical decisions are not always rational, but rather influenced by psychological mechanisms, for example, people being scared that showing doubt would risk the much-desired national consensus that was considered the best course of action.

It is this interesting psychology ... Why don’t people speak more about this? I discussed this with some colleagues, and it turned out that many were quite hesitant. But it is that psychological mechanism. (Interview with official at the Swedish Association of Local Authorities and Regions], March 8, 2013)

He concluded that it was a wrong decision to take, not because of fear of side effects, that were considered very unlikely, but because he considered evidence indicating that the pandemic would not strike as hard as predicted.



We knew from Australia ... that about 10 percent of the population would be ill. That turned out to be true. ... We knew that this pandemic differed from the seasonal flus in two respects, the older were largely immune, and that is where the biggest risk groups are. This was also shown. We knew that we had some scary cases among young people. In fact, we assessed very precise data. We have always said that you should vaccinate everyone if there is 30–40 percent risk of falling ill. We knew it would be 10 percent, yet we chose to vaccinate everyone. It is quite irrational.

My interviews with different officials were ways of making “second-order observations”, meaning that I tried to observe what my interviewees observed, according to Niklas Luhmann’s terminology (Caduff 2014b; Luhmann 1998). As Carlo Caduff has suggested, the focus on experts and their reasoning risks replicating “biosecurity’s ideology of efficiency and rationality” (Caduff 2014a: 8.4). This is very much the case, but this official’s remarks on what is rational or not, still reveal some tensions and contradictions concerning aspects of biosecurity. Governments and authorities with the responsibility to protect people face double-edged challenges or fears. One is the fear of having done too little and afterwards being accused of having disregarded the threat and thereby causing unnecessary damage. “There is always a political imperative to be seen to be doing something in the era of anxiety, worry and perceived threat” (Scoones 2010: 149). The other fear is over-reaction, “crying wolf” and to be accused of wasting money and trust. Behind these fears, there is also an underlying worry to lose control and be outflanked and powerless facing epidemics. This situation of “damned if you do and damned if you don’t” can explain why it was possible to simultaneously argue both that the pandemic would be severe and that it would be mild.

The official in the above quote also commented on the political involvement and, at times, the political interrelations with the medical expertise in the policy- and decision-making procedures. In August, the Ministry of Health and Social Affairs cre-

ated a special informal group including the National Board of Health and Welfare, the Swedish Institute for Communicable Disease Control, the Swedish Civil Contingencies Agency, and the Swedish Association of Local Authorities and Regions. This group was also described in the evaluation report (MSB & Socialstyrelsen 2011). The aim was “a political group as a complementary group to the NPG” (protocol August 25, 2009). This group should “synchronize the authorities’ and the government’s work and their public messages”. The Ministry took over the responsibility of handling the press conferences from September 1 and onwards. New routines unfolded. Up until then, there were press conferences only when something new had occurred. Now they were to be held every week at a fixed time and place.

Some officials also argued that politicians claimed the solidarity argument. One official remembered the meetings that the prime minister had with his council for crisis management, where the political representatives had stated that they would not accept that anyone should die in Sweden when you could vaccinate against it. Moreover, this vaccine was intended to the whole population (Interview with official at the European Centre for Disease Prevention and Control, February 28, 2013).

Another official also declared that the solidarity principle came from the politicians. This was an official guideline because of the previously mentioned separation between the national health authorities and the county councils. However, the solidarity argument was also discussed actively and independently in the main convening authority National Board of Health and Welfare (personal communication with former official at the NBHW).

These examples show that both the public health authorities and the politicians were highly engaged in propagating the mass-vaccination for the “whole population”. The Swedish nation was the targeted collective for both public health and state politics. Consequently, the political collaboration with the expert authorities made it possible to make science a component of politics and to motivate political interests and aims (Haas 1990: 11; Kamradt-Scott 2012: S118). Thus, an interrelation between solidar-

ity as a political argument and herd immunity as a medical and epidemiological argument arose.

