



OPEN ACCESS

# 'Rhyme or reason?' Saying no to mass vaccination: subjective re-interpretation in the context of the A(H1N1) influenza pandemic in Sweden 2009–2010

Britta Lundgren

► Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/medhum-2015-010684>)

## Correspondence to

Professor Britta Lundgren,  
Department of Culture  
and Media Studies, Umeå  
University, Umeå SE-90187,  
Sweden;  
[britta.lundgren@umu.se](mailto:britta.lundgren@umu.se)

Accepted 17 April 2015  
Published Online First  
15 June 2015

## ABSTRACT

During the swine flu pandemic of 2009–2010, all Swedish citizens were recommended to be vaccinated with the influenza vaccine Pandemrix. However, a very serious and unexpected side effect emerged during the summer of 2010: more than 200 children and young adults were diagnosed with narcolepsy after vaccination. Besides the tragic outcome for these children and their families, this adverse side effect suggests future difficulties in obtaining trust in vaccination in cases of emerging pandemics, and thus there is a growing need to find ways to understand the complexities of vaccination decision processes. This article explores written responses to a questionnaire from a Swedish folk life archive as an unconventional source for analysing vaccine decisions. The aim is to investigate how laypersons responded to and re-interpreted the message about the recommended vaccination in their answers. The answers show the confusion and complex circumstances and influences in everyday life that people reflect on when making such important decisions. The issue of confusion is traced back to the initial communications about the vaccination intervention in which both autonomy and solidarity were expected from the population. Common narratives and stories about the media or 'big pharma capitalism' are entangled with private memories, accidental coincidences and serendipitous associations. It is obvious that vaccination interventions that require compliance from large groups of people need to take into account the kind of personal experience narratives that are produced by the complex interplay of the factors described by the informants.

On 1 September 2009, a press conference was held in the Swedish government offices at Rosenbad, Stockholm. Several representatives from Swedish health authorities participated in the conference, and the Minister of Social Affairs started by expressing sympathy for the first Swedish fatality from the swine flu, the A(H1N1) pandemic. The purpose of the conference was to inform the public about the current state of the pandemic and that it was time to initiate a mass-vaccination intervention with the vaccine Pandemrix. The representative of the National Board of Health and Welfare was very clear that everybody should be vaccinated, stating that 'there is no rhyme or reason' for refraining from vaccination except for obvious medical reasons such as having an allergy to the vaccine or suffering from an autoimmune disorder.<sup>1</sup>

All Swedes were offered the vaccination free of charge. Schools, workplaces and various public venues were reorganised into preliminary centres

for vaccination, especially in the larger cities, in addition to the already existing primary healthcare centres and private vaccination centres.<sup>2–3</sup> From north to south, people queued up for the vaccination. This was sometimes associated with anxiety that there would not be enough vaccine to go around, but often the vaccination event was organised more like a community gathering with coffee and chat to make the waiting experience more pleasant. The practical and logistical preparations undertaken to persuade people to be vaccinated, including sending out letters, making announcements in different kinds of media, and providing the vaccine at ordinary visits to some healthcare units, also produced interfaces where parts of the 'vaccination chain' met at the global, national, local and personal levels.<sup>4</sup> As Leach and Fairhead described it, 'At the needle point the most global meets the most personal of worlds'.<sup>5</sup> The needle point certainly became even more crucial during a vaccination intervention such as this one, which was framed by a narrative about global solidarity as pronounced by Director General Margaret Chan in her address to the 62nd World Health Assembly on 18 May 2009: 'An influenza pandemic is an extreme expression of the need for solidarity in the face of a shared threat'.<sup>6</sup>

The mass-vaccination intervention followed logically from the pre-pandemic planning in Sweden, as it did in many other countries.<sup>3</sup> The pandemic preparedness, this 'infrastructural readiness',<sup>7–8</sup> led to processes of securitisation that involved preparedness planning, the development of operational capabilities to respond to the pandemic, and providing surveillance and monitoring systems. Kezia Barker<sup>7</sup> has argued that this securitisation itself caused a 'bureaucratic reflex' to materialise the measures envisioned in the planning documents. In Sweden, the most obvious example of this was an advance purchase agreement with a vaccine supplier and logistics plans for distributing the vaccine. When the WHO declared phase 6 of the pandemic, the built-in trigger was pulled to enact the purchase agreement.<sup>3</sup>

The uptake of the Pandemrix vaccine was high in Sweden (60%),<sup>2</sup> and the intervention was deemed a success in administrative and political terms. However, a very serious and unexpected side effect from the vaccine emerged during the summer of 2010: more than 200 children and young adults were diagnosed with narcolepsy after vaccination.<sup>9–11</sup> Besides the tragic outcome for the children and their families, this side effect suggests future difficulties with obtaining trust in vaccination in cases of



Open Access  
Scan to access more  
free content



CrossMark

To cite: Lundgren B. *Med Humanit* 2015;**41**:107–112.

emerging pandemics, and thus there is a growing need to find ways to understand the complexities of vaccination decision processes.

