

# Health policy and the media: The case of HPV-vaccination

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## **Abstract**

The effects of media coverage on health policy is a poorly developed field, and solidly documented behavioral responses in the wake of media reporting on adverse vaccination effects and reactions by the health authorities are rare. The present article is probably the first to provide documentation for a wide spectrum of behavioral responses. Within a framework of agenda setting by the press the case of HPV-vaccination and the debate about allegedly serious adverse effects associated with HPV vaccination is explored within a Danish and a multi country setting. Particular attention is paid to the increasingly important role of the social media. They are used to advantage by victims of serious adverse effects and anti-vaccination groups, and the authorities have had a hard time trying to cope with this media channel, in part because the social media persist – within a direct access and unedited framework - in claiming a causal relationship between symptom complexes like POTS (postural Orthostatic Tachycardia Syndrome) and CRPS (complex Regional Pain Syndrome) and vaccination despite consistent scientific evidence to the contrary. Danish data is used to document in a causal-like sense that the uptake of HPV-vaccination dropped dramatically following TV coverage, newspaper articles and social media reporting on serious adverse effects like POTS using a select number of personalized cases that invoked strong feelings and emotions. It is also shown how reported adverse effects and economic compensation claims spiked with the media coverage. The discussion section is used to reflect on the role of the media in health reporting and lessons learned for communication.

*Key words:* Media, agenda setting, HPV, adverse effects, health journalism

*JEL Codes:* I12 I18

## **1. Introduction**

Media reports on health care often have a major impact in terms of agenda setting for current health policy debate. The debate may lead to behavioral changes like uptake of for instance HPV-vaccination along with reactions by political and health authorities in view of allegedly serious adverse effects of HPV-vaccination.

Commonly cited media effects on their audience are: informing, agenda-setting, framing, priming, and persuasion. Media is here meant to be printed, airborne and social media, although our understanding of the latter still is incomplete and harder to document but increasingly important.

There is no doubt that the media influence health policy and public opinion on health issues. There is abundant evidence that news media influence public perception about the salience of issues, the severity of public health threats, and also affect community health behaviors. Also, there is no doubt that an important success criterion for most media is the setting of the agenda for discussion of a given topic. It is an open question whether mass media determine or codetermine the political agenda and the public's agenda? Available answers are mixed and contradictory.

Reporting on health care in the media raises a number of issues (1-3) apart from the ones above.

Health professionals focus on professional accuracy of the reporting realizing of course that journalists are not scientists and are not writing for a scientific but a lay audience. Journalists make use of simplifications – running the risk of distorting the message and hence misinforming the public and possibly inadvertently influencing health related behavior. Many journalists do not distinguish clearly between apparent association and causality – an issue that becomes important in this article. Secondly, many journalists reporting on health are not specialized in this field and hence may overlook finer details and also base their reporting primarily on criteria of newsworthiness like human interest by using individualized case stories, conflict like disagreement on strength of evidence, novelty or rarity like rare adverse events. Thirdly, the social media may be

the most important source of health information for the general public despite claims of being the source of misinformation due to unhindered and usually unedited access by interested parties. With the advent of for instance YouTube the social media are becoming important sources of information. A recent summary of YouTube videos on vaccines showed that 66% of them discouraged the use of vaccination (4). In a 2012 (5) review of 172 YouTube videos on HPV, the majority of the videos were negative in tone, disapproving of the HPV vaccine.

The uptake of human papillomavirus (HPV) vaccination decreased dramatically in Japan after extensive news coverage of serious adverse vaccine events (6-10). Vaccination rates plummeted from around 70% to only 1%. HPV vaccinations had been included in the Japanese vaccination program in April 2013, but the Ministry of Health withdrew the recommendation already in June 2013, and there is still no government recommendation. It is commonly believed that the news coverage of adverse events led to the withdrawal of the recommendation. An observer noted that a Facebook group - Cervical Cancer Vaccine Sufferers Organization – had had considerable impact (7) – a group with only 400 members. It was also possible to trace the effect of the Japanese decision in many other countries (10). Social media increasingly have a global diffusion effect.

Similarly, a 50 minutes long Irish TV-documentary “Cervical Cancer Vaccine - Is it safe?”, aired on December 14, 2015 led to a decline in HPV-uptake from 89.7% to 55.8%. The Irish documentary included references to the Danish documentary from Mach same year. The lobby group Regret and its homepage (11) and Facebook profile played a prominent role.

The aims of this study are to present and document the effects of Danish media reporting on the uptake of HPV vaccination, reporting of adverse events and filing of compensation claims following media coverage and subsequent reactions by political and health authorities along with a

general discussion of the role of media reporting on health issues with special focus on the social media.

A background section on HPV vaccination and evidence on serious adverse effect is followed by Danish media coverage of allegedly serious adverse events. Next comes a section where the effects of the media coverage is documented followed by fairly long discussion section and as always ending with conclusions.

### **Background: HPV-vaccination and possible adverse effects**

Human papillomavirus (HPV) virus of type 16 and 18 are the most frequent causes of cervical cancer – responsible for about 70% of the cases of cervical cancer. Current HPV vaccines are designed to protect against HPV 16 and 18; the quadrivalent vaccine also protects against low-risk genotypes 6 and 11(12). Today nine-valent vaccines are available protecting against 90% of cases of cervical cancer. In Denmark about 100 women die from cervical cancer every year.