Was the political involvement a double bind situation for the NPG? This involvement in the expert authorities' agenda implied that experts and officials became influenced by, or obliged to pay loyalties to, the political demands. If, from the standpoints of their own professions, from their personal convictions, or from evidence-based argumentations, they concluded differently than the politicians about what was the right thing to do, they were clearly in a double bind situation, because agreeing with the politicians meant giving up on their own knowledge or expertise-position. This double bind would add one more risk besides the one that Forster has pointed out – that communities of shared experiences will only propagate narrow technical solutions. In this case, the political involvement made visible by, for example, performative utterances at press conferences, etc., about solidarity and the “whole population” was at odds with some of the NPG members' professional or evidence-based practices and experiences in handling influenza epidemics. On the other hand, the weekly press conferences, framed by politicians, also said something about the pragmatics of biopolitical communication (Briggs 2009: 191). Although the different authorities involved realized the risk that journalists would tire of press conferences with no actual news, the health authorities also saw an opportunity to make themselves visible to the public and to make their competences broadly known.

The double bind also made itself obvious for some key professionals in the course of the pandemic even if they were not directly involved in the NPG. Signs of doubt came from three doctors and a journalist who criticized the vaccine purchase agreement in one of the leading Swedish newspapers (*Svenska Dagbladet*, October 6, 2009). The article argued that the influenza pandemic would not be severe, and yet authorities had put great emphasis on solidarity. They continued by arguing that this was a solidarity for the already rich because the purchase agreement placed Sweden ahead of poorer countries in the global distribution of vaccines. Because the agreement

contained secret paragraphs, it was not transparent enough to make it obvious who would be responsible if there were severe adverse effects from the vaccine.

A Swedish paediatrician, who for many years had been involved in child immunization programs, also had worries about the vaccination of children and the quality and safety of the vaccine. She knew that she would have to comply with a decision about mass-vaccination, but she wanted to know more of the facts. She wrote a letter to all the director generals who were members of the NPG.

If we are going to mass-vaccinate children, we need to have better knowledge about the basic data. I demanded that an expert meeting should be held to be able to find out what was in the vaccine. (Interview March 7, 2013)

The protocol of the NPG on August 25, 2009, also mentions her wish for the meeting. She wanted all the international experts available but was told this was too expensive. She remained worried about the adjuvant in the vaccine:

At the same time, because I was worried, I went out and tried to find out about the adjuvant ... and I found out that this is a substance used all over the world in health food stores where they claim it can cure cancer and strengthen your immune defence, or whatever. Nothing indicated it would be dangerous, but it was not tested on children. ... At the same time, we had this threat.

She was very eager to tell me about her way of *balancing* facts.

This was in the summer – August or September ... I was forced to find all this out for myself and I was interviewed on television in the autumn. I remember the most important thing for me was, “Would I be able to recommend this to my children and grandchildren?” I really made great efforts in finding information. On the one hand, it was the adjuvant, which was a bit scary. The other was the information that was brought forward

about the influenza. We had contacts with Australia and with London and we should inform every nurse in Stockholm. Before doing that, I had to take a stand. .... And we *weighed together* all the data we had from Australia that told us that this is dangerous. From London, we had data from July. Children *died!* *Children* died! And not only “at-risk children”. And I tried to weigh it all together, and finally could say to myself ... Yes, I can recommend this to my children and grandchildren – while at the same time there was a worry. (Interview March 7, 2013)

She told me she wanted to start a “worry group”. “If you are going to vaccinate this many children, why not have all the experts in for a hearing? ... But still, you probably wouldn’t have known about narcolepsy anyway.” She made a PowerPoint presentation and held lectures for vaccinators, doctors, and nurses based on her results of balancing and weighing different kinds of information. Being trapped in a situation where a pandemic was unfolding in real-time (Caduff 2010: 213), she felt sufficiently secure. However, on her way home from work one day the next summer, she saw a newspaper headline about the initial narcolepsy reports.

Frankly speaking, Hell! What is this? It felt like a stranglehold! Is this really true? (Interview March 7, 2013)

Phrasing it as a stranglehold meant that the main purpose of the mass-vaccination – to protect people’s lives and health – had backfired into something completely unexpected. This serious side effect, particularly hitting young people, would risk putting a definitive stop for containment measures of that kind during influenza pandemics. The side effect could also result in a backlash for the previously so successful child immunization programme. Her wish was that the reports would not be true and that these adverse reactions would eventually turn out to have another cause than the vaccine.

Even health authorities in general were sceptic to the news and a long procedure started for the afflict-

ed young people to get their symptoms diagnosed as narcolepsy and to prove that the disease was an effect of the vaccine (Lundgren 2015b).

