

Privacy Notice for British and International Styrene Studies

This privacy notice covers how IOM collects, uses, discloses, and stores individuals' data for the British and International epidemiological studies of styrene-exposed workers in the glass reinforced plastics manufacturing industry. For IOM's more general Privacy Policy, please see <https://www.iom-world.org/privacy-policy/>.

Epidemiology is the study of patterns and causes of diseases in people (in this case, workers in the glass-reinforced plastics manufacturing industry).

The Institute of Occupational Medicine (IOM) is one of the world's leading providers of occupational epidemiological research and consultancy services. IOM's expertise extends across a very wide range of related scientific disciplines used in epidemiological research.

This study was originally set up by the Health and Safety Executive (HSE) and in order to carry out this research, and HSE will be providing IOM with their original study.

What personal data IOM collects and how is it used?

For the purposes of the styrene studies, IOM is the 'joint controller' of the personal data along with the Health and Safety Executive (HSE). HSE will be providing the personal demographic and occupational data for this study. The data will consist of name, date of birth, sex, address and details of work in the glass-reinforced plastics industry.

IOM collects personal data for analysis in ethically approved epidemiological studies. The aim of the styrene studies is to assess whether occupational exposure to styrene is associated with an increased risk of contracting or dying from cancer. This is an important question to know the answer to because of the large numbers of workers occupationally exposed to styrene in Great Britain.

The personal data from HSE will be used to trace an individual on the National Health Service (NHS) Central Register, managed by NHS Digital, and then to determine the date and nature of any cancer registrations or deaths associated with relevant individuals in the study. Once IOM has used the data from NHS Digital to check that the cancer registration and mortality information has been assigned to the correct individuals, IOM will produce a "pseudonymised" data for analysis purposes. Pseudonymised means the data will be anonymised, but a reference number or code is retained in case the analyst has any queries about the data and so could refer back to the data provider without knowing the identity of the individual involved. The British data will be analysed separately for a British-only analysis by a limited number of named IOM staff and will also be provided to analysts in Denmark for an international pooled analysis of data from additional countries: Norway, Sweden, Denmark, Finland, Italy and USA. The data will be pseudonymised and held securely at Statistics Denmark and accessible only by named researchers from Aarhus University.

IOM also processes personal data when it is in IOM's legitimate interests to do this and when these interests do not override a study individual's rights. These legitimate interests include carrying out ethically approved epidemiological research that is widely regarded as being in the public interest.

IOM processes all personal data in accordance with the key GDPR principles unless there is a relevant exemption (see GDPR exemptions). IOM therefore processes personal data:

- Lawfully, fairly and in a transparent manner;
- Only for specified, explicit and legitimate purposes, and they are not further processed in any manner incompatible with those purposes;

- In an adequate, relevant and limited way that is necessary in relation to the purposes for which it is processed;
- Accurately and, where necessary, it is kept up-to-date;
- By not keeping data as identifiable data for any longer than necessary for the purposes concerned; and
- Securely and according to Legitimate Interests (see separate document containing IOM's Legitimate Interests Assessment).

IOM has a number of lawful reasons that mean IOM can use (or 'process') your personal information. One lawful reason is something called 'legitimate interests'. Broadly speaking legitimate Interests means IOM can process your personal information if:

- IOM has a genuine and legitimate reason; and
- IOM is not harming any of your rights and interests.

If you enter into a contract with IOM, there may be times when IOM needs to share the information you have provided with a third party to enable us to continue fulfilling the contracted work. If this is the case participants would be informed and notified of what information was being shared and why. IOM would only share the essential information needed to complete the service.

Legal Bases

IOM's legal bases for carrying out this research are Articles 6(1)(f) and 9(2)(j) of the General Data Protection Regulations:

- the processing is necessary for IOM's legitimate interests or the legitimate interests of a third party, unless there is a good reason to protect the individual's personal data which overrides those legitimate interests
- Archiving, research and statistics (with a basis in law)

HSE's legal bases for carrying out this research are Articles 6(1)(e) and 9(2)(j) of the General Data Protection Regulations:

- the processing is necessary for HSE to perform a task in the public interest or for HSE's official functions, and the task or function has a clear basis in law
- Archiving, research and statistics (with a basis in law).

Your rights

Under the General Data Protection Regulation, you have rights as an individual, which you can exercise in relation to the information IOM holds about you.

Read more about an individual rights, which apply to IOM's commercial and research work, on the Information Commissioner's Office website.

Access to personal information

IOM tries to be as open as it can be in terms of giving people access to their personal information. Individuals can find out if IOM hold any personal information by making a 'right of access' request under the General Data Protection Regulations. If IOM hold's information about you, it will:

- Give the person involved a description of it;
- Tell the person why IOM is holding it;

- Let the person have a copy of the information in an intelligible form.

Opt-Outs

As outlined in the worker leaflet for the study (<https://www.iom-world.org/research/our-expertise/styrene-study/>), if you believe you are a participant in the study, but no longer wish to remain in the study, please contact us and request for your details to be removed from the study. IOM will do that at any time before analysis of the study data begins.

Complaints

If you wish to make a complaint to IOM, you can do so via an online form, email, telephone or a letter. The complaint is logged on an internal database and account management system.

A complaint can be made anonymously. However if you do provide personal data, IOM requests your full name and address. IOM will only use the personal information it collects to process the complaint and to check on the level of service IOM provides.

By giving IOM your personal data, you consent to us processing it. IOM retain personal data obtained from complaints for five years and then confidentially destroy it.

If you are still unhappy, you have a right to complain to the Information Commissioner's Office – see <https://ico.org.uk/make-a-complaint/> for further details.

How to contact us

IOM tries to meet the highest standards when collecting and using personal information. For this reason, IOM takes any complaints it receives about this very seriously. IOM encourages people to bring it IOM's attention if they think that IOM's collection or use of information is unfair, misleading or inappropriate. IOMN would also welcome any suggestions for improving IOM's procedures.

This privacy notice was drafted with brevity and clarity in mind. However, IOM is happy to provide any additional information or explanation needed. Any requests for this should be sent to the address below.

Principal Researcher:

Professor Damien McElvenny
IOM Edinburgh
Research Avenue North
Riccarton
Edinburgh
Midlothian EH14 4AP
Tel: +44 (0)131 449 8000
Fax: +44 (0)131 449 8084
Email: styrene@iom-world.org

Data Protection Officer:

Ken Dixon
Research Avenue North
Riccarton
Edinburgh
Midlothian EH14 4AP
Tel: +44 (0)131 449 8000

Fax: +44 (0)131 449 8084

Email: styrene@iom-world.org