The aim of this article is to investigate how laypersons responded to and re-interpreted the message about the recommended vaccination in their answers to a short questionnaire from the Lund Folk Life Archive in Sweden. Particular attention is paid to the answers from those who decided not to be vaccinated and how they re-interpreted messages from the authorities and the media in their decisions. As a background, I use interviews with health officials carried out in 2013, and my aim is also to emphasise some of the values<sup>12</sup> communicated from the authorities during the pandemic. I will argue that vaccination interventions that require compliance from large groups of people need to take into account the kinds of personal experience narratives that are produced in the complex interplay of factors described by the informants. In order to generate dialogue, authorities and decision-makers must respect vernacular ways of re-interpreting governmental messages that lead to hesitance and resistance.

### VACCINATION DECISION PROCESSES

Vaccine decision processes are considered to be of utmost importance within public health measures. The increasing prevalence of hesitant attitudes since the influenza pandemic has been described in a review of the attitudes of public and healthcare professionals towards vaccination in Europe.<sup>13</sup> Discussing a strategy that includes the use of vaccination to attain herd protection, Bish *et al*<sup>14</sup> have also suggested that people should be encouraged to think of immunisation as a social norm, meaning that not complying ought to be regarded as an active decision to deviate from the norm.

Several studies investigating vaccination hesitancy or non-compliance start from the position of vaccination as a prescribed norm, and compliance as the desired outcome. The result is a taxonomy of categorisations describing reasons for non-compliance followed by suggestions to counter these arguments.<sup>13–18</sup> The categories include, for example, ‘religious reasons’, ‘free riding’, ‘divergent risk perception’,<sup>15</sup> ‘general distrust’, ‘cognitive bias’ and ‘fundamental objections’.<sup>18</sup> General distrust applies to people who are not convinced of the risks of or benefits from vaccines because they lack confidence in the science, the pharmaceutical industry, or health policies. The free riders do trust vaccination but believe it is unnecessary to be vaccinated themselves as long as others choose to do it. Cognitive bias in this context means thinking it is generally a greater risk to be vaccinated with unknown and potentially harmful consequences than the risk of acquiring the disease itself. A similar cognitive bias would be to under-rate the values of future benefits and over-rate the risk of immediate adverse effects. The fundamental objections are those derived from religious or philosophical worldviews that are antithetical to vaccination.

In the Swedish context of the swine flu, Ingeborg Björkman and Margareta A Sanner conducted interviews to explore the motives, beliefs and reactions of individuals with varying backgrounds who chose not to be vaccinated.<sup>19</sup> Five main categories of motives for vaccine rejection were identified, each containing several subcategories: ‘distinguishing between unnecessary and necessary vaccination’, ‘distrust’, ‘the idea of the natural’, ‘resisting an exaggerated safety culture’ and ‘injection fear’.

### METHOD

There are several folk life archives in Sweden dating from the beginning of the 1900s, and these document different aspects of

life, beliefs and traditions. The 123 contributors who make up the current respondents to the Lund Folk Life Archive have delivered written answers to different comprehensive questionnaires for many years.<sup>20</sup> One of the respondents has been answering questions from the archive for 40 years, and at least half have been sending responses for 20–30 years (Charlotte Hagström, e-mail communication 5 May 2014). The Swedish folklorist, Barbro Klein, has discussed the development of these archives and the role of their regular contributors. In the early 1900s, the respondents were supposed to provide facts about traditional life, but from the 1960s they were granted a more independent role as interpreters and subjective agents. This brings specific and unexpected advantages to the material. The respondents can choose voluntarily if they want to answer a questionnaire or not, and write whatever they want in connection with the questions. In many cases, the complexity and subjective associations provide rare and unexpected material that would have been hard to achieve in an interview.<sup>21</sup> The respondents are free to choose the style and length of writing, and they often use irony, satire or other stylistic approaches to strengthen their commentaries. The respondents are in a neutral position vis-à-vis future researchers using their material, and they have the freedom to express themselves in whatever way they prefer. The answers to this kind of questionnaire are a good way to gather personal experience narratives and evidence of life worlds, beliefs, rumours and legends, not as a source of factual knowledge resulting in objective proofs or truths, although some factual conclusions can sometimes be drawn.<sup>22</sup>

The specific ‘short questionnaires’ (kortfrågelistor) capture contemporary processes or events in society while they are still fresh in people’s minds. The first time a short questionnaire was used was after the attacks of 11 September 2001, in New York. In 2009 the questionnaire was about the swine flu vaccination and was entitled ‘The Swine Flu A(H1N1)’. One of the ethnologists at the archive explains why this topic was chosen:

It was about the swine flu because there was so much talk about it everywhere, and we considered it a topic in need of documentation. There was such a big buzz and it stayed in so many people’s minds. Everybody had to take a stand (to vaccinate or not?) and you did not know what would happen in the world. I remember that it was kind of like the turn of the century when everyone talked about the ‘millennium bug’ and how all the computers would go mad, elevators would stop working, etc. (Charlotte Hagström, e-mail communication, 8 April 2014).

