

## Privacy Notice | Exemplar 2

### Purpose of this document

This privacy notice is designed to help you understand how we use and protect the research data we are entrusted with for the purposes of this study. It applies to personal and special category personal data provided to us for the purposes of the study titled: **Prediction of Individual Risk of Dementia (PIPARD)**, a medical exemplar undertaken for and funded by the PICTURES programme of work. It supplements any other privacy notices which may apply for collaborating partners (available in the 'Your Rights' section below).

### What information we will use

We seek to discover new information from historical data previously collected for the purposes of routine healthcare, and we do not collect any new data on any individuals. We are interested in routinely collected data (as opposed to data collected specifically for a research study) because it is more representative of the general population that we aim to develop healthcare solutions for.

The purpose we use this data for is to develop and validate an algorithm that can estimate a person's risk of dementia from brain scans and clinical data. The algorithm we are developing through the use of this data is a Support Vector Machine (SVM), which is a type of machine learning model.

The data used in this study is:

Magnetic Resonance Image (MRI) scans linked to hospitalisation and prescription records (to identify predictor co-morbidities and medication) and mortality and cancer records (to determine type and date of diagnosis) for patients with a dementia diagnosis within 18 months of the date of their scan (cases), and for an age and sex-matched group of patients without evidence of dementia and who did not go on to develop dementia in available follow-up data (controls).

### How we will use the information

We only use the data when the law allows us to do so and only for the duration and purpose of this study. Our permission to use the data is granted by Scotland's Public Benefit and Privacy Panel (PBPP) under the following lawful bases from the UK General Data Protection Regulation (UK GDPR):

- article 6(1)(e) processing is necessary for the performance of a task carried out in the public interest.
- article 9(2)(j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) (as supplemented by section 19 of the 2018 Act) based on domestic law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

We do not share the data with any parties other than those collaborating on this project who have been bound by the provisions of data sharing agreements.

Personal data, or personal information, means any information about an individual from which that person can be identified. The data we use has been carefully prepared by Public Health Scotland (PHS) to ensure it does not contain any personally identifiable information and is limited to only what is required for our particular research aims.

The data used to develop the dementia predictor is made available to authorised researchers within the National Safe Haven, a research environment controlled by PHS. This data has standard de-identification processes applied which means it is pseudonymised (i.e., it has undergone techniques that replace, remove or transform information that identifies individuals).

### Your rights

Under certain circumstances, you have a range of rights in relation to your personal data when it is used for research purposes. These are described in the Privacy Notices of collaborating partners:

- Public Health Scotland <https://publichealthscotland.scot/our-privacy-notice/your-rights/privacy>
- University of Dundee <https://www.dundee.ac.uk/information-governance>

If you wish to exercise any of these rights with respect to this study, please contact the University of Dundee's Data Protection Officer by emailing [dataprotection@dundee.ac.uk](mailto:dataprotection@dundee.ac.uk).

You have the right to lodge a formal complaint with the UK Information Commissioner's Office. Full details may be accessed on the complaints section of the [ICO's website](#).

### Changes to our privacy notice

Our Privacy Notice may be updated from time to time. Any updates will appear on this webpage.

If you have any questions about our privacy notice, please contact the University of Dundee's Data Protection Officer on [dataprotection@dundee.ac.uk](mailto:dataprotection@dundee.ac.uk) or by post at University of Dundee, Nethergate, Dundee, DD1 4HN.