National Orthognathic Audit Information for Patients

You have been given this leaflet because you have been referred for corrective jaw treatment, known as orthognathic surgery. The surgeons and other health professionals who care for you would like to invite you to take part in the National Orthognathic Audit.

What is the National Orthognathic Audit?
The National Orthognathic Audit is a national clinical audit which collects information about patients undergoing orthognathic surgery. This treatment repositions the jaws to correct imbalance between the upper and lower jaws to enable the teeth to bite together correctly. It also has the benefit of balancing and enhancing the facial appearance. The National Orthognathic Audit aims to use the information it collects to measure the quality of care and to help surgeons understand more about the best treatment options for patients having this type of surgery. The fundamental aim of the audit is to improve patient care.

What is NFORC and what does it do?
The UK’s National Facial, Oral and Oculoplastic Research Centre (NFORC) is the first of its kind in the world. It is funded by the medical research charity Saving Faces - The Facial Surgery Research Foundation (Saving Faces) and has grown from a collaboration with the British Association of Oral and Maxillofacial Surgeons (BAOMS), the national surgical organisation specialising in the treatment of corrective jaw surgery, and the British Orthodontic Society (BOS). NFORC is the brainchild of UK surgeons, like yours, who want to improve treatment for all patients worldwide. Most surgical treatments for facial and oral conditions are relatively successful, but there is usually more than one treatment for the same condition and some may be more successful than others. Unfortunately, the evidence for which treatment works best is not yet available. NFORC is helping the UK lead the world in finding the most effective treatments for all mouth and face conditions and injuries. This work needs your help, and a lot of extra effort by your surgeon. It means collecting data on large numbers of patients, sometimes over many years.

Who is organising the audit?
The surgeons in BAOMS and the BOS have designed this project and asked NFORC to organise and lead it, working with your local surgeons and NHS Digital. NHS Digital is the UK’s national provider of information, data and IT systems for health and social care. In this audit NHS Digital will hold your data securely on behalf of your surgeons, BOS, BAOMS, NFORC and Saving Faces.

Why have I been chosen?
We are asking all people in the UK who are referred for corrective jaw surgery to take part in the audit. The more people that join the audit, the more meaningful and useful the results will be. Your surgeon and NFORC would be extremely grateful if you would take part.

What do I have to do to take part?
Taking part will take up a little extra time reading this leaflet and completing a questionnaire before your operation about the initial problems that caused you to seek treatment and a short questionnaire on whether you feel that the treatment has corrected these. This will save some time in your consultation with the surgeon and orthodontist as they normally ask these questions. The details collected will also include your name, NHS number, date of birth, postcode and gender. Your surgeon will use these details to contact you after treatment to ask you to complete the same or similar questionnaires to those you did before treatment. This is so we can understand how you feel about the treatment you received and whether it succeeded in dealing with your problems. You will be asked if you want to be contacted by phone or email.
Do I have to take part?
No. We understand that some people will not want to take part, and this decision will not affect your treatment or your relationship with your surgeon and orthodontist in any way. Your care will be exactly the same whether you take part or not.

How do I join the audit?
If you wish to take part you will be given further information by your local team who will explain the process in detail and ask you to sign a consent form.

How will information about me be collected and stored?
Information will be collected locally on a paper form or computer file by the clinical team looking after you and they will then enter it onto NHS Digital’s secure internet-based data collection system. NHS Digital will store it securely for NFORC. NHS Digital will provide a version of your information to the NFORC researchers at Saving Faces. The researchers will not have access to your personal information (name, NHS number, date of birth, postcode or any other confidential identifying details).

What will NFORC do with my information?
The results of these studies will be published in medical, dental and scientific journals to define best treatment practice and improve the management of corrective jaw treatment. It will never be possible to identify an individual patient in any publication. The publications will be available for you to view on BAOMS, BOS, NFORC and Saving Faces websites.

We would like your permission for:
1 NHS Digital to link the information you give us to other records, such as:
   Hospital Episode Statistics (HES). These are data about visits to hospitals in England, held by NHS Digital.
   Data about deaths (including date and cause of death and civil registration data) supplied by the Office for National Statistics and held by NHS Digital.
2 For NHS Digital to send some of your details, (NHS number and date of birth) to NHS Wales Informatics Service for linkage to Patient Episode Database for Wales (PEDW) data. These are data about visits to hospitals in Wales. This information will be returned to NHS Digital.
3 We would also like your permission to share your data with other researchers who might want to use it for valuable research. They will not have access to your name or any other confidential details (NHS number, date of birth or postcode) and the research would always be in line with the aims of the audit.