The questionnaire was sent out in December 2009 before the side effects were reported and at a time when the message about protecting yourself and others was still dominant in the media and in public debate. The questionnaire was composed of the four themes of illness, vaccination, information and media (see online supplementary appendix).

The questionnaire was sent out to 123 persons (33 men and 90 women); 66 (53.6%) responded. The respondents were born between 1917 and 1979 (21 men and 45 women), meaning that 63.6% of the men and 50.0% of the women answered. Only five were under 50 years of age. Forty-seven of the respondents (72%) had received the vaccination, and 19 (28%) had chosen not to. The vaccine uptake for the whole of Sweden was around 60%, so this particular group had a higher uptake.

As previously mentioned, Björkman and Sanner<sup>19</sup> used interviews, whereas my study is based on written responses. The participants in Björkman and Sanner’s study varied in age, while most of the respondents in my material were older people. Both studies have a larger proportion of women than men (67% and

61%, respectively). One important difference is that Björkman and Sanner's interviews were carried out in the winter of 2010/2011 *after* the side effect of narcolepsy had become public knowledge.

The responses were sometimes handwritten, sometimes written on a manual typewriter, and sometimes word-processed. The answers gave the impression of being composed spontaneously and following the respondents' thoughts at that moment. The responses swayed back and forth, and issues from the four themes overlapped in the texts. The style of response to this short questionnaire was similar to those of folk life questionnaires in general. In many respects, the material resembles the genres that Andrea Kita discusses in her analysis of vernacular vaccination discourse—that is, contemporary legends, rumours and personal experiences.<sup>23</sup> My interpretations of the responses are based on the methodology of ethnographic cultural analysis,<sup>24</sup> which aims to elucidate meaning-makings and cognitive patterns in different sources. This means that I tried to trace the respondents' main reasons for saying no, but also how other reasons or circumstances were articulated. In analysing written responses to folk life questionnaires, close reading is important to capture the sensory and material details in the answers, as well as the representations of values and worldviews.

As a background I will also use interviews with Swedish officials who were involved in the course of the pandemic. Overall, I conducted nine interviews during 2013,<sup>i</sup> and I will use three of them in this text. These were chosen because they represent two of the standpoints that eventually caused confusion. One was about solidarity as a self-evident value for public health interventions, and the other was about free choice and personal autonomy, meaning that people should decide after having information and that solidarity should not be used as an argument. Unlike the questionnaire, the interviews were made after the reports about the side effect.

## SOLIDARITY AND/OR AUTONOMY—MESSAGES AND COUNTER MESSAGES

Besides the 'bureaucratic reflex', I suggest that the pandemic also caused an emotionally framed reaction rooted in decades of earlier Swedish welfare health politics that had consolidated trust in successful vaccination programmes. This reaction manifested itself in an articulation of solidarity in the argumentation for successful mass vaccination. Angus Dawson has argued that it is very rare that the concept of solidarity is used in public health ethics.<sup>12</sup> In Sweden, however, the solidarity argument was used both as a substantive and rather emotional value and as a procedural value in the decision to recommend vaccination for the whole population. Vaccination was emphasised to protect other people (besides oneself), and the argument implied solidarity as a core value and a building block in public health work. One official explained the solidarity argument:

I think the argument holds. I think it is one of the best arguments for vaccination in society. It is not only to protect other people, you don't know where you will end up next time, maybe you are

in the risk group yourself. So it is not only about solidarity. I think it is a rather fine argument, so to speak. (Interview with health official, 26 February 2013).

This quotation shows solidarity to be a combination of 'both cognitive and affective recognition of human interdependencies'.<sup>12</sup> One of the highest-ranking health officials in Sweden commented on the use of emotional arguments:

You really don't want to play with emotions as a governmental authority. That would only be ridiculous. I think we should be very careful not to enter an emotional level.

But, of course, the solidarity argument was a kind of emotional manipulation. That has to be said. But we did think it [solidarity] was an important strategy, so there was logic behind it. (Interview, 27 February 2013).

Turning what could be labelled emotionality into a rational and logical argument was a pragmatic way for this official to dismantle the divide between emotionality and rationality and to place solidarity safely within a framework of rationality.