As of mid 2016 - 10 years after licensing - 74 countries reported that the HPV vaccine is on the national vaccination schedule or reimburse vaccine (13, 14) . This represents more than one third of countries in the world. More than 270 mio. doses of vaccines have been distributed.

Bonnani et al (15) and numerous other studies (14, 16-18) note that pre- and post-licensure studies confirm that HPV vaccines are generally safe and well-tolerated. Site injections symptoms are the most common adverse events (AEs) reported, and pain is the most frequently referred local symptom. Serious AEs are rare and not associated with severe sequelae. No vaccine-related deaths have occurred although it is claimed to be the case by vaccination opponents (19).

Some AE syndromes discussed in connection with HPV vaccination are demyelinating diseases, Complex Regional Pain Syndrome, CRPS, or Postural Orthostatic Tachycardia Syndrome, POTS.

POTS is a condition in which a change from lying to standing causes for instance dizziness. CRPS is a long term pain syndrome that often worsens with time. It is characterized by severe pain out of proportion to the original injury.

POTS and CRPS have been known long before the introduction of the HPV vaccines. The European Medicines Agency, EMA, notes that the majority of POTS cases have been reported from one clinic in Denmark (20). These syndromes can occur in the general non-vaccinated population, and it was therefore important to undertake further review to determine whether the number of cases reported with the HPV vaccines is greater than would ordinarily be expected in the absence of vaccination and whether the currently available data supports a causal association with HPV vaccines. EMA found this not to be the case and overall conclusion was that taking into account the totality of the available information EMA's Pharmacovigilance Risk Assessment Committee concluded that the evidence did not support that HPV vaccines (Cervarix, Gardasil, Gardasil 9, Silgard) cause CRPS or POTS (20).

WHO's independent Global Advisory Committee on Vaccine Safety, GACVS, provides independent, authoritative, scientific advice to WHO on vaccine safety issues. It has followed HPV safety closely and concluded mid 2017 (21) that there is still no evidence to suggest a causal association between HPV vaccine and CRPS, POTS or the diverse symptoms that include pain and motor dysfunction. With large population level data from several countries, the Committee saw no new evidence for a causal association between HPV vaccine and those conditions.

In 2017 the WHO commissioned a systematic review of serious adverse events (SAEs) following HPV vaccines. Data for 73 697 individuals were reviewed. For all outcomes, the evidence from randomized controlled trials was supported by good quality cohort studies, with

no difference in rates of selected SAEs between exposed and unexposed to HPV vaccine observed.

GACVS notes(21) that there are now accumulated safety studies that include several million persons and which compare the risks for a wide range of health outcomes in vaccinated and unvaccinated subjects. However, despite the extensive safety data available, attention has continued to focus on spurious case reports and what GACVS calls unsubstantiated allegations. However, despite the clear rejection of a causal relationship to HPV-vaccination debate continues among the victims of the syndromes and a few doctors. Fear of possible serious AEs and frustration over lack of effective treatment for POTS and CRPS among the affected girls dominate the discussion of HPV-vaccination, not the beneficial effects. In Denmark it caused considerable dissatisfaction among the affected teenagers and women that their illness by doctors was categorized as a functional disorder. This is a medical condition that impairs the normal function of a bodily process, but where every part of the body looks completely normal under examination, dissection or even under a microscope. It stands in contrast to a structural disorder (in which some part of the body can be seen to be abnormal) or a psychosomatic disorder (in which symptoms are caused by psychological or psychiatric illness).

Other health professionals (22, 23) talk about mass psychogenic illness: “When vaccines are administered to groups, the physical reactions of the recipients may be similar, causing a form of mass reaction, the mechanism for which is the same as that for mass reactions from other causes. These phenomena have been categorized as mass psychogenic illness (MPI), and have been defined as the collective occurrence of a constellation of symptoms suggestive of organic illness but without an identified cause in a group of people with shared beliefs about the cause of the symptom(s)”(24).



Recent Danish research (25) on the adversely affected girls in a matched study showed that before receiving the first HPV vaccination, females who suspected adverse reactions have symptoms and a health care-seeking pattern that is different from the matched population concluding that pre-vaccination morbidity should be taken into account in the evaluation of vaccine safety signals. In another matched-case-control study (26) the conclusion was that women referred to HPV centers because of suspected adverse events after vaccination more often had preexisting psychiatric conditions, psychological symptoms or frequent GP attendance prior to HPV vaccination.

Other postulated adverse effects have also been investigated. A study with nationwide coverage of Denmark and Sweden (18) showed that HPV vaccination was not associated with the development of multiple sclerosis or other demyelinating diseases and hence did not support concerns about a causal relationship between HPV vaccination and demyelinating diseases. In another matched study (27) it was found that HPV vaccination during pregnancy was not associated with a significantly higher risk of adverse pregnancy outcomes than no such exposure.

### **The Danish media coverage of allegedly adverse events:**

Media-coverage of possible serious adverse effects of HPV-vaccination started during the first quarter of 2013 in the leading national newspaper, Politiken.. During summer and autumn the debate spread facilitated by the social media that had a double role: Passing on news coverage in the traditional media and the build-up of Facebook groups – both of victims and more or less passionate opponents of vaccination in general. TV2, one of the two national Danish TV channels, carried some news spots, and in parliament there were questions to the minister of health and a so-called open parliamentary consultation with the minister of health (open to press and the public). During

the summer of 2013 the Danish Cancer Society reported contacts from GPs who reported that due to critical postings on Facebook teenagers were opting out of the vaccination program.

