**INFORMATION SHEET FOR PARTICIPANTS**

*Ethical Clearance Reference Number: HR-18/19-12011*

**YOU CAN DOWNLOAD A COPY OF THIS INFORMATION SHEET**

**Improving the way we talk to parents and children about the HPV vaccine**

The aim of this study is to improve official communications with parents and children about the HPV vaccine. We are also interested in what parents and children have heard about the HPV vaccine and side effects from the vaccine and whether your child experiences symptoms after the vaccinations.

We would like to invite you and your child to participate in this research project. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

**What is the purpose of the study?**

The HPV vaccine has been offered to girls since 2008. Recent recommendations mean that the HPV vaccination programme has been extended to boys, beginning this school year (2019/2020). Many communications, previously written for parents of girls, will have been changed so that they are also appropriate for parents of boys. The aim of this research is to see what parents think about the new HPV vaccine leaflet published by Public Health England and the NHS. We are also interested in what your child has heard about the vaccine. We are interested in hearing everyone’s view, regardless of whether or not you decide to vaccinate your child.

Another aim of this study is to investigate whether your child experiences symptoms after the vaccine. We would like to investigate whether there is a difference in the number of symptoms reported by children before and after the vaccine and between those who are and are not vaccinated.

**Why have I been invited to take part?**

We would like to invite you and your child to take part in this study. You are being invited to participate in this study because your child is eligible to receive the HPV vaccine through their school.You can both take part in this study even if you decide not to vaccinate your child for HPV.

**What will happen if I take part?**

If you choose to take part in the study, we would like both you and your child to complete the following questionnaires.

You will be asked to complete two questionnaires: one before the day of the HPV vaccinations at your child’s school, and one two days after the HPV vaccinations take place at your child’s school. Both questionnaires would be completed online. The first questionnaire will take about 15 minutes to complete and will ask you what you think about the HPV vaccine leaflet published by Public Health England and the NHS. You will be also be asked about what you have heard about the HPV vaccine and about your beliefs about vaccines. We will ask you if you have spoken to your child about the HPV vaccine, and if so, which topics you spoke about. We will also ask you how likely you think side-effects from the HPV vaccine are, as well as how sensitive you think your child is to medicines and how often your child experiences common symptoms. Finally, you will be asked for some demographic information about you and your child.

The second questionnaire will take about 5 minutes to complete and will ask you if you think your child has experienced any symptoms in the last two days, whether you think these are due to the vaccine and how worried you were about the symptoms. You will be also be asked if there was anything else that you would have liked to have known about the HPV vaccine, either before or after the vaccinations.

Your child they will be asked to complete two questionnaires in school: one on the day of the HPV vaccinations at their school, and one two days after the HPV vaccinations. Completing the questionnaires will not interfere with their regular school timetable. The first questionnaire will take your child 10-15 minutes to complete. We will ask your child what they think the HPV vaccine does. We will ask your child how much they have spoken to their parents, teachers and friends about the HPV vaccine in the past week. We will also ask your child how much they have seen on social media about the HPV vaccine and side-effects from the HPV vaccine in the past week. We will ask your child to tell us about any rumours they may have heard about the vaccine and how worried they were about the rumours. We will also ask your child how likely they think side-effects from the HPV vaccine are. We will also ask if they have experienced any symptoms in the last two days.

The second questionnaire will take your child 5-10 minutes to complete and will ask your child if they have experienced any symptoms in the last two days. They will also be asked whether they think the symptoms were caused by the HPV vaccine and how worried they were about the symptoms. We will ask your child how many people in their school had side-effects from the vaccine, and how worried they were about these side-effects. We will ask how much your child has spoken to their friends about side-effects of the HPV vaccine since the vaccinations were given. We will also ask your child if there was anything they would have liked to have known about the HPV vaccine, either before or after the vaccinations.

**Do I have to take part?**

The study is entirely voluntary. You should only take part yourself and let your child take part if you want to; choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, please click on this [link](https://kclbs.eu.qualtrics.com/jfe/form/SV_eqYKsCqFhV4Xvdr%20) to begin. This will take you to a webpage where you will be asked to give consent for you and your child to take part in the study. Your child will also need to give assent using the appropriate form. You will be able to download this information sheet, the information sheet for your child and your completed consent and assent forms from this webpage.

**Incentives**

We would like you and your child to take part in the study together. As a thank you to you both for taking part, when you and your child complete both questionnaires we will donate £10 to one of three charities (your choice of either the Teenage Cancer Trust, Young Minds or your child’s school’s PTA). We will donate a maximum of £2000 to charity. We will also enter your child into a prize draw for £20 of Amazon vouchers.

**What are the possible benefits of taking part?**

As thanks to you and your child for taking part, we will donate money to charity on your behalf and will enter your child into a prize draw for some shopping vouchers. At the end of the study, if you would like to receive a copy of the final report, you can contact the lead researcher (louise.e.smith@kcl.ac.uk) for more information.

**Data handling and confidentiality**

You and your child’s data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

We would like to link data from each parent and their child. In order to do this, we will use an identification number to substitute names on all data. We will use a separate password-protected document with a list of names and identification numbers, as an additional level of confidentiality. At the end of the study, after all data has been analysed and written up, we will delete the document with the list of names and identification numbers, so that all data will be completely anonymous. No individual participants will be identified in the final report.

The data will be retained for seven years after it has been collected. Data will be archived in the form of an encrypted spreadsheet file on a password-protected space on the King’s College London main server; data will be stored in a completely anonymous form. Anonymous data will only be available to the research team (Louise Smith and G James Rubin); data will not be shared with any third parties.

**Data Protection Statement**

The data controller for this project will be King’s College London (KCL). The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a ‘task in the public interest’ You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the King’s College London Data Protection Officer Mr Albert Chan [info-compliance@kcl.ac.uk](file:///%5C%5Ckclad.ds.kcl.ac.uk%5Canywhere%5CUserData%5CPSStore02%5Ck1217397%5CMy%20Documents%5C2018%5Cinfo-compliance%40kcl.ac.uk). If you wish to lodge a complaint with the Information Commissioner’s Office, please visit [www.ico.org.uk](http://www.ico.org.uk).

**What if I change my mind about taking part?**

You are free withdraw yourself and your child at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until two weeks after the second questionnaires (two weeks and two days after the HPV vaccinations at your child’s school), after which withdrawal of your data will no longer be possible as we will start analysing it/it will be committed to the final report. If you choose to withdraw from the study, before this date we will not retain the information you have given thus far.

**What will happen to the results of the study?**

The team from King’s College London hope to publish the results of this study in a scientific journal. If you would like to receive a copy of their final report, you can contact the lead researcher (louise.e.smith@kcl.ac.uk) for more information. Results from the study might also be presented at academic conferences. The anonymous results from this survey may also be shared with other researchers who are interested in this work in the future.

**Who should I contact for further information?**

If you have any questions or require more information about this study, please contact me (Louise Smith) using the following contact details:

Email: louise.e.smith@kcl.ac.uk

Phone number: 0207 848 5684

Address: Department of Psychological Medicine, Weston Education Centre, Cutcombe Road, London, SE5 9RJ.

**What if I have further questions, or if something goes wrong?**

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, Psychiatry, Nursing and Midwifery Research Ethics Subcommittees (PNM RESC) rec@kcl.ac.uk

**Thank you for reading this information sheet and for considering taking part in this research.**