One important contributing reason for claiming solidarity was that, in comparison with seasonal influenza, this flu pandemic would affect young people more severely. The National Board of Health and Welfare launched a Facebook and Twitter campaign called 'Say no to the swine flu—get vaccinated' that was particularly aimed at young people. The tacit message about solidarity was played out in the incitements to 'get vaccinated': 'I want to protect myself'; 'I want to protect others'; 'I want to prevent the spreading of the disease'.<sup>25</sup> In this context, there were no reasons listed for not being vaccinated.

The focus on the need for solidarity was combined with the concept of autonomy together with the neoliberal free-choice argument and people's attributed capacity to make well-grounded decisions.<sup>26 27</sup> This message embraces substantive values such as individual liberty and privacy. Another high-ranking health official explains:

No, that [solidarity] is an argument that we shouldn't use so much. Individuals should decide, make their own choices. What we are trying to do is to give them as much information as possible, to allow them to choose, and then you should respect that choice. (Interview, 1 March 2013).

As I will show, these somewhat contradictory messages, with solidarity, trust and reciprocity on the one hand and autonomy and privacy on the other, also created several re-interpretations and confusion.

## TO BE VACCINATED OR NOT—A PROCESS OF RE-INTERPRETATION

The main motivations from the 47 respondents who complied with vaccination were grouped into the following main reasons, showing both active demand and passive acceptance:<sup>28</sup> 'self-evident choice' (12 answers), 'solidarity reason' (11), 'being in a risk group' (9), 'fear of falling ill' (5), 'doing it although in doubt' (9) and 'advice from healthcare' (1). It is interesting that 'self-evident choice' and 'solidarity reason' made up the largest group in relation to the messages sent out from the authorities. This could be regarded as positive evidence that solidarity was a dominant motivation for vaccination, which has also been strengthened by recent research.<sup>18 29 30</sup> The motivation of 'self-evident choice' was sometimes complemented by arguments such as trust in authorities, associations with Spanish flu, and personal memories of severe illness from Asian flu and Hong Kong flu. These arguments could also be linked to tacit

<sup>i</sup>During 2013 I interviewed nine officials from the National Board of Health and Welfare, the European Centre for Disease Prevention and Control, the Medical Products Agency, the Swedish Institute for Communicable Disease Control and the Swedish Association of Local Authorities and Regions. These informants were part of one of the three groups involved in my project "Epidemics, Vaccination, and the Power of Narratives". The other two groups are patients (both swine flu patients and parents to children with narcolepsy), and health care professionals.

dimensions of solidarity. Those particularly arguing ‘solidarity reasons’ explained their choice with reference to young people being in danger, that they felt offended by people not having the vaccine, that parents were crazy when they did not get their children vaccinated, that the authorities had acted decisively, etc. There were also complementary and sometimes contrary assertions pointing to other lines of argument—that the threat was overexaggerated, that pharmaceutical companies made big profits, that there could be side effects, or that all the information caused confusion.

The sometimes contradictory and ambivalent positions in the responses also showed a certain amount of hesitancy. As Yaqub *et al*<sup>13</sup> have argued, hesitancy, defined as expressions of concern or doubt, does not necessarily imply an actual decision to reject vaccines. One example of this ambivalent position was shown as follows:

I was vaccinated although I was against it, but I felt forced to because I work with cancer patients. One thing is certain, I will not be vaccinated against the seasonal flu. It is better to squeeze out the bad than to induce it. (Woman, born 1953).

### Reasons for saying no

None of the 19 persons (12 women and 7 men) who decided not to have the vaccine said anything about belonging to or sympathising with antivaccination groups. The main reasons (table 1) for their decisions were, for the most part, clearly explained in their answers. However, it was sometimes difficult to determine what the main reason was because their motivations could be complex. Other articulated reasons for hesitancy are described in the third column of table 1.

Nobody in my or in Björkman and Sanner’s study expressed the argument usually described as ‘free riding’—that is, acknowledging risk but depending on the protection conferred by other people being vaccinated. There were many reasons for saying no, but the most common explanation that I found concerned how the threat was judged. Of these eight answers (the last row of table 1), four came from men (aged 57–88 years) and four from women (aged 53–79 years).

**Table 1** Reasons for saying no to vaccination

Main motivation	N	Also articulating:
Too long a distance to the vaccination centre	1	No vaccination for seasonal flu
Wanting to have antibodies in a ‘natural’ way	1	Pharmaceutical companies are the winners
‘Too old’, not caring for vaccination	1	
Afraid of side effects	1	
Already got the flu	1	
Doctor’s advice not to vaccinate	1	
Allergy or other illness	2	Media overexaggerated the threat
Having a cold at the time for vaccination	3	Afraid of side effects. Feeling confused. Media overexaggerated the threat
The threat is overexaggerated and there are other things to worry about	8	Not in a risk group. Very much confused and in doubt. Afraid of side effects. Pharmaceutical companies are the winners

To provide an overview of the collected material and to demonstrate the narrative evidence for the different and complicated meanings that events have for people,<sup>31</sup> I will present some of the themes in those eight answers in order to describe the process of re-interpretation and the common topics of ambiguity and confusion.