In Denmark there is a national media-database, Infomedia - the leading Danish provider of Media Intelligence(28) where all media (paper, airborne, web, except social media) report their content on a daily basis. Therefore, it is possible to track media coverage. The number of news pieces during 2013 was a total of 809. However, not unique pieces, e.g. dailies also post many of their stories on their website and are included in the count, but this just increases the reach of the media.

The news coverage on the TV2 national TV-channel subsequently was criticized by the channel's internal 'ombudsman' for being one sided in presenting only the patient perspective of a young woman giving the impression that adverse side effects were frequent, well documented and unambiguously linked to vaccination (29) and not questioning this, including presenting the beneficial effects of vaccination. Similarly, the readers' ombudsman at Politikenoted a lack of balance in two articles that focused on HPV-vaccination. In both cases the feelings and emotional aspects got the upper hand.

TV2 had introduced a new strategy urging viewer to contact the channel with their personal stories (29) – and the above news spot was the result of this strategy. The ombudsman cautioned that in such cases their stories needed careful scrutiny.

Via Facebook about 30 adversely affected HPV-vaccinated teen-girls organized a meeting in September 2013 to discuss a strategy for developing a wake-up call to the health authorities hence documenting the community-building dimension of Facebook. TV2 also reported from this meeting.

However, in March 2015 a 36 minutes long TV2 documentary about 'The Vaccinated Girls – Sick and Betrayed' (30) became a turning event media wise. It created considerable public and

political attention with immediate strong negative impact on the vaccination take up, figure 1.

Politically the chairperson of the Parliament's health committee called for a halt to the vaccination program (31) however, changing her mind two weeks later (32) after heavy criticism and a hearing in Parliament, where the Danish Health Authority confirmed that possible adverse effects were followed very closely.

In terms of number of TV-viewers the documentary was not among top 20 of the week, but it created debate in the media and intensive reaction on the social media. According to Infomedia 1009 occurrences of HPV side effects stories were registered during 2015, disregarding the social media. Google Trend showed a clear spike during March 2015 in Google searches.

A closed Facebook page set up for suspected victims of adverse reactions to HPV-vaccine reported having 398 members before this documentary was aired (33). Less than two weeks later membership had increased to 938.

A total of 47 girls with what they considered serious adverse events caused by HPV-vaccination were involved in the documentary and provided the backdrop for assertions by two hospital doctors about what they considered to be rare but serious adverse side effects (POTS) although they were cautious not to claim a causal relationship with the HPV-vaccination and expressed support for the HPV-vaccination, but wanted more research on the causal mechanism and more therapeutic support for the girls. TV2 had found the girls by contacting various HPV-related groups on the social media and others contacted TV2 after having heard about the initiative (34) through the social media, and TV2 brought them all together including a panorama group photo of the 47 girls.

The perspective of the documentary was mainly that of the girls – “the victims vs the uncomprehending authorities” is a well-known media setup. The girls all believed that the cause of their symptoms, typically POTS, were caused by the HPV-vaccination. The health authorities essentially were accused of abandoning the girls in that they did not take the girls complaints seriously and could not offer effective treatment. TV2 had gained access to documents in The Danish Health Authority by the using the law about right to document access and found the material lacking, for instance the correspondence with one of the two doctors who raised a number of issues around adverse effects was not included and by implicit implications left the viewers with a feeling of a collusion.

A case based approach was used. The documentary showed how a girl and her mother travelled to London for treatment by an English doctor implicitly indicating that treatment was available, but not in Denmark. The girl’s family paid up to 120,000 DKR (about 16,000 Euros). Not a word about the documented effect of treatment. The English doctor was a pioneer of Ecological medicine — a systems approach to health/Detox therapy - with a Harley Street address at the time. No relevant published articles from his hand were identified by searching Pubmed in connection with this article. The TV2 documentary reported that the girl subsequently thought that her condition improved.

The documentary was nominated for the Danish equivalent of the Pulitzer Price in journalism (Cavling-Prisen), but was subsequently heavily criticized for misrepresenting the issues by journalists and doctors and did not receive the coveted prize. The criticism was essentially that viewers were left with the impression of a (causal) relationship between vaccination and serious adverse effects that to this day as noted above has not been demonstrated. The criticism has continued to this day with TV2 continuing to insist that the coverage was balanced but concede that unintentionally it might have led to a decrease in vaccination uptake (35).

