Written evidence from TIME FOR ACTION – UK Families Affected by HPV Vaccinations

TIME FOR ACTION is a UK campaign group formed by a group of parents whose daughters have experienced serious health problems after HPV vaccination.

Executive Summary

- Statistics from sexual health clinics on HPV vaccinations given and course completed
- Statistics from sexual health clinics on major and minor cervical abnormalities
- Paper from Public Health England indicating reduction in HPV 16 & 18
- Adverse reactions reported to MHRA from people older than school vaccinated cohorts
- Situation regarding adverse reactions reported to MHRA and quotes from parents

Statistics from sexual health clinics on HPV vaccinations given and course completed

The dosing schedule for those under 15 is two doses (at least 6 months apart), for those over 15 it is three doses (2nd after 1 month and 3rd within 12 months). Looking at the figures to 2017 from the PHE data ‘All STI diagnoses and services by gender and sexual risk’, since 2013 it reports that 27,730 HPV first vaccinations have been given in sexual health clinics to men, with 17,010 second vaccinations and only 8,820 third vaccinations given – indicating that the completion rate is poor. Similarly, for women, 827 first vaccinations have been given, 556 second vaccinations and 391 third vaccinations given. Has there been any follow up of those who have not completed the programme yet? If the full programme of doses are not given, what impact will this have on immunity? As women who attend sexual health clinics are likely to already be sexually active, what information are they given on reduced efficacy in those who have already been exposed to HPV infection (as noted in clinical trial data and many publications since)?

Statistics from sexual health clinics on major and minor cervical abnormalities

According to the same data from PHE, the number of women attending sexual health clinics for cervical smear tests has decreased from 27,435 in 2012 to 21,188 – although there was a peak of 34,428 in 2014. However, the number of cervical abnormalities found has increased:

- Minor abnormalities increased from 2,239 in 2012 (8.1%) to 2,496 in 2017 (11.7%)
- Major abnormalities increased by percentage from 374 in 2012 (1.3%) to 363 in 2017 (1.7%)

These figures are not broken down by age, but the data table from PHE for attendance at sexual health clinics indicates that 51% of women attending are under the age of 25 and so would have been offered HPV vaccination at school.

Has any analysis been done to determine what percentage of women with cervical abnormalities had been vaccinated? And, if so, what type of HPV is present?

Recent publication from PHE on reduction in HPV 16/18 from sexual health clinic data

We have concerns that the data recently published in the paper:

The Impact of the National HPV Vaccination Program in England Using the Bivalent HPV Vaccine: Surveillance of Type-Specific HPV in Young Females, 2010–2016
We are in the process of writing to the lead author, from Public Health England, to raise some important questions, notably that an increase in non-vaccination HPV types was found in the age group 22-24 years (so the age group that would have been included in the school catch-up programme but not yet in the cervical screening programme) – but also that in 2015 and 2016 no samples were collected from this age group. We find this concerning, since this is the oldest cohort to have been vaccinated and the most important in terms of looking at prevalence of both vaccine and non-vaccine types of HPV. We also think the authors should have looked at the presence of minor or major abnormalities from sexual health clinics in this age group. The vaccination was marketed to our daughters for the prevention of cervical cancer, so we regard cervical cancer statistics as more important than HPV statistics.

We are also concerned that samples from women attending sexual health clinics have been used without their permission to provide data to GlaxoSmithKline and question the independence of the data, given the conflict of interest statement:

“Potential conflicts of interest. C. E., D. M., and K. S. reported financial support to their institution from GlaxoSmithKline for reports on HPV surveillance.”

The public should be able to rely on data from Public Health England as being completely independent of any influence from pharmaceutical companies and are surprised that public bodies are allowed to accept this sort of financial support.

Adverse reactions reported to MHRA from people older than school vaccinated cohorts

Freedom of Information data for Gardasil 9 for 2017 shows 11 cases of delayed menstruation or menstrual problems in the age group 18 to 35. Our assumption is that these are vaccinations being given to women in sexual health clinics or high street pharmacies, as Gardasil 9 is not yet in use in the school programme. We think this is concerning and warrants further investigation.

Situation regarding adverse reactions to MHRA and quotes from parents

We are concerned about the very high number of Yellow Card reports to the MHRA for the HPV vaccination and the lack of long-term follow-up, particularly of women now in their 20s who reported serious illness when the vaccination carried a black warning triangle. As at 30th June 2018, the MHRA had received 9,215 Yellow Cards for the HPV vaccination and of those 2,608 have an outcome that is showing as not recovered, not resolved or unknown. We believe the MHRA have no idea how many of those girls are unable to work or take part in education – or how seriously they are affected.

Our concerns are particularly relevant this week when the BMJ have published a paper revealing that GlaxoSmithKline and public health authorities knew that there were side effect problems with the Pandemrix swine flu vaccination and did not inform the public – this relates to a very high number of side effects reported in comparison to other swine flu vaccines. Cervarix was released by GlaxoSmithKline at around the same time and we have no confidence that the same is not true. We have seen data submitted to the EMA for the investigation into POTS and CRPS in 2015 and also the PSURs submitted for regular review and it is very clear that the manufacturers dismiss reports of side effects without reference to medical records or consultants. Side effects are frequently attributed to possible other medical conditions or dismissed because they were reported by patients or did not include test results.