### The notion of media ‘hysteria’ articulated together with fear of side effects

I did not vaccinate. My husband had the opinion that Sweden was struck by a vaccine-hysteria through all the media attention, and this attention was not relevant. I was partly influenced by his thoughts, and partly because the danger did not seem as great at the end of December 2009, and this was also according to the media. (Woman, born 1939).

The expression ‘hysteria’ was also very common in Björkman and Sanner’s study.<sup>19</sup> The quotation above also indicates that the respondent trusted the media more when they showed less hysteria. Besides the argument about ‘media hysteria’, this woman continued to motivate her hesitancy by also mentioning a letter that was forwarded to her from a Bosnian friend. The original sender was said to be a pharmacist, and he or she was very certain that the vaccine was risky and that everyone should refrain from having such a dangerous injection. The writer of the letter claimed that he or she was not the only one to warn against the vaccine, and this had also made the woman hesitant.

Another woman also reacted to the media attention and was hesitant about the safety of the vaccine:

The media really have made too much noise, I think. Some say that we will wipe out our immune defence for years to come; that sounds very horrifying if it is true. But the truth is that it is not tested enough and we cannot know if this will have consequences. ‘Only time will tell’ will be true in this case. (Woman, born 1957).

Sanner and Björkman reported 15 individuals who also expressed the opinion that the vaccine was not tested enough and that they feared potential side effects.<sup>19</sup> Yaqub *et al*<sup>13</sup> and Bish *et al*<sup>14</sup> reported that the most commonly cited reason for general population hesitancy towards vaccination is safety concerns. Needless to say, in this particular instance with the Pandemrix vaccine, the safety concerns indeed proved to be relevant because of the side effect of narcolepsy.

Some also mentioned that they were not in the risk groups:

Neither I nor my wife took the vaccine. We found it all too hysterical and we did not feel that we belonged to the risk-groups. We were called to get the vaccine, but we didn’t bother to go. (Man, born 1931).

### Not particularly afraid of the swine flu, but addressing other fears

A woman made comparisons with other flu threats and the winter vomiting bug:

There has been too much speculation and too few facts. This made me think of the bird flu the other year. All of a sudden the media reported about dead seabirds everywhere. That these kinds of birds have always been at the beaches without causing infection among humans is well known among everyone who has homes on the coast. But there were huge headlines. Yes, sure, the threat from the swine flu is not over. I can only hope that it will be mild and maybe can be stopped by washing hands and using sanitary solutions and garlic. In fact, I am more worried about



the winter vomiting bug that is supposed to be worse this year than before. (Woman, born 1931).

This woman used her experiences, commonsense knowledge and knowledge about hygiene to come to the conclusion that the threat was overblown and that other threats might be greater.

### 'Big pharma'

I thought the whole story about the swine flu seemed like something from an American movie. Everything—from statements that one half of the Swedish population would be wiped out to rumours about the mess of corruption between WHO and the pharmaceutical companies. Time will tell, that's how it is. The shareholders earned billions. Today nothing is mentioned about the swine flu, but the money has reached its destination. (Man, born 1952).

Pharmaceutical companies were perceived as 'winners' both by those who were vaccinated and those who did not. This 'conspiratorial' thinking is very common in the antivaccination discourse.<sup>12</sup> Following Kitta,<sup>23</sup> Farmer<sup>32</sup> and Goldstein,<sup>33</sup> it might be more useful to dig further to find answers to why these concerns are expressed instead of simply labelling them as 'conspiratorial'.

A former worker at a government laboratory used his professional knowledge to distance himself from the threat and wrote about pharmaceutical companies and how media narratives are produced:

Let a journalist find something extra stunning, most of all something that fills the reader with horror, or at least makes the reader think that we live in a miserable world and that death is near. Then find a researcher, no matter how obscure, and preferably working at a pharmaceutical company, and let him comment on this. This should be done very vaguely but with some muttering about a pandemic that is going to spread worldwide and it will be worse than the Spanish flu in the 1910s when millions of people died. Then he would have to say that everybody under 5 and over 60 (and maybe those in between) will have to get vaccinated more or less immediately, otherwise it is time to order the coffin.

Then one paper after the other will blow up the story until it can travel by itself and people will rush to the GP to get a shot. In today's *The Independent* I read that the pharmaceutical companies have made millions selling vaccines, and that is the most important thing. My opinion is that media of all kinds and the pharmaceutical companies are to blame and that the authorities just agreed without realizing the harm they caused. (Man, born 1936).

This 'fabula' example with a structured narrative plot from a rather satirical writer contains all the elements needed, with events, actors, times and places to constitute a truth-value in the story. This respondent deliberately used elements from the stories he had come across to produce a 'hysterical' counter-narrative to what he regarded as the dominant narrative of producing fear.