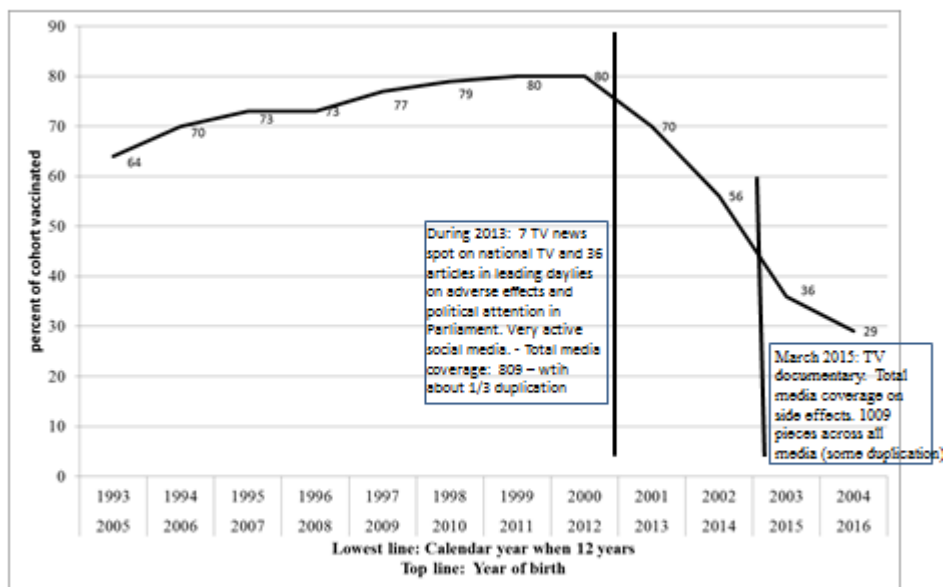
The other national Danish national TV channel, DR2, in April 2016 in a series on complementary medicine looked at complementary treatment of a single woman who was clearly seriously physically impaired allegedly due to HPV-vaccination (36). It is available on YouTube. The question was: Does complementary treatment have an effect? Based on 4 months treatment by a body therapist it was visually shown that the woman's condition improved from crawling around in her apartment or using a wheelchair at the beginning to using crutches at the end of the treatment – and by implication leaving viewers with the impression then that this treatment was an effective option, and no cautioning about drawing conclusions from one case. However, throughout the documentary there was careful phrasing about no causality between vaccination and the physical impairment. The journalist who made the documentary did not have previous experience covering health. The format was the wellknown: a case calling on empathy and compassion, pro and con experts on vaccination adverse effects, and apparent balanced reporting. However, by giving equal weight to both views despite the fact that established scientific evidence was totally lacking on the effectiveness of treatment, left an impression of impartiality in reporting, but in essence led to a misrepresentation of the issues. .

### **Effects of media coverage**

The figures and the table below clearly document the behavioral reaction to the media coverage of possible serious side effects. It does not leave much doubt about a causal relationship between media reporting and effects.

The first effect was a dramatic decline in the uptake of vaccination, figure 1. A drop from a high of 80% in 2012-2013 to 29% in 2016. Hence, the important herd immunity effect in connection with contagious diseases totally disappeared. In the figure the extent and nature of media coverage is shown for 2013 and 2015 respectively.

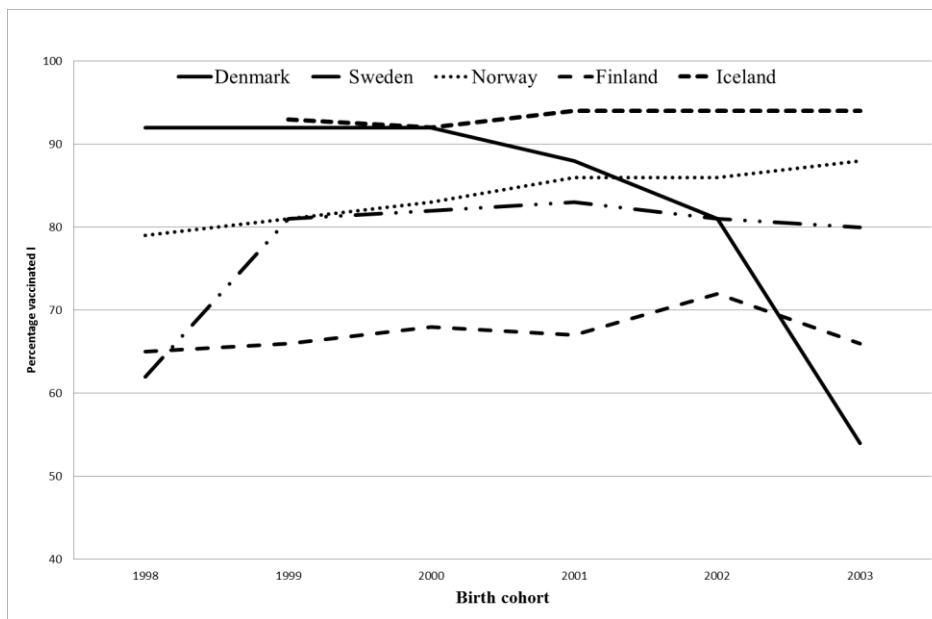
**Figure 1: Development of percentage vaccinated and media coverage**



Note: Source: Statens Serum Institut (37) and Infomedia (media database). Note: In October 2016, the calculation method used to establish the HPV vaccination coverage was changed as it needed to take into account that girls may be fully protected after either a two-dose or a three-dose programme.

