

# Rare & Benign Lesions of the Jaws registry

Date of collection 

D	D	M	M	Y	Y
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Collected by: \_\_\_\_\_

## Patient information

NHS or CHI number 

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*Do not use hospital number*

DOB 

D	D	M	M	Y	Y
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 Patient's postcode 

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 Sex Female  Male

### Ethnicity

Caucasian  Any other ethnic group   
 Caucasian and Afro-Caribbean  Afro-Caribbean 

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 Caucasian and Asian  Asian 

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### Performance status (WHO/ECOG)

PS1 Normal   
 PS2 Light work   
 PS3 All self-care but no work, up >50% of day   
 PS4 Limited self-care, bed/chair >50% day   
 PS5 Disabled - bed/chair bound, no independent self-care

## Lesion / Tumour location and size

Date of initial referral 

D	D	M	M	Y	Y
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### Source of patient referral

General dental practitioner   
 General medical practitioner   
 Secondary care/specialist dentist   
 Secondary care/specialist medical or surgical specialties   
 Nurses/allied health professionals   
 Other (give details below)

### Presenting symptom(s)

Asymptomatic – incidental finding from clinical/radiographic examination   
 Delayed eruption of teeth   
 Jaw infection   
 Facial asymmetry/swelling   
 Jaw fracture   
 Paraesthesia   
 Other (give details below)

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Collected by:

## Lesion / Tumour location and size

Site	Mandible	<input type="checkbox"/>	Maxilla	<input type="checkbox"/>					
Subsite									
Incisor	<input type="checkbox"/>	Molar	<input type="checkbox"/>						
Premolar	<input type="checkbox"/>	Posterior jaw	<input type="checkbox"/>						
Max size / dimension (mm)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>					
Extent of defect using Brown classification (see figures)									
Mandible defect		Maxillary vertical defect							
Class I	<input type="checkbox"/>	Class Ic	<input type="checkbox"/>						
Class II	<input type="checkbox"/>	Class IIc	<input type="checkbox"/>						
Class III	<input type="checkbox"/>								
Class IV	<input type="checkbox"/>	Class IVc	<input type="checkbox"/>						
		I	<input type="checkbox"/>	II	<input type="checkbox"/>	III	<input type="checkbox"/>		
		IV	<input type="checkbox"/>	V	<input type="checkbox"/>	VI	<input type="checkbox"/>		
		Maxillary horizontal defect							
		a	<input type="checkbox"/>	b	<input type="checkbox"/>	c	<input type="checkbox"/>	d	<input type="checkbox"/>

## Imaging

Imaging provided	OPG	<input type="checkbox"/>	CBCT	<input type="checkbox"/>	CT	<input type="checkbox"/>	MRI	<input type="checkbox"/>
Appearance on radiograph								
Is the lesion/ tumour...?	Radiolucent	<input type="checkbox"/>	Radiopaque	<input type="checkbox"/>	Mixed	<input type="checkbox"/>		
Is the lesion/ tumour...?	Unilocular	<input type="checkbox"/>	Multilocular	<input type="checkbox"/>	Not known	<input type="checkbox"/>		
Any of the following features present? Tick all that apply								
Tooth associated with the lesion	<input type="checkbox"/>	Displacement of teeth	<input type="checkbox"/>					
Jaw expansion	<input type="checkbox"/>	Resorption of teeth	<input type="checkbox"/>					
Radiology pictures provided?	<input type="checkbox"/>	<input type="checkbox"/>	(If yes, upload them to the registry)					

