

QOMS Rare and Benign Lesions of the Jaws registry

Patient Information Leaflet

You have been given this leaflet because you have been diagnosed with a rare benign lesion or tumour of the jaws. The surgeons and other health professionals who care for you would like to invite you to take part in this registry dedicated to similar conditions to yours.

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?

Benign lesions and tumours of the jaws are a rare and relatively varied group of conditions. Because they are rare, they are not very well understood and there are various recommendations for their management. One possible approach to this challenge is to collect information about these conditions in a specialised registry. A clinical registry collects organised information about patients affected by a condition and the treatment received. This can be used to find patterns in disease presentation, treatment outcomes and ultimately improve patient care.

WHY ARE YOU COLLECTING THIS INFORMATION?

We would like to find out how your condition was treated and followed up, if you have experienced any complications or recurrence. We would like to understand how frequent these tumours are and how they are treated in the UK. We hope this information about patients and their treatment will help clinicians and healthcare commissioners understand more about the best treatment for those tumours and improve care for patients in the future.

WHAT WOULD TAKING PART INVOLVE?

Taking part in this registry will not take up any of your time after you have consented to the study. Your surgical team will collect data directly from your medical records and pass it onto us securely.

WHAT INFORMATION ABOUT ME ARE YOU COLLECTING?

To be able to follow-up your progress over time, we need to collect your NHS number, date of birth and information about your conditions, treatments, and long-term outcomes. We would also like 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 procedures 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, data that can directly identify you (e.g. NHS or CHI number) will never be shared.

HOW LONG WILL MY DATA BE KEPT FOR?

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

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, you can withdraw at any point without providing any reasons. Simply contact your treating team or email the project team and put "Opt-out" in the subject line (see email address below). You will be asked whether you want all your information removed or whether you are happy for us to keep the information we have so far but no new information will be collected.

WHO IS ORGANISING AND FUNDING THIS STUDY?

This project was designed by oral and maxillofacial surgeons in collaboration with pathologists. 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 carers, 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:

British Association of Oral and Maxillofacial Surgeons | Royal College of Surgeons of England, 38/43 Lincoln's Inn Fields, London WC2A 3PE | Project Team's email: goms@baoms.org.uk | W: <https://bit.ly/goms-at-baoms>