University of Bristol Privacy Policy for the project:
“Screening for papilloedema to diagnose brain tumours”

Contact details of the data controller

Name: University of Bristol
Address: Beacon House, Queens Road, Bristol BS8 1QU
Phone Number: 0117 928 9000
Website: www.bristol.ac.uk

The name and contact details of the data controller's representative

Dr Denize Atan; Denize.Atan@bristol.ac.uk

The contact details of the data controller's data protection officer

Henry Stuart, Information Governance Manager & Data Protection Officer, Secretary’s Office, Senate House, Tyndall Avenue, Bristol, BS8 1TH; Henry.Stuart@bristol.ac.uk

The purposes of the project: how we access personal information and why we have it

The study group are accessing historical data from the National Cancer Registration and Analysis Service (NCRAS) and Hospital Episodes Statistics (HES).

The purpose of the study is to determine any changes or trends in the proportion of people diagnosed with a brain tumour over the last 5 years who initially presented to an eye specialist with papilloedema.

Brain tumours increase the pressure inside the head, which leads to headaches and papilloedema (swelling of the optic nerves at the back of both eyes). As only 50% of brain tumour patients with papilloedema are symptomatic, eye specialists in the community or hospital may be the first to diagnose papilloedema.

However, brain tumours are uncommon, with an annual UK incidence of 7 per 100,000 people. Earlier detection improves their prognosis and treatment outcome, but the diagnosis of brain tumours is often delayed for several months, particularly when vision is affected before the tumour causes other symptoms.

The data from NCRAS and HES will be accessed to find out whether there has been any change in the proportion of people diagnosed by an eye specialist with a brain tumour over the last 5 years. We will also compare whether people diagnosed with a brain tumour by an eye specialist had a better or worse prognosis than people who were diagnosed via other routes to diagnosis.

Only pseudonymised patient level data will be used for analysis. Personal information will only be used to link information in the NCRAS and HES databases.

The following datasets are required from 2015 onwards:

1. Cancer Registration Patient table
2. Cancer Registration Tumour Table
3. Cancer Registration Treatment Table
4. Index of Multiple Deprivation Income domain
5. Route to Diagnosis
6. National Radiotherapy Dataset
7. Systemic Anti-Cancer Therapy Dataset
8. Cancer Waiting Times
9. Diagnostic Imaging Dataset
10. HES inpatient
11. HES outpatient
12. HES A&E

These datasets are required to find out about people who were diagnosed with a brain tumour in England from 2015: their type of brain tumour, the treatment they received (e.g. surgery, radiotherapy, chemotherapy), their socioeconomic position, whether a hospital specialist or GP made the diagnosis and which imaging tests they had to make the diagnosis.

No data will be used for commercial purposes and only aggregated data will be provided to third parties (e.g. in preparing reports for publication).

The lawful basis for processing personal information

Under the General Data Protection Regulation (GDPR), the lawful base we rely on for processing this information is performance of a task by a public organisation in the public interest (Article 6(1)e of the Data Protection Act 2018). The lawful basis of access to special category data is article 9(2)j of the GDPR.

Your data protection rights

All opt-outs reported through the National Disease Registration Service will be respected. As data accessed by the study team will be pseudonymised, it will not be possible for the study team to provide access, rectify or erase individuals’ data - such requests should be made directly to:

National Cancer Registration and Analysis Service

Public Health England
6th Floor, Wellington House
133-155 Waterloo Road
London SE1 8UG
Email: optout@phe.gov.uk

The type of personal information we collect

We collect and process the following information to link information from NCRAS and HES:

- Age, sex, ethnicity
- NHS number
- Date of Birth
- Postcode

Only pseudonymised patient-level data is being used for analysis.

How we store your personal information

Your information is securely stored at the University of Bristol. This information will only be accessed by named healthcare researchers working directly on the research project.

We will keep pseudonymised data for up to 15 years following study completion to ensure all statistical analyses are completed, available through peer review, and published. We will then dispose of your information in accordance with GDPR.

How to complain

If you have any concerns about our use of your personal information, you can make a complaint to the Information Governance & Data Protection Officer at the University of Bristol (see above).

You can also complain to the ICO if you are unhappy with how we have used your data. The ICO's address is:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Helpline number: 0303 123 1113
ICO website: https://www.ico.org.uk