### **Advocating Social Justice in the Association for Narcolepsy**

Narcolepsy is a serious and debilitating chronic neurological condition, characterized by excessive daytime sleep, cataplexies, hypnagogic hallucinations, sleep paralyse and also learning disabilities, depression, obesity and disturbed metabolism. The disease is lifelong and there is no existing cure, only symptomatic relief from different kinds of medication for sleeping disorder and cataplexies, and central stimulants for sleepiness (see Lundgren 2015b).

The NA was formed in 2010 in response to the narcolepsy cases that resulted from vaccination with Pandemrix. Rather than joining the national neurological patient organization, the parents of the diseased children started a new association. The members of the association came from all over the country, with the majority from the south and middle of Sweden. The board meetings were held mostly through telephone meetings and during some family gatherings every year. As described elsewhere (Lundgren 2015b), their work can be summarized as a quest for social justice in their fight to influence researchers and decision-makers to find a cure or a treatment, in their struggles for economic compensation for the narcoleptic children, and in their work to build networks, share knowledge, and provide support to afflicted families ([www.narkolepsiforeningen.se](http://www.narkolepsiforeningen.se)). They have also played an important role for the development of narcolepsy research in Sweden. As a concerned group, through intermediary representatives, they have searched for affiliations with research collectives, and thereby broadened the scope for new scientific problematizations (cf. Callon, Lascoumes & Barthe 2011: 87). Their critical narratives about the mass-vaccination and the lack of state culpability that they experience have been enacted as performances for justice in public spaces as well as in the media and in political meetings (Lundgren 2015b). Their voices have come to represent the experiences that pre-pandemic prepared-

ness and earlier evidence-based practice deemed very unthinkable, or an unknown unknown (Kerwin 1993: 178) – a serious side effect, particularly one afflicting young people.

Although the association dates formally back to 2010, the individual narratives start from their respective vaccination decisions and will probably continue at least as long as the children who have the disease are around to tell them. In many cases, the stories go back to a time before the vaccination, when the children were well and healthy and the disease that would strike them was impossible to anticipate in their minds.

Even if the interviews show cracks in the consensus, members of the NPG and other actors often spoke clearly of the inherent qualities of health policies, of vaccination in general as a success story, and of the importance of taking responsibility for the Swedish population as a whole, as well as for the specific groups that were at risk. Some talked about their own subjective experiences of infectious diseases and about their parents' generation when vaccination as a preventive measure started to be available for everyone. Their basic trust in medicine and in medical knowledge was evident.

Not surprisingly, the parents of the narcoleptic children did not share these opinions, but instead presented different kinds of critical narratives while at the same time emphasizing the positive qualities of the association, the parents, and the children. In addition, the pandemic preparedness itself was criticized. One of the parents rather cynically commented on the NPG:

The NPG was put together in relation to the avian flu; they needed something to play with. And they found something, the swine flu virus, and they went ahead... (Interview with Cecil, December 7, 2012)

Several parents were also very critical about the arguments of solidarity and of herd immunity that had made them feel emotionally trapped. Their vaccination decisions arose both out of solidarity with those who could not take the vaccine and because they

wanted to protect their own children against a disease that was said to hit young people especially severely (Lundgren 2015b; Lundgren 2016). Ironically, it was the children, young adults and the middle-aged persons that authorities feared would get the swine flu in its most severe form. This is why they also put much emphasis on young people to vaccinate. The reports after the pandemic have shown that the incidence of laboratory-confirmed cases of the flu was highest among children, and the number of cases decreased with increasing age (Smittskyddsinstitutet 2011).

The parents' stories were about the different difficulties that the families so suddenly were faced with (Frank 2010: 28), but the stories were also largely about morals, guilt and issues of responsibility. The emotional content was apparent in all the interviews, in their different ways of presenting what Anne Hunsaker Hawkins has labelled "angry pathographies". They presented critical opinions about the cause of the disease, claiming political reasons for their illness. They were also critical regarding health professionals, politicians, and what one should expect from the state but did not receive ("the moral culpability of the state") (Hunsaker Hawkins 1999: 128; Trundle & Scott 2013: 503). Some also criticized the use of the solidarity argument and the Swedish obedience to the health politics of the WHO and the EU.