We have recently obtained evidence through FOI that PHE puts pressure on media and press not to report on possible problems with the vaccination meaning that we believe that healthcare professionals, parents and girls are not aware that some girls have long-term illness after the HPV vaccination, even though these girls represent a very small proportion of the number of girls that
have been vaccinated. We should stress that we are not anti-vaccination as our families are all fully vaccinated. We are not calling for the vaccination programme to be stopped, but for there to be a thorough investigation into what went wrong for the girls who have become unwell.

Here are quotes from some of the parents in the Time for Action group that illustrate our concerns:

"We suspected at age 14 xxx had pots. No paed doctor to diagnose it and we were told we would have to wait until xxx was 16 for a diagnosis. xxx was diagnosed early 2017. We are in Northumberland. Should add we have now been discharged with just water and salt for treatment"

"GP said all in head. Rang Dr Thakker and saw him privately. Referred to Dr Whitehouse NHS one appointment a year and he's ignored all letters from GP asking for advice. Daughter 15 now"

"diagnosed with tachycardia privately. Scotland. Has balance and some vertigo but won't really talk about it unless gets more severe like flare. Gp treated for inner ear infection but did not help. Consulted private cardiologist bc worried about symptoms: panic attack, dizziness. 2017. has since had flares and GP did not refer to nhs cardiologist bc seeing one privately and he referred her back to private consultant. Made her feel embarrassed to have parent in appointment- clearly parents paying for private. Just sent her out with that advice with suspected murmur as said would be quicker. Private eeg. On beta blockers but always tired. I do not believe help quality of life much. I asked daughter if put on waiting list for cardiologist on nhs. No. No one on nhs. Is monitoring her care. Or meds"

"Wakefield. Paeds. Daughter ill at 13, diagnosed with POTS 2 years later. Suspected POTS but paed and GP both refused to refer for assessment. Paed wanted to refer to psychiatrist. Found specialist ourselves (Nottingham) and contacted direct - GP eventually agreed to refer, but only seen for diagnosis - had no ongoing monitoring. Had to wait until 16 to be seen at adult POTS clinic where treatments were tried. Treatments got daughter from being housebound & home educated to attending university - wasted 3 years & could have ruined her education. Current POTS clinic is not thorough & not interested in autoimmune causes. Emphasis on management of symptoms rather than investigating underlying cause. Have to travel to London for urogynae specialist & have had to see private consultants for help."

"10 years ago we were totally ignorant about POTS and so even when our daughter was strapped to a tilt table at the local hospital and she was fitting, there was no explanation of what they were doing or why. She was taken from there and put in a psychiatric unit. Over a period of more than a year, several times a week she was man handled by up to 6 people, from a lying position as totally bedbound to sit in a wheelchair where she lasted no more than 10 seconds at best before fainting/fitting and we were told they would strap her in whilst she was fitting and we could take her outside for a picnic. Utterly disgusting. Previous GP just put symptoms down to deconditioning. She is too poorly now to be put on a tilt table or even getting her into any hospital as she is not able to attend as an outpatient. Consultant has diagnosed her with POTS on the basis of history and the results of the blood test from BerlinCures, Germany as has her GP and Dr Gall at Kings but dr Delamont of Kings with no sight of her or her history said it was likely to be psychological. The local CCG say without the tilt table test etc the diagnosis is questionable so adds to their decision to offer no primary health care to her."

"Swansea - Paeds - discharged by cardio after normal echo cardiogram, 24hrs BP monitor, 24hrs heart monitor. Wrote direct back to consultant who agreed to see again and after listening to symptoms again and what everyday is like for my daughter, agreed that she does fit criteria for POTS, Feb 2018 - symptoms for 4yrs." "Forget to mention Originally said it was because she had had a growth spurt and lots of teenage girls have same symptoms that
would settle!!! She's been on 99th centile for height since birth. 'treatment' offered at 2nd consultation - Beta Blockers which we refused. Recommended to add more salt to diet - how much is more salt - no guidelines. Drink plenty of water, tense your calf muscles throughout day. Nothing works."

"initially diagnosed with ME/CFS, syncopal episode led to A&E visit and consultant advised us to see neurologist. Neurologist sent on to cardiologist for assessment for POTS, tilt-table was negative but IST diagnosed. Further autonomic testing done privately 2 years later resulted in diagnosis of POTS. Had testing done privately as we were told waiting time would be a year on NHS. Followed with NHS clinic appointments but not really helpful - if you don't improve with salt, water (unable to exercise) you are assumed to be not managing your symptoms well enough/not trying hard enough. Referred for group CBT but unable to travel to attend appointments."

Our concern for this inquiry is that men and women are being vaccinated in sexual health clinics (as in schools) without full information about possible side effects – despite dismissal from PHE and statements that there are no side effects, the experience of parents in our group says otherwise and they are completely frustrated by the lack of recognition or help for their daughters.

We would be happy for a representative to speak at the inquiry or to provide further information on request.

On behalf of parents from

Time for Action – UK Parents Affected by HPV Vaccination

September 2018

REFERENCES:

Sexual Health Clinic statistics (Table 4):

The Impact of the National HPV Vaccination Program in England Using the Bivalent HPV Vaccine: Surveillance of Type-Specific HPV in Young Females, 2010–2016

BMJ, September 2018, Pandemrix vaccine: why was the public not told of early warning signs?
https://www.bmj.com/content/362/bmj.k3948

Time for Action – UK Families Affected by HPV Vaccinations:
www.timeforaction.org.uk