**Privacy Notice for MORSE Study**

This privacy notice covers how the Institute of Occupational Medicine (IOM) collects, uses, discloses, and stores individuals’ data for the MORSE (MORtality Study of former professional footballers in England and Wales) Study. 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, footballers over 40 years old who have played professionally in England and Wales).

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 is Funded by the Colt Foundation (<https://www.coltfoundation.org.uk/>).

**What personal data IOM collects and how is it used?**

For the purposes of the MORSE study, IOM is the data controller of the personal data. The data will consist of name, data of birth, and career history, including years at each club. We will use an exposure matrix to estimate number of headers and non-heading head impacts for the professional playing careers of the participants in the cohort study.

IOM collects personal data for analysis in ethically approved epidemiological studies. The aim of the MORSE is to assess whether heading footballs and other repeated subconcussive head impacts (RSHIs) is associated with an increased risk of mortality from neurological disorders. This is an important question to know the answer to because of the relatively large number of professional footballers in England and Wales and (perhaps more importantly) the much larger number of amateur players in these countries and globally.

The publicly available data from websites such as Barry Hugman’s Footballers (<http://barryhugmansfootballers.com/>) will be used to trace an individual on the National Health Service (NHS) Central Register, managed by NHS England, and then to determine the date and causes of death associated with relevant individuals in the study. Once IOM has used the data from NHS England to check that the 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 original data without knowing the identity of the individual involved. The data will be analysed by a limited number of named IOM staff.

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 participant’s individual 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 they are processed;
* Accurately and, where necessary, they are 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, sometimes indirectly, and notified of what information was being shared and why. IOM would only share the essential information needed to complete the research.

**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)

**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 (if you are a member of the study population).

You can 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/morse-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. IOM 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.

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