The parents (for example Peter and Cecil) both used very lively and expressive language in knitting together the story of the pandemic with this critique of politicians, authorities, and decision-makers and even of Swedish culture as a whole. Peter defined himself as always "ambivalent towards group behaviour" and contrasted this with a description of Swedish culture as an "army of people thinking the same way" (interview with Peter, May 20, 2013). Peter's narrative formulated a strong critique rooted in his opinion that authorities had overreacted to the pandemic threat and underreacted when it came to taking responsibility for the people who suffered from the effects of the bad decisions about the need for mass-vaccination. They directed their anger towards the lack of responsible action from authorities and

politicians. Peter compared this with other state institutions that he also criticized for having lost their trustworthiness. He warned about the breakdown of the welfare state while at the same time its citizens were unaware of what was happening – “we are not sceptical enough, we are too credulous and simple-minded”. He concluded by stating:

Sweden is most badly hit because we deserve it... we need to have more integrity. Every day we are manipulated... Go on and make a Hollywood movie about that! (Interview with Peter, May 20, 2013)

While speaking about narcolepsy, the parents also spoke about character, including their children’s and their own and that of other actors. Experiencing trauma, injustice, and a persistent struggle for support and compensation led to uniform descriptions of “the other”, in this case “authorities”, “politicians”, or “doctors”. The characterizations of individuals in these groups seldom escaped the stereotypes. Instead, they remained indistinct but still powerful or even dictatorial. These descriptions also shaped the self-identity of the suffering community as being made up of well-defined and worried parents and knowledge-seeking and responsible citizens.

The stories were strong, often heart-breaking, and informed about what was perceived as good or bad, about how to behave, and what is deplorable (Frank 2010: 36). The inherent morality was shown, for example, in the choice of words. “Authorities only say blah-blah”, Peter said, and he went on saying, “In ten years’ time the scandal and the violation will be obvious.” He used the word “injection-plants” (*injiceringsanläggningar*) to describe the vaccination stations and made a morbid joke saying, “it was almost like gas chambers being established within a very short time” to describe the mass-vaccination at workplaces and hospitals. He was critical of the mass-vaccination effort when the flu had already reached its peak – like “giving artificial respiration when the patient is already dead” (interview with Peter, May 20, 2013). By linking his story to a lack of state culpability,

he argued in favour of a political etiology as an explanatory cause of the side effect, interacting with the biomedical etiology no matter the definition of the latter – whether as genetic disposition, the vaccine adjuvant, or the virus itself. Expressions of cynicism and mistrust were also apparent regarding what parents considered as the bureaucratic reductionism played out in different authorities’ guidelines in handling the narcolepsy. Strict and formal guidelines were implemented in testing each individual’s disease progression to determine if there was an obligation to provide state support. The issue of the state’s lack of moral culpability ran through all interviews with the parents. In some stories, the critique contained recognition of the state’s good intentions and the unfortunate events that occurred in the process of the pandemic and the vaccination intervention. According to most parents, the remaining responsibility of the state and the politicians was to secure whatever was left of trust by giving sufficient support to the patients (cf. Trundle 2011: 887). Another kind of critique apparent in the interviews was more radical and placed authorities and politicians alongside biomedical agents as *primary causes* for the suffering. This critique was directed against the different intersecting power structures no matter whether they were derived from the state, the biomedical community, or from the corporate interests that offered or denied resources for recognition and legitimation (cf. Trundle & Scott 2013: 512).

Elsewhere, I have shown that the NA besides being critical and seeking justice also took great responsibility in collaborations with researchers, with authorities, and with politicians (Lundgren 2015b). In addition to speaking of how authorities had exaggerated the pandemic and that the side effect was caused by profit-seeking big pharma and corrupt researchers, they worked with the problems in ways characterized by reflective consciousness.

### **Enunciatory Communities – Politics and Ethics for the Future**

In 2017, eight years have passed since the pandemic outbreak and the mass-vaccination. The NA still continuously reports that they receive new mem-

bers. The Pharmaceutical Insurance (Svenska Läke-medelförsäkringen) has previously established 8 months as the time limit for documented side effects after the vaccination. In an update report in 2016, the limit was extended to 24 months.<sup>4</sup> Some researchers have even begun discussing the possibility of a “second hit” of narcolepsy if people vaccinated with Pandemrix get an infection or something else that could trigger the immune system into an auto-immune reaction (comment from a medical expert during a meeting with the NA, medical experts and public health officials at the Sahlgrenska University Hospital in Gothenburg, April 3, 2014).