There are no other significant events around 2013 and 2015 that possibly could have triggered this dramatic decline. To buttress this consider figure 2 with uptake data from the other Scandinavian countries providing a quasi-experimental setting. It clearly demonstrates that the Danish development is unique. In the other Scandinavian countries there has not been as much HPV-related debate as in Denmark (38). Even a 20 minutes long Swedish documentary from April 21 2013 (39) – ‘Cold facts’ - cannot be seen to have influenced the Swedish HPV-uptake in figure 2 eventhough the program caused some debate and criticism (40). Two cases of serious adverse effects were shown in the documentary: On American, one Swedish (Guillain-Barré syndrome)

**Figure 2: HPV uptake in the Scandinavian countries**



Source: Statens Serum Institut (41)

HPV-vaccination became part of the Danish free child vaccination program in 2009. It is offered to girls between 12 and 18 years of age (two doses). To date more than 600,000 girls have been vaccinated. 0.4% (N=2403) have reported adverse effect believed to be caused by the vaccination. Less than 0,2% report what is classified as serious adverse effects, table 1.

**Table 1: Officially registered adverse events and file compensation claims**

Kolonne1	2009	2010	2011	2012	2013	2014	2015	2016	2017
Not serious a	263	60	35	78	333	134	347	125	n.a.
Serious adver	25	6	8	18	177	91	475	182	n.a.
Filed comper	4	3	2	1	57	42	105	95	20

Source: The Danish Medicines Agency and The Patient Compensation Association (by year of registration)

Table 1 shows a clear pattern: The number of filed complaints about adverse effects spiked in 2013 and 2015 – far more than what one would expect by chance. It is of interested to note that the balance between not serious and serious adverse effects changed in 2015 and may have been influenced by the public debate. There is no evidence that the incidence of serious adverse events should have changed, leaving a changed classification as a likely explanation.

In the third line of table 1 yet another aspect of the AE-issue is presented, namely filed compensations claims with the Patient Compensation Association that administers and decides the Danish no-fault compensation scheme for patients harmed in connection with treatment. However, due to the lack of a causal relationship between HPV vaccination POTS and CRPS no compensation has been granted.

### **Reactions by the authorities**

The Danish Health Authority in 2014 asked the Syncope Centre at a Copenhagen hospital (Syncope: temporary loss of consciousness) where the two doctors from the March 2015 documentary worked to make a report about the clinical aspects of POTS. The Health Authority sent the report to the European Medicines Agency, EMA, along with additional information. In December 2014 EMA published a new assessment noting that a causal relationship between the dizziness and fatigue syndrome, Postural Orthostatic Tachycardia Syndrome (POTS) and Gardasil can neither be confirmed nor denied (42). This message was used in TV2 documentary leaving the question of causality hanging in the air. The EU's group of pharmacovigilance experts had made a new assessment of the vaccine and still considered it to be safe and that the benefits outweighed the risks. However, available material on reported adverse effects around 2014/2015 showed that the Health Authority at that time did not unambiguously claim that a causal relationship did not exist, but used cautious language like that a possible causal relationship could not be ruled out in connection with comments on very few, 6, of the 158 reported serious adverse effects from the second quarter of 2015 of which 3 were related POTS (43).

In the wake of the TV documentary the Danish Health and Medicines Authority in July 2015 asked the European Commission to request EMA to give its opinion on whether there is evidence of a causal association between HPV vaccines and CRPS and/or POTS, and if available information



may require updates to the advice to healthcare professionals and patients, including changes to product information or other regulatory measures on the marketing authorizations concerned. The report was available early November same year and concluded (44) that overall – in contrast to the 2014-report - available data did not provide support for a causal association between HPV vaccines and POTS, CRPS. The report triggered a complaint to EMA on procedural grounds (45) co-signed by among others a Danish member of the European Parliament and one of the doctors involved in the TV documentary, followed by an appeal to the EU Ombudsman after rejection by EMA (45). However, the criticism was refuted both by EMA (46) and the Ombudsman.

One of the recurring complaints from the girls was and is that their problems were not taken seriously and no treatments were available. Therefore, in an effort to respond in an appropriate manner the five Danish healthcare regions established a single point of hospital entry - “one entrance” - in each of the regions to accept and examine anyone suspected of having a negative reaction to vaccination. The language in Danish Health Authority’s guidance about establishment of from the new centers was guarded: ‘unexplained symptoms risen in a timewise relation to HPV-vaccination’ (47) in the unending struggle to stress that no causality had been established. The centers had been promised already mid 2014, but were not formally announced by the regions until one day before the airing of the documentary – a coincidence, the Danish Regions claimed.

Two incidents are of interest. First, a working group was established to develop the above mentioned guidance. The CEO of The Danish Association of the Physically Disabled was not a member of the working group and tried to gain entry by threatening the CEO of the Danish Health Authority to discredit the vaccination program (48). The Danish Association of the Physically Disabled in 2015 had established a homepage, HPV-update.com, to support the girls and teenagers

with symptoms from HPV-vaccinations where the TV2 documentary is available. The editor of a bi-annual magazine with a tendency to vaccine negative reporting is the mother of a vaccinated girl with symptoms.

Secondly, a newspaper article (49) reported about considerable disagreement at a meeting of the doctors from the designated 'one entrance' centers documenting considerable perplexity about what to do as regards treatment of the symptom complex because the doctors could not agree on identification of somatic causes of the syndromes presented by the girls pointing towards functional diseases with no clearly established treatment.