### Who can actually tell?

One woman vacillated in her answer:

I am not vaccinated against the swine flu. My son is vaccinated, with no side effects. My daughter is not vaccinated. She claims that if you live healthily you should be able to manage without vaccination. For a while I have had pain in my shoulders, arms, and knees. Partly because of that I am hesitant about getting vaccinated, but I have not asked a doctor. And I am no wiser about

being vaccinated or not. Some have had side effects from the vaccine, which seems a bit scary, but some have been ill from the flu and some have died. It's not an easy decision. I don't think I will be vaccinated. I feel quite confused about all the reports about side effects, speculations that too much vaccine was bought and it has to be put to use, that the vaccine is not tested enough, and so on. You wonder where all the 'information' comes from. I am afraid that not even the 'experts' know for sure. (Woman, born 1932).

This woman compared herself with her son and her daughter who each had come to different conclusions. She mentioned her bodily pain, but took no advice from a doctor. She was worried about side effects and reported confusion and scepticism concerning the 'experts'. A decision to refrain from vaccination seemed easier because she did not have any trustworthy knowledge to rely on. The quotation is also an example of the so-called 'omission bias'—that is, it is easier to accept the harm caused by not doing something than to take action.<sup>14 34</sup> According to Bish *et al*,<sup>14</sup> a few studies report social influence or pressure associated with the intentions to be vaccinated. This is also shown in some of the answers—for example, one man who had an agreement with his wife not to be vaccinated, but 'unfortunately she surrendered to peer pressure in her work at the hospital' (Man, born 1952).

### CONCLUSION

Despite the global and national 'buzz', the answers to the questionnaire describe the confusion and complex circumstances and influences in everyday life that people reflected on when making the important decision about vaccination. The issue of confusion has its roots in the communication about the vaccination intervention where both autonomy and obedience were expected. But instead of this 'procedural' confusion in the communication from the authorities, the answers showed a more 'substantive' confusion regarding concrete risks and benefits and the proportionality of the threat appraisal in relation to their own health together with trust or distrust in authorities, pharmaceutical companies and the media. In the responses, different competing narratives were interwoven into the descriptions of how they came to their decision. Common narratives and stories about the media or 'big pharma capitalism' were entangled with private memories, accidental coincidences and serendipitous associations.

Before and during the pandemic, the Swedish government played with solidarity from a foundational aspect, with the key thought that solidarity requires public action.<sup>12</sup> However, the foundational aspect as a constitutive concept coincided with a voluntarist concept and a pursuit of individual choice. Most people were unable to analyse all of the premises, conditions and consequences of these discourses and found themselves in a position where both compliance and autonomous decisions were expected.

Björkman and Sanner's<sup>19</sup> conclusion was that a 'prerequisite for taking the vaccine would be that people feel involved in the vaccination enterprise to make a sensible decision'. This conclusion is not obvious from the answers to the Lund Folk Life Archive questionnaire, perhaps because many of these respondents were older. Although Björkman and Sanner do not explain what might be implied in 'feeling involved', it is clear from the written answers presented here that there are many grey areas where individuals navigate between their own beliefs, social pressures, previous experiences, bodily sensations, rumours, health proclamations, media messages and authorities' advice. If 'feeling involved' were interpreted as an acknowledgment of the complexities that people experience, the road to

'sensible' autonomous decisions would probably be easier travelled.

My results resonate with Blume *et al*<sup>4</sup> in their discussion about how decision processes at different points of the vaccination chain emerge from complex interactions and re-interpretations between actors and arguments. The written answers from the respondents fit well with the review by Yaqub *et al*, who state that 'each individual has his or her own mix of risk factors and vulnerabilities'. They stress that mainstream vaccination literature and physicians need to 'take time to familiarise themselves with personal narratives' to prevent people from feeling that the information they receive is confusing or irrelevant to their own concerns.<sup>13 16</sup> The answers in the questionnaire provide ways of understanding what people are afraid of, how they experience living in a 'normal' condition of health and illness, and if, why and when they feel the need for authorities to intervene. In the light of their own experiences, people perceived media reports as exaggerated and the pharmaceutical companies as profit-maximising. The recommendations from authorities were judged against what friends, relatives and colleagues said and did, and also what their own nurses and general practitioners expressed.

Following Biehl and Petryna<sup>35</sup> together with Harper and Parker,<sup>36</sup> these kinds of narratives should not be dismissed as 'anecdotal, non-generalisable, and inherently impractical'. This also goes for Briggs and Nichter's discussion about biocommunicability and the 'pragmatics of biopolitical communication'.<sup>37</sup>

In their report 'Science, H1N1 and society: towards a more pandemic-resilient society',<sup>38</sup> the HEG Expert Group has pointed out the general lack of knowledge from humanities and social sciences in pandemic preparedness: 'Current knowledge about public perceptions, citizens' preferred sources of information and also the impact of health professionals were not taken into consideration'. For the future, the sort of data I have discussed in this article, created by disciplines such as ethnology and folkloristics, provide an unexpected and fruitful source of information for policy-makers to draw on when discussing prerequisites for vaccination—not only when searching for rhyme or reason but also for re-interpretation of trust and fears.