My interviews together with biomedical research confirm the high rate of medical disablement that comes with the disease (Vetenskapsrådet 2012). The disease also affects social relations, sexuality, working life, economy and the general sense of well-being. The main administrative problem for the families during 2017 is the process of judging the criteria for assessing invalidity for the narcoleptics. Insurance Sweden and its Committee for Insurance of Persons has proposed an invalidity rate from 5% to 20% (which is the same as if a person has lost half or a whole thumb).<sup>5</sup> The NA is protesting against the proposal and the outcome of this issue is still unknown. This procedure is the latest of a long range of administrative, long-during painstaking processes that the families have undergone since 2009, all of which have demanded tremendous patience.

The collected ethnography from the NPG shows both the unanimousness of the strategies in upholding core categories such as solidarity and herd immunity, and some obvious doubts, dilemmas, and double bind situations. It is not easy to know if these situations would have been recognized if the side effects had not occurred. The narcolepsy side effect could very well turn out to be the strongest corroding factor for the chosen strategy of mass-vaccination – but the fact that the pandemic eventually turned out to be milder than expected was also an undermining factor. The mildness of the pandemic could be verified early in the process (cf. Caduff 2010: 213), but the side effect was only possible to observe in retrospect.

The struggles and strategies in the NA also point to dilemmas and double bind situations in their advocacy for social justice. In fact, the very creation of the association in response to a vaccine-caused disease is a consequence of the double bind described earlier: decisions derived from political imperatives about solidarity and expert authorities and medical professionals’ devotion to evidence-based policy and practice. The common-sense argument about mass-vaccination that was established was a way to combine these two concepts, although many doubts and dilemmas remained. Some members of the association clearly have gone on the offensive against medical authorities and politicians, while others have chosen a path following a strategy of collaboration with authorities and medical experts (Lundgren 2015b).

During 2014, the association formulated its statement of opinion regarding a governmental proposal on economic compensation for the afflicted patients. This instance was one example when the differences between the strategies were handled as an asset. Rather than forcing one single unanimous answer, the association arranged a meeting where parents could formulate their personal opinions, resulting in many different opinions forwarded as statements. In this particular case, the pluralism and the multi-vocal responses to the government was accepted as a strategy for the association and as evidence of individually competent and responsible parents (Field notes from a gathering with the association, September 26–28, 2014). What would be the corroding factors for the advocacy performed by the NA? One factor that was sometimes mentioned both with anger and with fear was that of using a *genetic* disposition as a prerequisite for getting narcolepsy as an argument against state culpability. The specific genotypes that are found in almost 100% of the narcoleptic patients are also common in the Swedish population (20%–30%). Still, narcolepsy is a very rare disease. Although medical research is clear about the vaccine’s role in the rise of incidence, some parents or young people have met the argument that “you would have gotten narcolepsy later on anyway”. For the advocating as-



sociation, such an argument risks undermining the collectivizing efforts that constitute their politics and instead push the patients and the disease into individualized positions (Rabinow & Rose 2006: 215).

The two enunciatory communities represent different aspects of “temporal incongruity” (Caduff 2014b: 302). As Caduff argues, pre-pandemic experts are often ruled by the so-called precautionary principle: “prepare for the worst and hope for the best”. This precaution also enables actors to “commit a leap of faith” to have trust in a particular kind of future and to intervene even if there is not a full understanding of the risks in question (Caduff 2014b: 302). Caduff concludes: “Faced with an unknown future and uncertain probability calculation, the decision to proceed and intervene becomes an eminently political one, even if it does not appear as such” (Caduff 2014b: 303).

For the NA, the temporal incongruity was of another kind. They contemplated their own decisions made while balancing supposed “known knows” (influenza could be life threatening), and maybe worrying about “unknown knows” (virus can mutate into even more dangerous forms), but not fearing “unknown unknowns” (side effects that were unthinkable) (cf. Kerwin 1993; Braun 2007: 18; Leung & Nicoll 2010). Their position afterwards, as both the subject and object of the unknown unknowns, has put them into a specific ethical position. Elsewhere, I have discussed the state of political invisibility that the families have experienced (Lundgren 2016). The side effect was unexpected, unwelcome, and almost unthinkable. The disease and talk of the disease has made the invisibility of side effects from influenza vaccination evolve into visibility. What the narcoleptic families often experience is that authorities or actors of the state re-manufacture invisibility through silence and defense or shift the focus from the health effects to economic costs and administrative problems (cf. Beck 2016: 101). This causes hidden spaces of unwanted circumstances, “a production of margins”, as Seljema and Siim have formulated it in their introductory article about silence and silencing (2016: 6). The mass-vaccination was