Funds for research in adverse effects were also made available. For instance, government approved 1 million euros in 2015, and the Medical Research Council and other have also funded research on a possible causal relationship to serious adverse effects. This has resulted in much focused research using case-control matching of adversely and non-adversely affected women (18, 25-27). However, all studies come up without demonstrating a causal effect.

## **Discussion**

There is no doubt that the media, in particular TV and the social media, for at least a couple of years managed to set the public and political agenda for the HPV discussion in Denmark if we by agenda setting understand the classic definition of a strong correlation between the emphasis that the media place on certain issues, e.g., based on relative placement or amount of coverage, and the importance attributed to these issues by the media audience, or in one sentence: the ability to influence the salience of topics on the public and political agenda (50).

There is also no doubt that the 2015-TV2 documentary aimed at setting an agenda, and succeeded supported by lively activity on the social media. It is, however less clear what to name it. It would

be misleading to call it HPV-vaccination, and the media did not as such explicitly argue for the abandonment of the HPV vaccination. The appropriate heading should be HPV Adverse Effects.

However, successful agenda setting that is an important success criterion for the media is not identical to correct, nuanced and unbiased reporting or interest in the consequences of the reporting.

In the case of the TV documentary it was clear that sympathy more or less explicitly was on the side of the victims which is a traditional news angle, and implicitly leaning towards a conclusion that the vaccination was the cause in the face of all available scientific evidence to the contrary. The health authorities seemed to find it difficult to participate in the debate because they had to balance on a knife edge. On the one hand unwavering and staunch support for a safe and evidence based vaccination program and on the other hand also show and demonstrate concern for the teenagers with for instance POTS and CPHR without actually knowing an effective treatment. The victims confused the health authorities' insistence on no causality between the symptom syndromes and HPV vaccination with lack of empathy and understanding of their situation which was real – they did have pain and suffered from dizziness and fatigue which was also what the media saw - but most doctors considered it as an example of mass psychogenic illness or a functional disease which agitated many of the victims who wanted a 'real diagnosis' and not what they considered a denigrating classification or a stigmatizing psychiatric-like diagnosis. Today it is commonly believed that everything is treatable which was the stance of the victims: 'do something', and the health authorities did not come forward and say outright that they were at a loss about what to do. The end-result was that an antagonistic stand developed between the social media organized groups of victims and the health authorities. This antagonism is still clearly present today on many Facebook groups using rather harsh language.

An observer who has followed the HPV situation closely (7, 8, 51), recently noted that public, provider or political trust in vaccines may have been broken. Her research group has heard many testimonies of the anxiety that politicians and decision-makers face when pressured about suspected vaccine reactions while also hearing scientific evidence exonerating the vaccines. An important lesson is the importance of monitoring public sentiment, responding promptly to concerns and engaging and listening to the public early on. This advice would have been highly relevant in the Danish case even though the ‘One entrance’ centers were introduced along with increased research.

Agenda setting is rarely, if ever, associated with harm, but in the present case harm has been done in the sense that many girls have abstained from vaccination with increased probability of getting cervix cancer later in life – for some with possible subsequent mortal consequences. Harm was an unintended side effect of agenda setting based on journalistic criteria for reporting of health news. The approach was news reporting, not in depth science reporting based coverage of a particular topic, e.g. serious adverse effects.

Health journalism is a field within journalism. The Encyclopedia of Journalism says that the health journalists' primary function is to translate often technical medical information into lay language (52). However, the Danish media's treatment of HPV side effects was not covered by professional health journalists but by news journalists. Science writers have observed that consumer-focused health reporting is edging out science coverage in the media (52). Immediate impact on the daily lives of readers and viewers is what sets health journalism apart from science journalism along with disregard for the scientific principles of causality – mirroring the Danish situation.

A summary of the general situation in health journalism (52) noted that physicians and scientists have criticized journalists for misleading the public with incomplete, incorrect, oversimplified, or premature medical coverage. Some researchers believe that poor health reporting constitutes a public health threat. Issues like simplification, polarities of opinion, sensationalism, and lack of time, space, and scientific knowledge exist because health stories appear in media that must abide by traditional news values, such as the rituals of objectivity. One reason why people heavily criticize health journalism is because the stakes are assumed to be higher with such reporting than with most other subjects. Inaccurate medical reporting can cause panic, cultivate false hopes, or profoundly affect an individual's health decisions like the decision to be vaccinated.

It is hard to come up with remedies, but some guidelines for good health news reporting have been suggested (2, 53). For instance that journalists who do not have a basic understanding of clinical trials and causality should not report on them. A television station or newspaper with no one on staff with specialized training in health journalism should consider leaving such reporting to others. The latter is utopia, but ought nonetheless be considered in some form, for instance on an ad hoc basis employ relevant specialists. Alternatively, every media reporting on sports has journalists with a thorough knowledge of particular sports, for instance football and the rules, e.g. offside. That would seem to be a minimum requirement for health reporting. Self criticism like what is found on for instance HealthNewsReview.org is another way to go as discussed in a recent article on fact based health journalism. Furthermore, despite fierce competition among news organizations journalists need not accept that their reports need to be sensational to get attention. In addition journalist ought to be careful to avoid what is taught in journalism schools, namely that they should think in terms of real people to effective communicators pointing to case-based journalism that easily lead to being captured by feelings and emotions. Finally, as noted above 'fair' reporting is

taken to mean representation of opposing expert views. This seems reasonable in situations where there is real and mainstream scientific doubt about a matter, but when this is not the case as for serious adverse effects of HPV-vaccination this approach should be questioned.