**Funding** The article is part of the project 'Epidemics, Vaccination, and the Power of Narratives' funded by the Marcus and Amalia Wallenberg Foundation in Sweden.

**Competing interests** None declared.

**Ethics approval** Ethics approval was from the Regional Ethics Review Board, 29 May 2012 (Dnr 2012-133-31).

**Provenance and peer review** Not commissioned; internally peer reviewed.

**Open Access** This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

## REFERENCES

- 1 Presskonferens om svininfluensan. (Press conference about the Swine flu) Svenska Dagbladet. 1 Sep 2009. [http://www.svd.se/nyheter/inrikes/presskonferens-om-svininfluensan\\_3448513.svd](http://www.svd.se/nyheter/inrikes/presskonferens-om-svininfluensan_3448513.svd) (accessed 10 May 2014).
- 2 Smittskyddsinstitutet. *The Influenza A(H1N1)2009 Pandemic in Sweden, 2009–2010. A Report from the Swedish WHO National Influenza Centre*. 2011;1–43, at p. 11–34.
- 3 Socialstyrelsen. *A(H1N1) 2009 An evaluation of Sweden's preparations for and management of the pandemic*. 2011.
- 4 Blume S, Roalkvam S, McNeill D. Concepts and approaches. In: Roalkvam S, McNeill D, Blume S, eds. *Protecting the world's children. Immunisation policies and practices*. Oxford University Press, 2013;1–233, at p. 41.
- 5 Leach M, Fairhead J. *Vaccine anxieties. Global science, child health and society*. London: Earthscan, 2007;1–209, at p. 2.
- 6 Dry S, Leach M. *Epidemics. Science, governance and social justice*. London: Earthscan, 2010, at p. 1.
- 7 Barker K. Influenza preparedness and the bureaucratic reflex: anticipating and generating the 2009 H1N1 event. *Health Place* 2012;18:701–9, at p. 703.
- 8 Lakoff A. From population to vital system. National security and the changing object of public health. In: Lakoff A, Collier SJ, eds. *Biosecurity interventions. Global health and security in question*. New York: Columbia University Press, 2008;33–60.
- 9 Medical Products Agency. <http://www.lakemedelsverket.se/Alla-nyheter/NYHETER-2011/Rapport-fran-fallinventeringsstudie-om-Pandemrix-och-narkolepsi/>
- 10 Wijnans L, Lecomte C, de Vries C, *et al*. The incidence of narcolepsy in Europe: Before, during, and after the influenza A(H1N1)pdm09 pandemic and vaccination campaigns. *Vaccine* 2013;31:1246–54.
- 11 Lundgren B. Narrating narcolepsy—centering a side effect. *Med Anthropol* 2015;34:150–65.
- 12 Dawson A, Jennings B. The place of solidarity in public health ethics. *Public Health Review* 2012;34:65–79, at p. 70.
- 13 Yaqub O, Castle-Clarke S, Sevdalis N, *et al*. Attitudes to vaccination: a critical review. *Soc Sci Med* 2014;112:1–11.
- 14 Bish A, Yardley L, Nicoll A, *et al*. Factors associated with uptake of vaccination against pandemic influenza: A systematic review. *Vaccine* 2011;29:6472–84, at p.6482.
- 15 Asveld L. Mass-vaccination programmes and the value of respect for autonomy. *Bioethics* 2008;22:245–57, at p. 247–57.
- 16 Velan B, Kaplan G, Ziv A, *et al*. Major motives in non-acceptance of A/H1N1 flu vaccination: the weight of rational assessment. *Vaccine* 2011;29:1173–9.
- 17 Poland GA. The 2009–2010 influenza pandemic: effects on pandemic and seasonal vaccine uptake and lessons learned for seasonal vaccination campaigns. *Vaccine* 2010;28:5:D3–13.
- 18 d'Alessandro HD, Launay O, Bassinet L, *et al*. Determinants of refusal of A/H1N1 pandemic vaccination in a high risk population: a qualitative approach. *PLoS One* 2012;7:e34054.
- 19 Björkman I, Sanner MA. The Swedish A(H1N1) vaccination campaign—Why did not all Swedes take the vaccination? *Health Policy* 2013;109:63–70.
- 20 Salomonsson A. Folkliksarkivet och frågelistorna. In: Nilsson BG, Waldetoft D, Westergren C, eds. *Frågelist och berättarglädje. Om frågelistor som forskningsmetod och folklig genre*. Stockholm: Nordiska museets förlag, 2003;89–100, at p. 89.
- 21 Klein B. Nm 223. Personlig hygien. Reflektioner kring frågelistor, meddelarsvar och vetenskap. In: Nilsson BG, Waldetoft D, Westergren C, eds. *Frågelist och berättarglädje. Om frågelistor som forskningsmetod och folklig genre*. Stockholm: Nordiska museets förlag, 2003;69–88.