intended to be an act both of compassion (expressed as solidarity), and of containment (of the epidemic to reach herd immunity). However, the families experience the “*containment of themselves*, their removal into an unwanted space of societal failure and paradoxical feelings of shame and guilt” (Lundgren 2016: 1112). As I have argued, the fragmentation or muting of the side effect – also if it is placed within specific national domains – will reduce the cosmopolitical potentials for pandemic preparedness and response. Looking at it from another angle, this actual side effect could in fact enable a possibility to create strengthened reflexive awareness, which in turn can strengthen public trust regarding possible future interventions (Lundgren 2017).

Although the narratives from the two enunciatory communities run in parallel, they differ in almost every way in their histories of inception, their ways of working, and their agendas. They share one important characteristic – they are both “performing ethics in anticipation of the future” (Fortun 2001: 16). This is obvious in their ways of handling the knowledge of the past to shape and legitimate certain strategies for the future. In this articulation of ethics, solidarity and responsibility are important sense-making categories for both groups, although used in separate ways.

According to Fortun, the differences within enunciatory communities are resources rather than problems (Fortun 2001: 13). In the NPG, it is obvious that differences were a problem and a threat to the group’s strategy and activities. If the goal for the future is to create more usable tools in participatory preparatory work preceding decision-making and implementation, the NPG needs to take seriously, what Sheila Jasanoff has called the four “technologies of humility”. These would be *framing* of the problem, assessing *vulnerability*, analysing the *distribution* of technology, and *learning*, “through which societies can collectively reflect on the ambiguity of their experiences” (Jasanoff 2003: 238 ff.).

In 2017 eight years have passed, but the H1N1 pandemic is still “produced, suffered, and remembered” (cf. Fortun 2001: 6). While looking at the national implications of influenza in relation to global

biological complexes (e.g. Braun 2007; Dehner 2012) the works of Paul Rabinow and Nikolas Rose are important. Their definition of biopower, with elements such as truth discourses, strategies for intervention and modes of subjectification (Rabinow & Rose 2006: 97), is certainly applicable to the work within the National Pandemic Group. However, the argumentations put forward by Bruce Braun (2007) and Sujatha Raman and Richard Tutton (2010: 728) in defining biopolitics as something broader, that also include “a multiple politics with inequalities, opportunities, complexities, and dilemmas both individually and collectively”, require a more nuanced exploration (Raman & Tutton 2010: 730). This is important because such a standpoint makes way for collectivity and “the complex links between power-from-above and power-from-below” (2010: 728). The complex links that are discernible in the juxtaposition of these two enunciatory communities provide necessary tools for future pandemic preparedness and response. These tools are for example the different interpretations of solidarity. On the one side solidarity is an emotional actor involved in preventive measures taken from public health authorities and from politicians. On the other side, its emotional power is an argument for social justice from the NA. Another tool is the use of ethnography and reflexive dialogues as ways to explore doubts and dilemmas, that otherwise are hidden from official declarations (Lundgren 2017). If taken into account, this study would not only be contributing to some of the uncomfortable truths that Atlani-Duault and Carl Kendall asked for in their article (2009) in the early phase of the pandemic, but also to suggestions for handling them.

## Notes

- 1 I want to express my gratitude to the Marcus and Amalia Wallenberg Foundation for granting this project and to all my informants whom I have interviewed. Ethics approval was from the Regional Ethical Review Board, May 29, 2012 (dnr 2012-133-31).
- 2 <http://www.who.int/csr/disease/swineflu/phase/en/>.
- 3 [www.cochrane.org/CD004876/ARI\\_vaccines-for-preventing-seasonal-influenza-and-its-complications-in-people-aged-65-or-older](http://www.cochrane.org/CD004876/ARI_vaccines-for-preventing-seasonal-influenza-and-its-complications-in-people-aged-65-or-older).

- 4 <http://lff.se/wp-content/uploads/2016/07/Pandemrix-och-narkolepsi-uppdatering-13.pdf>.
- 5 <http://www.narkolepsiforeningen.se/assets/files/narkolepsi-tabellverk-remiss-161211.pdf>.

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