Today one must not overlook the role of the social media. In particular not when the target groups are teenagers and young adult whose main source of news is the social media. Reuters recent Digital News Report (54) showed for Denmark that in the age groups 18-24, 25-34, and +55 years old 30%, 18% and 4% respectively get their most important news from the social media, while the percentages for newspapers are 3%, 4%, and 14% and for TV news 18%, 17% and 40%.

In Denmark and elsewhere the social media has been an outlet for vaccination sceptics and vaccination victims in that their access to traditional media has been limited and undoubtedly severely edited, while the social media is unedited. Social media here is for instance Facebook and YouTube along with dedicated homepages and their role is illustrated in several places above. Numerous Facebook groups have grown up with frequent postings. Some of them require that prospective members apply for membership. The number of members goes from a few hundred to three thousands. For instance the Irish R.E.G.R.E.T with almost 3,000 members and the Danish HPV Adversely Affected with about 1,700 members. The groups are based on the idea of community building around the common cause with frequent skeptical postings where members confirm themselves in a number of HPV related issues. The social media keep alive the issue during periods where it does not receive attention from the traditional media.

The mechanism of the social media, for instance Facebook, is interesting. Affected persons, e.g adversely HPV-vaccinated women, can relatively easy find other persons who know what it is like.

They can compare notes and say: Your story sounds like mine and before long they start believing all the like-minded anecdotes about, say, HPV vaccinated women and their experienced syndromes. Not only are their experiences very real to them, but people like them, who understand them, are regularly reinforcing their ideas. "Sustained encounters with a small group of like-minded people almost inevitably lead to the conclusion that everyone thinks the way you do" an observer noted (55). This is the essence of community building.

The social media also spread news fast. For instance, in December 2013 a well-known anchorperson on the American CBS network covered the HPV vaccine controversy, supposedly in a balanced way, but afterwards quickly admitted that some of the criticism of having been too anti-vaccine and anti-science was valid (56). An American observer noted in line much of the above that the problem in TV and all media, is the human interest/personalized individual case drives the story, but in science and public health, "it doesn't, or it's at risk of grave harm" (56). Interestingly, however, a Danish hpv-critical website was able to report that CBS would cover the vaccine controversy even before it had been broadcast in the US (57), and provided a link to the show.

There is no doubt that the Danish authorities did not pay sufficient attention to the social media and could gain a better understanding of the thinking of adversely affected women by doing so. When the Danish HPV-program was relaunched in 2017 to increase participation the social media were used intensively. The Facebook page has about 7,500 followers. It is unclear, however, how successful it has been even though vaccination uptake has increased quite a bit. The approach to information seems a traditional enlightenment approach: More information and you will understand that we are right, including references to scientific article! When critical questions are fielded the responses seem rather defensive probably because it has been impossible to find a causal

relationship. One lesson from the whole period discussed above: Don't argue feelings with facts, which also was the message after a meeting mid 2017 of scientists (58). The CEO of the Danish Health Authority recently noted that many lessons had been learned but belatedly (59): Medical authority in general is questioned and on occasion invoking evidence almost makes it worse and pay more attention to complaints about symptoms that are hard to explain medically and for which treatment is not available. "This was the biggest letdown" (59). He also noted that it was a mistake to assume that people automatically listen to the Health Authority. "We have to work hard to deserve it and we must never seek monopoly on authority", and called for a more proactive and agenda setting approach.

Social media and the post-factual/post truth society are not identical, but linked. Post-factual relates to or denotes circumstances in which objective facts are less influential in shaping public opinion than appeals to emotion and personal belief. Fukuyama (60) says that one of the more striking developments of 2016 was the emergence of a "post-fact" world, in which virtually all authoritative information sources are challenged by contrary facts of dubious quality and provenance. In a world without gatekeepers, Fukuyama goes on, that there is no reason to think that good information will win out over bad. It is in this environment that the debate about adverse effects has taken place reflecting a 'new reality' for communication with social media leading the way. It has been extremely challenging for the health authorities to adapt to this situation.

In three rather culturally diverse countries: Denmark, Ireland, and Japan, we have seen a radical drop in the uptake of HPV vaccination in the wake of press reports. The only common features seem to media reporting showing cases of women adversely affected, purportedly due to HPV vaccination, and very active and aggressive, but relatively small Facebook-based groups. However,



these two features have also been present in other countries without the consequences seen in these three countries. Based on available evidence it is not possible to say whether the authorities handled the situation inadequately, and to what extent for instance respected doctors have supported the women in the debate about serious adverse effects.

However, a historical caveat. To ascribe the discussion about HPV adverse effects alone to the post-factual society and social media is too hasty because we forget history. One needs only recall the 1982 TV documentary – The vaccine Roulette - an hour-long television documentary about pertussis vaccination (whooping cough) - aired locally in the Washington DC-area, but amplified the next morning on national TV with excerpts on the Today Show. The documentary is available on YouTube. The documentary was, of course, case based showing children who had been permanently brain damaged purportedly following DPT vaccinations. Their little bodies were twisted, contorted. In the documentary it was presented as caused by pertussis vaccination. However, this was a misunderstanding of the underlying scientific report (61). The medical community reacted immediately with a rebuttal, but the harm had been done and mistrust sowed. However, the producers of the program claimed that they for 18 months had tried to gain cooperation from the medical authorities who had been evasive about risks of the vaccine (61). The documentary went on to win an Emmy Prize (62).

