# The PIPAH Study

The Prospective Investigation of Pesticide Applicators' Health Study



# Information about the Research Study

You are invited to take part in our research study. Before you decide, we would like you to know why the research is being done and what it will involve for you if you do take part. Please read the following information carefully. Contact details for the study team are provided at the end of the leaflet, and they will be happy to answer any questions you may have about the study.

# Why is the Health and Safety Executive carrying out this research?

Many people work with pesticides or live in areas where they are used. At times there has been public concern about whether pesticides might be a risk to people's health. The medical evidence available to HSE suggests that pesticides pose no significant risks to health when used properly. However we are aware that there are some gaps in our knowledge.

This research study is part of the Health and Safety Executive's (HSE) programme to monitor the health of men and women who work with pesticides in Great Britain. HSE is committed to reducing the risks people face through work activities. The research is carried out by HSE's Health and Safety Laboratory (HSE, Buxton). HSE is funding this research study.

# What is the purpose of this research study?

The purpose of this research study is to investigate whether there is any evidence of a link between working with pesticides and health. In the long-term the information will help to ensure that any risks identified are properly controlled.

# Why am I being invited to take part in this research study?

We would like to involve men and women who work with pesticides in this study. So we are inviting you, as a member of the National Register of Sprayer Operators (NRoSO), to take part in this study.

We have contacted all the members of NRoSO because it is important that as many as possible of the NRoSO members join the study to increase the validity of any findings. However it is up to you to decide to take part in the study.

# How is the research team able to contact NRoSO members?

City & Guilds maintain the National Register of Sprayer Operators. They are fully supportive of this research study, and have posted this invitation and study questionnaire to you on our behalf. The research team at HSE has not been given your name or contact details.

# What would I be asked to do if I take part in the study?

If you decide to take part in the study, then please sign the consent form and complete the enclosed questionnaire.

In the questionnaire, we ask questions about your health, the types of pesticides you have used, and the time you have spent using them.

We also ask questions about other factors that can affect your health. These include your lifestyle, diet, smoking habits, and alcohol intake, as well as your social circumstances. It is important to ask questions about these factors. We can then separate the effects of these factors on health outcomes from any possible effects of pesticides.

After this first questionnaire, we would like to contact you once every year to ask about your pesticide usage during the previous year. This will involve completing a questionnaire.

We would also like to contact you again at five-year intervals so that we can update the information you have provided in the enclosed questionnaire. This will ensure that we have up-to-date information on your current health and other factors that may affect your health. Even if you stop working with pesticides, you will still have an important contribution to make to this study.

We have not set an end-date for this study, so we will continue to contact you on a regular basis until the study ends, unless you choose to withdraw from the study.

### Does the Health and Safety Laboratory have plans for other research studies?

We may wish to contact you again in the future about taking part in other occupational health studies. We would always explain the research we wanted to do, and exactly what taking part in the new study would mean for you. You would be free to choose whether or not you wanted to take part.

# What will the research team do with the information I give to them?

Health information is regarded as a special category of information. We will use the information for health research only, and not for any other purpose.

HSE is the sponsor for this study based in Great Britain and will be using information from you in order to undertake this study. HSE will act as the data controller which means that HSE is responsible for looking after your information and using it properly. HSE will keep identifiable information about you for 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information on the PIPAH study website (https://www.hsl.gov.uk/resources/major-projects/pipah) and in HSE's Privacy Policy Statement (http://www.hse.gov.uk/privacy.htm).

# Will the research team collect any other data about me?

We would like to follow up your health status on a long-term basis. To do this we will contact central bodies of the National Health Service (NHS). We will ask them to notify us about important health events, such as cancer and death registrations, and hospital admissions, that they record for you and we may ask them to help us to contact you.

We will send your name, address, date of birth, and sex to NHS Digital (England and Wales) or the NHS Central Register (Scotland) so that you can be linked to the relevant data sets. For cancer and death registrations, NHS Digital will send the study team information on the date of the event and the cancer type and cause of death. The hospital episode statistics information sent to the study team will include the date of hospital admission, the length of the stay and the condition being treated.

By doing this for as many men and women who work with pesticides as possible, the researchers can assess whether there are any health risks linked to working with pesticides.

# Will my information be kept confidential?

We will treat any information you provide or any health information sent to the study team as strictly confidential. Access to personal data will be restricted to authorised people, which are the small number of individuals working on the study and may include auditors who check that the study is being carried out correctly. The study team will include the PIPAH study researchers and any contractor employed to print, post, process data, or host the online questionnaire. Your personal data will be protected by the Data Protection Act 2018, the General Data Protection Regulation and by other laws protecting the privacy of information obtained through the National Health Service.

HSE may seek the help of other expert researchers with our research. Also, other expert researchers may ask us for permission to use the information we have collected during the study. This may include researchers, who work on similar studies in other countries. It is important to stress that all information collected about you during the course of the research will be kept strictly confidential. Any information about you, which is used by other researchers, will have your name, address and any other information that may identify you removed so that you cannot be recognised. We will not pass any information that can be linked to you as an individual to anyone, other than the NHS central bodies mentioned above, unless you have given us your permission to do so.

We must publish the findings of our research if they are to help improve health and safety. **But personal** information that could be linked to you as an individual will not be made public. We will only report research findings that are summarised over many individuals.

#### What will happen to the results of this study?

A key part of this study will be to report any findings. Important results from the research will be made freely available on the HSE website, and will become part of the evidence base for policy makers in Britain. The results will also be published in scientific journals and other appropriate publications. If you decide to take part, then we will keep you up-to-date on progress with the study.

# How long will the study last?

The PIPAH study is a long-term study and HSE has not set an end date for it.

# What if I change my mind?

If you agree to take part you can ask to withdraw from all or part of the research study at any point in the future, using the contact information given at the end of this leaflet. However, we will need to use the information collected up to the time you withdraw from the study. This is because the information will already be part of earlier analyses and published statistics. These reports do not contain any identifiable data and it is not possible to remove individual data from them.

### What if I have any health concerns?

If you have any concerns about your health after completing the questionnaire, it is important that you discuss these with your doctor.

# What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions (see contact details below). If you are still unhappy, they will advise you on how to make a formal complaint.

### Who has reviewed the study?

This study has been reviewed and given favourable opinion by the National Research Ethics Service Committee North West – Greater Manchester North (Reference 12/NW/0654). The role of the committee is to protect the interests of study participants.

## How do I complete the questionnaire?

If you decide to take part in the research study, please complete the enclosed consent form and questionnaire and return them to us in the stamped, addressed envelope.

You may wish to ask a relative or friend to help you complete the questionnaire, if you find this easier.

# What is the Study ID number on the questionnaire used for?

The study ID number is a unique number that we will use to keep track of questionnaires as they are returned. The study ID number will also let us keep track of your data without having to use personal information like your name and address. The consent form, where you provide your name and contact details, will be stored separately to the information we collect on your health, pesticide usage, and so on. In this way, we can maintain the confidentiality of the data you give us.

#### How do I get further information about the study?

If you have any questions about the research or you have any difficulty in completing the questionnaire, please contact the research team on the freephone number or at the email or postal address provided below.

Freephone: 0800 093 4809 Email: PIPAH@hse.gov.uk

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The PIPAH Study

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