BAOMS BOS Orthognathic PROMs project

Patient information leaflet

You have been given this leaflet because you have been referred for corrective jaw treatment. The surgeons, orthodontists and other health professionals who care for you would like to invite you to take part in this BAOMS BOS Orthognathic PROMs project.

Please read this leaflet carefully. It explains who we are, what we are doing & how we treat your information to guarantee your confidentiality and anonymity.

WHY WAS I GIVEN THIS LEAFLET?

Orthognathic treatment refers to treatment to reposition the teeth (orthodontics) and/or the upper, lower or both jaws (orthognathic surgery).

The British Association of Oral and Maxillofacial Surgeons (BAOMS) and the British Orthodontic Society (BOS) want to hear your opinion about your treatment and how you feel, before and after treatment.

To do that, we would like to complete a questionnaire at various stages of your treatment (i) prior to the start of your orthodontic treatment, (ii) immediately prior to your surgery, (iii) 4-8 weeks after surgery and (iv) 1 year after surgery.

WHY ARE YOU COLLECTING THIS INFORMATION?

We want to find out how your quality of life has been affected by your condition and by your treatment. We hope this information, received directly from patients, will help clinicians and NHS commissioners understand more about this type of treatment and therefore improve care for patients in the future. Secondary evaluation may also be performed to look at how different aspects of the patients' experience affect each other; this is where anonymised data is looked at some time later to potentially explore other aspects of your care linked to the data collected.

WHAT WOULD TAKING PART INVOLVE?

Participation will take up a little bit of your time. If you agree to take part, you will be asked by your clinical team to complete a questionnaire about your motivations, outcomes, and experiences of your orthognathic treatment at the 4 time points described above.

WHAT INFORMATION ABOUT ME ARE YOU COLLECTING?

Your answers to the questionnaires will be stored completely separately to your consent form. Only your clinical team will be able to link your questionnaire responses with your personal details. No information that could identify you directly is collected as part of the questionnaire.

WHAT WILL HAPPEN TO MY INFORMATION?

Your consent form will be stored as part of your clinical record at the hospital where you are being treated. The information from your questionnaires 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 answers will be restricted to your clinical team and a limited number of approved members from QMUL and the project team. No identifiable information is being collected.

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.

How long will my data be kept for?

Records of your consent will be kept for 10 years after the end of data collection. Your answer to the questionnaires will be kept for at least 10 years but this could be extended.

Can I not take part?

Participation is voluntary and you can change your mind at any stage without it affecting your care. If you decide to not take part, when you complete the consent form, this will not affect your care in any way.

If you change your mind about taking part, you can withdraw at any point without providing any reasons. Simply let know your treating team. You will be asked whether you want all your information removed or whether you are happy for us to keep the information we have from your questionnaires so far, but we will not be contacting you for follow-up.

Who is organising and funding this study?

The surgeons in BAOMS and the orthodontists in BOS have designed this project. BAOMS leads this project and, as data controller, is responsible for looking after your information and using it properly. The costs for the project are being supported by BAOMS.

Who has reviewed this initiative?

This project has been reviewed by BAOMS, BOS and by patient representatives. The project has also been reviewed and authorised by this hospital for data protection and security prior to their participation.

What if there is a problem?

If there is a problem, please tell your clinician in the first instance, or someone else at the hospital. If you still have concerns, you can 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:

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