- 22 Waldetoft D. Vad vill vi med våra frågelistor? In: Nilsson BG, Waldetoft D, Westergren C, eds. *Frågelist och berättarglädje. Om frågelistor som forskningsmetod och folklig genre*. Stockholm: Nordiska museets förlag, 2003;9–16, at p. 12.
- 23 Kitta A. *Vaccinations and Public Concern in History. Legend, Rumor, and Risk Perception*. New York and London: Routledge Studies in the History of Science, Technology, and Medicine, 2012;1–172, at p.24, 82.
- 24 Ehn B, Löfgren O. *Kulturanalytiska verktyg*. Malmö: Gleerups, 2012.
- 25 Socialstyrelsen. *Influensa A(H1N1) 2009: Delrapporterna från utvärdering av förberedelser och hantering av pandemin*. Stockholm, 2011.
- 26 Fjell TI. Fri tvang eller tvingande frihet—eller begge deler? *Tidsskrift for kulturforskning* 2005;4:41–54.
- 27 Vallgård S. Appeals to autonomy and obedience: continuity and change in governing technologies in danish and swedish health promotion. *Med Hist* 2011;55:27–40.
- 28 Nichter M. Vaccinations in the third world: a consideration of community demand. *Soc Sci Med* 1995;41:617–32, at p. 617.
- 29 Rönerstrand B. Social capital and immunization against the 2009 A(H1N1) pandemic in Sweden. *Scand J Public Health* 2013;41:853–9.
- 30 Shim E, Chapman B, Townsend JP, *et al*. The influence of altruism on influenza vaccination decisions. *J R Soc Interface* 2012;9:2234–43.
- 31 Polkinghorne DE. Validity issues in narrative research. *Qualitative Inquiry* 2007;13:471.
- 32 Farmer P. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley: University of California Press, 1992, at p. 235.
- 33 Goldstein DE. *Once Upon a Virus. AIDS Legends and Vernacular Risk Perception*. Utah State University Press, 2004;ix–210, at p. 53–54.
- 34 Luyten J, Desmet P, Dorgali V, *et al*. Kicking against the pricks: vaccine sceptics have a different social orientation. *Eur J Public Health* 2013;24:310–4, at p. 310.
- 35 Biehl J, Petryna A, eds. *When people come first. Critical studies in global health*. Princeton and Oxford: Princeton University Press, 2013;1–446, at p. 20.
- 36 Harper I, Parker M. The politics and anti-politics of infectious disease control. *Med Anthropol* 2014;33:198–205, at p. 203.
- 37 Briggs CL, Nichter M. Biocommunicability and the Biopolitics of Pandemic Threats. *Med Anthropol* 2009;28:189–98, at p. 191.
- 38 The European Commission's Directorate for Science, Economy and Society decided in mid 2010 to set up an Expert Group on Science, H1N1 and Society ('H1N1 Expert Group', or 'HEG') in order to clarify the 'Science in Society' (Sis)-related research questions raised by the H1N1 pandemic and associated crisis management. Report "Science H1N1 and Society. Towards a more pandemic resilient society", 2011, at p. 5. [http://ec.europa.eu/research/swafs/pdf/pub\\_archive/sis-heg-final-report\\_en.pdf](http://ec.europa.eu/research/swafs/pdf/pub_archive/sis-heg-final-report_en.pdf)

## APPENDIX

Short questionnaire (*Kortfrågelista 7*) Folk life Archive at Lund's University, Sweden

- 1) Illness. Did you fall ill from the flu or did somebody you know? What were the symptoms? For how long time were you ill?
- 2) Vaccination. Did you vaccinate against the flu? Why/why not? Did you get a specific call followed by sub-questions or did you contact a vaccination centre yourself? Did the other members of the family also take the vaccination? Do you know if your friends and neighbours were also vaccinated? Did you give a lot of thought to the issue of vaccination? What made you decide?
- 3) Information. Do you remember the first time you heard about the flu? How did you get the information about the flu and about the vaccination? From newspapers, radio, TV, internet, your work, the school, or other? What kind of information did you get? Do you think you had enough information?
- 4) Media. What is true or false, right or wrong, fact or fiction is not always obvious. In the media there have been mixed messages about the reports about lack of vaccine and dangers from the vaccine. Those who have got the flu have talked about the flu, other people have created or spread jokes. Is there something you specifically remember? Something outrageous, thought-provoking, interesting, funny, peculiar, terrible or stupid?