

Patient/ Participant Information Leaflet

Study title: A National survey of parents' views on childhood vaccinations in Ireland

Principal investigator's name: Dr Chantal Migone_____

Principal investigator's title: Specialist in Public Health Medicine at the National Immunisation Office

Telephone number of principal investigator: 01-8676107_____

Consultant co-investigator's name: Dr Suzanne Cotter

Consultant co-investigator's title: Specialist in Public Health Medicine at the Health Protection Surveillance Centre

Data Controller's/joint Controller's Identity: Dr Chantal Migone. Dr Suzanne Cotter

Data Controller's/joint Controller's Contact Details: National Immunisation Office, Manor St Business Park Stoneybatter Dublin 7 and Health Protection Surveillance Centre, Middle Gardiner St, Dublin 1

Data Protection Officer's Identity: Ms Vicky Mc Kenna (Data Protection Officer in the National Immunisation Office)

Data Protection Officer's Contact Details: National Immunisation Office Manor St Business Park Stoneybatter Dublin 7

You are being invited to take part in a research study to be carried out by IPSOS MRBI on behalf of the National Immunisation Office of the Health Service Executive

Before you decide whether or not you wish to take part, you will be read out information provided.

Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.

You should clearly understand the benefits and risks of taking part in this study so that you can make a decision that is right for you. This process is known as 'Informed Consent'.

You don't have to take part in this study. If you decide not to take part it won't affect you in any way.

You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don't have to give us a reason. If you do opt out, rest assured it won't affect you in any way in the future.

Why is this study being done?

We are carrying out a survey of parents' views on the vaccines that are given to babies. We hope to find out what parents think about childhood vaccines; for example how important they think vaccines are, how safe they think they are and if they have had any difficulties in getting vaccines for their child/children. The information that we get during the survey will help the HSE to understand what parents think of vaccines and so help them to improve how they communicate with parents about vaccines, and make improvements to the service.

Who is organising and funding this study?

The HSE is organising this survey and is providing the funding. The HSE received funding for this survey from the Department of Health.

Why am I being asked to take part?

You are being asked to take part because you are a parent or guardian of a young child aged 48 months or less so we are interested in your views.

How will the study be carried out?

The study is a survey of how you feel about vaccines. We will ask you some questions about how you feel about vaccines, the diseases that the vaccines protect against and a few questions about yourself.

What will happen to me if I agree to take part?

If you agree to take part, the researcher will go through some questions with you. The questions include how important you think vaccines are how safe you think they are and if you have had any difficulties in getting vaccines for your child/children.

The researcher will ask you some questions about yourself as well, like your age, which county you live in and whether you are the person in the house who makes the decisions about vaccinating your baby.

If there are any questions you don't want to answer, you can tell the researcher that you don't want to answer the question. You can also decide at any time during the survey that you don't want to answer any more questions. The researcher won't ask you your name, your address or your date of birth, so you can't be identified in any way. They won't have any access to your or your baby's records or immunisation records.

What are the benefits?

The results of the survey will help the HSE to understand what parents think of vaccines and so help them to improve how they communicate with parents about vaccines, and make improvements to the service.

What are the risks?

Answering the survey will take about 10-15 minutes so it will make demands on your time.

What if something goes wrong when I'm taking part in this study?

Taking part in this survey is completely voluntary. You can decide if you want to participate or not, and if you decide to go ahead with the survey, you can refuse to answer specific questions, or you can decide to

withdraw from it during the survey. We won't collect any information that could identify you, and all of the answers that you give will be completely anonymous.

Will it cost me anything to take part?

No it will not cost you anything

Is the study confidential?

Yes the study is confidential. The data we collect will be anonymous and you cannot be identified from the data. We won't ask you or collect any information that might identify you, like your name, your address, your date of birth or who your GP is. We will not ask to look at your or your child's medical records.

Any information we do collect (the answers to the questions we will ask you) will not be shared with anyone outside of the research team. It will be stored securely and the only people who have access to the information are the research team.

When we have collected the answers to the questions we have asked from hundreds of parents, we will analyse the data, but the results will be about the overall replies from the hundreds of parents we asked. Our results might look like this:

70% of parents replied that they think vaccines are important for children to have, 10% said they weren't important, and the rest didn't answer.

The results of our survey will be published in a report, and we may also publish the results in a scientific journal.

We hope to repeat the survey in future years to see if there are changes over time to how parents' feel about vaccination and we may compare the overall results of the survey to future surveys.

Data Protection

1. The purpose or reason for processing the data (your answers to our survey) is as follows: we will be using the answers to the survey that you gave us in our research to help us study how parents in Ireland feel about children's vaccination in order to improve how we communicate with parents about vaccines and improve our services
2. The legal basis under which we are processing the data we collect is: legitimate interests interest and for scientific research purposes – see Article 6 and 9 of the General Data Protection Regulation 2016.
3. The study team from IPSOS MRBI and the study team from the HSE are the recipients of the data and the only people who will have access to the data. IPSOS MRBI have been contracted by the HSE to carry out the survey.
4. The data will be stored by IPSOS MRBI for the duration of the study which is 6 months. After that it will be stored by the HSE's National Immunisation Office, for up to 10 years. We want to monitor how parents' feel about vaccines over time so we may compare the results of this survey to surveys done in future years,
5. You have a right to withdraw consent. If you decide that you don't want to be included in the results of the survey, you can tell the interviewer during the interview. You can contact the HSE research team also and let them know.
6. You have a right to lodge a complaint with the Data Protection Commissioner.
7. You have a right to request access to your data and a copy of it
8. You have a right to have any inaccurate information about you corrected or deleted
9. You have a right to have your personal data deleted, however, if you request this once the data has been analysed, this may not be possible.

Consent to Future Uses

We hope to repeat the survey in future years to see if there are changes over time to how parents' feel about vaccination and we may compare the overall results of the survey to future surveys.

Where can I get further information?

If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won't affect the quality of treatment you get in the future.

If you need any further information now or at any time in the future, please contact:

Name: Dr Chantal Migone

Address: National Immunisation Office, Manor St Business Park, Stoneybatter, Dublin 7

Email: immunisation@hse.ie