## Pre-operative diagnosis

Biopsy	<input type="checkbox"/>	<input type="checkbox"/>						
Molecular testing	<input type="checkbox"/>	<input type="checkbox"/>						
Molecular test(s)			Molecular finding(s)			Which BRAF mutation		
Immunohistochemistry (IHC)	<input type="checkbox"/>		BRAF mutation	<input type="checkbox"/>		BRAF V600E	<input type="checkbox"/>	
Next-generation sequencing (NGS)	<input type="checkbox"/>		EWSR1 rearrangement	<input type="checkbox"/>		BRAF V600K	<input type="checkbox"/>	
Whole-genome sequencing (WGS)	<input type="checkbox"/>		Other (give details)	<input type="checkbox"/>		Other (give details)	<input type="checkbox"/>	
Polymerase chain reaction (PCR)	<input type="checkbox"/>							

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Collected by:

Other molecular finding(s)

Other BRAF mutation(s)

Initial diagnosis (use list provided)

Date of initial diagnosis

D	D	M	M	Y	Y
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Diagnosis details

New index presentation Recurrence 

## TREATMENT

Treatment provided / Management

Medical management 

Complete the "Medical Management" questionnaire

Surgical management 

Complete the "Surgical Management" questionnaire

## Comment

## WHO list of RLJ diagnosis (only use the ones in bold)

- |  |  |
|--|--|
| <p>1. Benign epithelial odontogenic tumours</p> <p>Ameloblastoma</p> <p><b>Ameloblastoma, unicystic type</b></p> <p><b>Ameloblastoma, extraosseous/peripheral type</b></p> <p><b>Metastasizing ameloblastoma</b></p> <p>Squamous odontogenic tumour</p> <p>Calcifying epithelial odontogenic tumour</p> <p>Adenomatoid odontogenic tumour</p> <p>2. Benign mixed epithelial and mesenchymal odontogenic tumours</p> <p><b>Ameloblastic fibroma</b></p> <p>Primordial odontogenic tumour</p> <p>Odontoma</p> <p><b>Odontoma, compound type</b></p> <p><b>Odontoma, complex type</b></p> <p>Dentinogenic ghost cell tumour</p> <p>3. Benign mesenchymal odontogenic tumours</p> <p><b>Odontogenic fibroma</b></p> <p><b>Odontogenic myxoma/myxofibroma</b></p> <p>Cementoblastoma</p> <p><b>Cemento-ossifying fibroma</b></p> <p>4. Malignant maxillofacial bone and cartilage tumours</p> <p><b>Chondrosarcoma</b></p> <p><b>Mesenchymal chondrosarcoma</b></p> <p>Osteosarcoma</p> | <p>5. Benign maxillofacial bone and cartilage tumours</p> <p><b>Chondroma</b></p> <p><b>Osteoma</b></p> <p><b>Melanotic neuroectodermal tumour of infancy</b></p> <p><b>Chondroblastoma</b></p> <p><b>Chondromyxoid fibroma</b></p> <p><b>Osteoid osteoma</b></p> <p><b>Osteoblastoma</b></p> <p><b>Desmoplastic fibroma</b></p> <p>6. Fibro- and chondro-osseous lesions</p> <p><b>Ossifying fibroma</b></p> <p><b>Familial gigantiform cementoma</b></p> <p><b>Fibrous dysplasia</b></p> <p><b>Cemento-osseous dysplasia</b></p> <p><b>Osteochondroma</b></p> <p>7. Giant cell lesions and bone cysts</p> <p><b>Central giant cell granuloma</b></p> <p><b>Peripheral giant cell granuloma</b></p> <p><b>Cherubism</b></p> <p><b>Aneurysmal bone cyst</b></p> <p><b>Simple bone cyst</b></p> <p>8. Haematolymphoid tumours</p> <p><b>Solitary plasmacytoma</b></p> <p>If "Other diagnosis" , provide details</p> |
|--|--|

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Collected by:

## MEDICAL MANAGEMENT

Start date of medical treatment

D	D	M	M	Y	Y
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Source of treatment

- Compassionate access
- Trial
- NHS
- Private patient (PP)



Details of the trial

Medical treatment

- |  |   |
|--|---|
| Dabrafenib (brafi) <input type="checkbox"/>  | Dabrafenib and trametinib (brafi and meki) <input type="checkbox"/>   |
| Encorafenib (brafi) <input type="checkbox"/> | Encorafenib and binimetinib (braf and meki) <input type="checkbox"/>  |
| Vemurafenib (brafi) <input type="checkbox"/> | Vemurafenib and cobimetanib (brafi and meki) <input type="checkbox"/> |

Other (provide details)

Number of cycle(s)

--	--

Complications / side effects of medical treatment?

