Salivary Gland Cancers Regsitry – Patient Information Leaflet

You have been given this leaflet because you have been diagnosed or are being treated for with a salivary gland cancer. The surgeons and other health professionals caring for you would like to invite you to take part in this registry. Please read this leaflet carefully. It explains who we are, what we are doing and how we treat your information to ensure confidentiality and anonymity.

Why was I given this leaflet?

Salivary gland cancers (SGC) are rare (<800 cases per year in the UK) and relatively varied (> 20 types of cancers). They can at times be slow-growing tumours and may require follow up for many years. These features mean that salivary gland cancers are not very well understood and there is shortage of high-quality evidence to produce recommendations for their treatment. One possible approach to this challenge is to collect information about a patient's SGC treatment in a specialised registry. A clinical registry collects organised information about patients affected by a condition and the treatment received. By accumulating this information, disease patterns can be found, treatment outcomes identified and ultimately patient care improved.

Why are you collecting this information?

We would like to find out how your cancer was treated and followed up, if you have experienced any cancer recurrence or complications. We would like to understand if and how the treatment of salivary gland cancers changes over time. We hope this information, received directly from patients and carers, will help clinicians and healthcare commissioners understand more about the best treatment for those cancers and improve care for patients in the future.

What would taking part involve?

Taking part will take up some of your time. It is not expected to be too onerous. Your surgical team will collect data directly from your medical records and pass it onto us securely. If you agree, we will contact you on a yearly basis to ask you to complete a questionnaire about your quality of life. The questionnaire is 16 question-long and should take less than 10min to complete.

What information about me are you collecting?

To be able to follow you over time, we need to collect your NHS number, date of birth and information about your conditions, treatments, and long-term outcomes. We would like also your permission to access and share any imaging or biological specimens routinely collected as part of your diagnosis, treatment or follow-up, to be reviewed by a panel of experts and potentially used for secondary research.

What will happen to my information?

Your information will be collected and stored on secure computers managed by the Barts Cancer Research UK Centre at Queen Mary University of London (BCC, QMUL). Access to your information will be restricted to your clinical team and a limited number of approved members from QMUL and the project team. No identifiable information will be shared.

Is my information safe?

Yes, your information is safe. Very strict rules and secure procedures are in place to ensure that your information is kept safe. The systems and processes in place at QMUL comply with international standards and QMUL continuously monitor and adapt them as necessary to maintain security over the lifetime of the project.

Because this information is valuable, it may also be used for secondary research e.g. evaluation of treatment outcomes, surveillance strategy and translational studies. Should this be the case, any future research will be ethically approved and your clinical information but not your name and contact details or NHS number would be shared with researchers.

How long will my data be kept for?

Your information will be kept for 10 years after the end of data collection. It will either be anonymised (i.e., NHS number, date of birth … will be deleted) or completely deleted after this period of time.

Can I not take part to this registry?

Participation is voluntary and you can change your mind at any time without it affecting the care that you receive.

If you decide to not take part, when you complete the consent form, simply select "I do not agree". This way, we will keep a record of your decision and we will not ask you again at a later stage.

If you change your mind about taking part later, you can withdraw at any point without providing any reasons. Simply email the Team and put "Opt-out" in the subject line. You will be asked whether you want all your information removed or whether you are happy for us to keep your information we have so far, but we will not be contacting you for follow-up.

Who is organising and funding this study?

This project was designed by oral and maxillofacial surgeons in collaboration with pathologists and the Salivary Gland Cancer UK charity. The British Association of Oral and Maxillofacial Surgeons (BAOMS) leads this project and as data controller, is responsible for looking after your information and using it appropriately. The costs for the project are being supported by BAOMS (Registered charity number: 1062067).

Who has reviewed this initiative?

This project has been reviewed by clinicians and a group of patients and the audit department of this hospital and authorised by this hospital for data protection and security prior to their participation.

What if there is a problem?

You also have the right to lodge a complaint with the Information Commissioner's Office (ICO), the supervisory authority in the UK responsible for the implementation and enforcement of data protection law, if you have concerns about the way your personal data is being handled. You can contact the ICO via telephone (0303 123 1113) or email (W: https://ico.org.uk/concerns/).

Finding out more

If you would like further information or have any questions, please contact:

QOMS
Quality Outcomes in Oral and Maxillofacial Surgery

British Association of Oral and Maxillofacial Surgeons | Royal College of Surgeons of England, 38/43 Lincoln's Inn Fields, London WC2A 3PE |Tel: +44(0) 207 405 8074| E: qoms@baoms.org.uk | W: https://bit.ly/qoms-at-baoms