Disregarding the role of the then non-existing social media there are similarities to the Danish HPV-situation: Drop in uptake of the vaccination, reluctance by the medical community to address risks, almost immediate political attention in that a senator called a hearing in the Senate, the same senator was instrumental in passing The National Childhood Vaccine Injury Compensation Act 1984/85, research into adverse effects, the establishment of the still existing vaccination skeptical

movement of concerned parents etc. and ongoing debate for several years (63). However, news spread more slowly then. For instance, a scare in the UK about the same vaccination a few months before the TV-documentary did not get attention in the US. Jumping to 2011 where New Scientist reviewed (55) three books that investigated how so many people have become so dangerously irrational about vaccines and noted that it was part of a general confusion between fact and belief.

The reviewer aptly captured a general flow of events. Each vaccine scare follows a broad pattern: Anti-vaccine activists and a few sympathetic scientists raise concerns that, although implausible, draw uncritical media attention. The medical and public health communities then respond with a wave of scientific studies that refute the concerns, but these studies take time, are tough reading, and draw much less attention. As the science mounts, the activists and their sidekick scientists are increasingly rebuked by responsible sectors of society, including the courts. For instance, US courts have ruled against claims about the link between vaccines and autism. But the activists continue to draw followers and, if anything, only grow more extreme in their convictions. They continue to garner media attention, and so the irrationality the media let out of the bag is never put back in (55). All of the preceding was written and concluded well before the debate about the purportedly HPV adverse events.

In closing the discussion it should be noted that (fraudulent) scientific work on vaccination also has done harm as witnessed by the Wakefield scandal, a hallmark of scientific misconduct, and subsequently amplified by media reporting.

In 1998, Andrew Wakefield and 12 of his colleagues published an article the Lancet (64) suggesting that the measles, mumps, and rubella (MMR) vaccine might be related to autism and bowel disease

based on 12 cases. The paper and the ensuing controversy received wide publicity, and MMR vaccination rates began to drop both in the UK and Ireland (65), ultimately leading to a MMR-scare that was at its heights around 2003. In the UK the uptake dropped from 92% to 80% in 2003 (66) – below the 85% believed to secure herd immunity. The incidence of measles and mumps increased, resulting in deaths and serious permanent injuries. Wakefield in connection with the article said that he thought it prudent to use single vaccines instead of the MMR triple vaccine. Skipping a long process - the longest medical disciplinary inquiry ever (67) - about scientific misconduct the Lancet completely retracted the paper in February 2010 (67). Wakefield was struck off from the UK medical register. Already in 2004 10 of Wakefield's coauthors had retracted the interpretation of the findings. Later articles in BMJ showed that the article was fraudulent (68). The uncovering was led by Sunday Times investigative reporter Brian Deer. He was also responsible for a November 2004 television documentary: "MMR: What they didn't tell you" on UK Channel 4.

The media had two roles: Uncovering the fraud and fueling the vaccination scare. The latter has been well documented (69-71) and many of the above points on HPV can be found in the research around MMR, and the media reporting has been criticized harshly (72). However, a worthwhile new observation is that in a survey at the height of the MMR scare showed that less than one in four people were aware that the bulk of the evidence favored the vaccine. The authors of the same good study(69) noted that although almost all scientific experts rejected the claim of a link between MMR and autism, 53% of those surveyed persons at the height of the media coverage of the issues assumed that because both sides of the debate received equal media coverage, there must be equal evidence for each. Only 23% of the population were aware that the bulk of evidence favored supporters of the vaccine (71) pointing towards problematic contrived balanced coverage – equal

voice in cases where there is something close ‘truth’ and ‘nonsense’ are at stake and where the journalists cannot unravel what is what.

## **Conclusion**

This article is the first to clearly document the effects of HPV media coverage and behavioral response: HPV-vaccination uptake, reporting of adverse events, filing of harm compensation claims, political reactions, increased research and establishment of ‘one entrance’ at hospitals for the victims. The pattern is so clear that formal statistical analysis (73) is superfluous to document the effects. Two earlier articles have document a relationship between reporting of adverse events of HPV and social media coverage, incl. the internet (74, 75) but not addressed the multiple effects reported her. There are parallels to two earlier vaccination scares based on heavy media coverage and decline in uptake: the US 1982 pertussis and the UK 1998-2003 MMR scare in the wake of the infamous Wakefield article in the Lancet.

The communication challenge posed to health authorities in the post-factual world with the social media has been addressed, however without strong conclusions apart from noting that this media world is still rather poorly understood and that the authorities are still struggling to cope this situation. However, it is of more than passing interest to note that the pattern from earlier scares seem to repeat themselves starting with the 1982 TV documentary on the Vaccine Roulette, but that the authorities still are not catching on to the new communication reality.

Health journalism needs yet again to do some soul-searching in the aftermath of the HPV adverse effects debate. The attempt at agenda setting with no regard to subsequent effects need to

reevaluated and it seems relevant to discuss a codex for health journalism stressing the unintended health effects of hunting for an agenda setting role.

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