Will my privacy be protected?
Your privacy will be protected at all times. When collecting medical information there are very strict rules about confidentiality, including those of the 1998 Data Protection Act. We must follow these rules and keep your information safe. Access to your Personal Data is restricted to a limited number of staff within NHS Digital.

If NFORC researchers wish to seek your help with research not directly related to this audit they will apply for approval for this from Research Ethics Committees. They will have to confirm to the Research Ethics Committees that you will be contacted by NFORC/Saving Faces to gain your consent to be contacted by the researchers to ask you to participate in this new research and you would be free to refuse. You would be given full information about the purpose of the new research and what would be required from you to help with this.
Can I withdraw from the audit once it has started?
You may withdraw from the audit at any time. If you have agreed to participate and have completed a questionnaire you can still change your mind later. This will not affect your treatment; you just need to let your surgeon and orthodontist know. Your surgeon/clinical team can remove your information from the audit and, if you prefer, we will not contact you again.
If you would prefer to contact NHS Digital directly to ask them to delete your information you can contact the NHS Digital Governance team at the following email address ig.compliance@nhs.net indicating that you wish to have your information removed from the National Orthognathic Audit.

Will I find out the results of the audit?
It may be some time before the results of the audit are available. We will not contact you directly about the results but they will be publicised on the BAOMS, BOS, Saving Faces and NFORC websites.

Contact details
If you have a query about any aspect of this audit please feel free to contact your local team or the Saving Faces Research Office, who will do their best to answer your questions or direct you to a lead clinician.

NFORC/Saving Faces Research Office
Tel: 020 82238049 or email info@nforc.co.uk

National Orthognathic Audit –
Lead Clinician: James Gallagher
Ex-Chair of British Association of Oral and Maxillofacial Surgeons (BAOMS) Clinical Effectiveness Committee
Tel: 0207 405 8074 or email office@baoms.org.uk

NFORC/Saving Faces –
Director: Professor Iain Hutchison
Consultant oral and Maxillofacial Surgeon
Bart’s Health NHS Trust
Tel: 020 8223 8049 or email savingfaces@mail.com

Thank you for taking the time to read this information leaflet and helping UK’s surgeons find best treatment for all facial surgery patients worldwide. If you want to find out more about the National Facial and Oral and Oculoplastic Research Centre, or if you’d like to be part of our patient advisory groups, please visit our website at www.nforc.co.uk
# National Orthognathic Audit - Patient Consent Form

**Patient’s Full Name***: 
…………………………………………………………………………………

*please print name clearly

**Hospital Name**: ……………………………

**Hospital No**: ………………………

**NHS No**: ………………………………………..

**Date of Birth**: ……………………………

## Consent for Data Collection

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<th>Initials</th>
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<tr>
<td>I confirm that I have read the information leaflet National Orthognathic Audit - Information for Patients’ and have had a chance to ask questions about the audit.</td>
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I understand that:

- My data will be stored and treated in a strictly confidential manner, in accordance with the Data Protection Act 1998, and that all future users of my data will abide by this Act.
- I am free to withdraw my consent at any time.
- My data may be shared in a fully pseudonymised form, which does not identify me, with other scientists or medical research organisations for use in ethically-approved research studies
- No publications using my data will identify me in any way.
- My data may be linked to records held in other datasets, such as Hospital Episode Statistics from NHS Digital, mortality data supplied on behalf of the Office for National Statistics by NHS Digital and Patient Episode Database for Wales
- My data will never be given or sold to a commercial or insurance organisation.

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<tr>
<td>I give permission for NFORC to contact me after my treatment to ask about my recovery from this treatment and my current health status. <strong>My contact details are:</strong></td>
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<td>I understand if NFORC wish to conduct a new research project, which involves collecting more data from me which is not directly related to this treatment and its outcome, it will be necessary for NFORC to obtain ethical approval from a Research Ethics Committee for each project before they can contact me and seek my consent again for that specific project.</td>
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<tr>
<td>Name of Patient</td>
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<td>Name of Person taking consent</td>
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