Which complication(s) or side effect(s)?

- |  |   |                                     |
|--|---|-------------------------------------|
| Rash <input type="checkbox"/>  | Hepatic-enzyme abnormalities <input type="checkbox"/> | Arthralgia <input type="checkbox"/> |
| Diarrhoea <input type="checkbox"/>                                   | Vomiting <input type="checkbox"/>                     | Fever <input type="checkbox"/>      |
| Photosensitivity <input type="checkbox"/>                            | Fatigue <input type="checkbox"/>                      | Nausea <input type="checkbox"/>     |
| Rare (skin, eye, cardiac) - provide details <input type="checkbox"/> | Other - provide details <input type="checkbox"/>      |                                     |

Worst side effect grading (CTCAE)

- G1 mild     G2 moderate     G3 severe     G4 life-threatening

Change in treatment as consequence of side effect(s) (you can provide details in text box below)

- None     Dose reduction     Interruption     Cessation

# Rare & Benign Lesions of the Jaws registry

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Collected by:

Add comment / give details

End date of medical treatment

D	D	M	M	Y	Y
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Post-medical management assessment

Clinical

Radiological

Pathological on post-op sample



Follow-up imaging modality

OPG

CBCT

CT

MRI

Follow-up imaging frequency

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Weekly

Monthly

Yearl

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Collected by:

## SURGICAL TREATMENT

Date of first surgical treatment

D	D	M	M	Y	Y
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Surgery details

- Enucleation
- Enucleation + Carnoys solution
- Enucleation + bony curettage (with bur)
- Rim resection (mandible or maxilla)
- Segmental resection or maxillectomy
- Other (provide details)

Other surgery details

Was reconstruction required?  Y  N

What was used for reconstruction?

Implant

Free flap

Pedicled flap

Flap used for mandible reconstruction

Flap used for maxilla reconstruction

Treatment details

Single stage resection (and reconstruction) \*

Decompression followed by enucleation \*

Other (provide details)

Other

Date of final surgical treatment

D	D	M	M	Y	Y
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Date of final diagnosis

(definitive post-op pathology)

D	D	M	M	Y	Y
---	---	---	---	---	---

Final diagnosis (use list provided)

Stage

Locally advanced

Metastatic

Pathology slides provided?

Y  N

(If yes, upload them to the registry)

## Use of decompression tube

Was a decompression tube was placed?

No

At biopsy

At surgery

At a different time

When was the decompression tube placed?

D	D	M	M	Y	Y
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Did the decompression tube need resetting?

Y  N

How many times?

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Collected by:

## Surgical complications within 30 days of index surgery

Did the patient develop a post-operative complication within 30 days of surgery?

Surgical Medical None 

↓  
 Complication(s) at the donor site? No

Surgical site wound infection Haematoma Haemorrhage Dehiscence Other 

Complication(s) at the resection / recipient site? No

Surgical site wound infection Haematoma Haemorrhage Dehiscence Orocutaneous fistula Pharyngocutaneous fistula Sialocele Salivary fistula Other 

Other surgical complication(s)?

↓  
 Cardiac instability? No

Atrial fibrillation (AF) Cardiac arrest Myocardial infraction (MI) Congestive heart failure Other 

**Respiratory compromise?** (Pneumonia, Pneumothorax/Atelectasis, Pulmonary embolism [PE], Unspecified respiratory compromise, COPD, LVRI...)

Infective  Non-infective  No

**Other medical complication(s)?** (Gastrointestinal: upper GI bleed, pancreatitis; Genitourinary: urinary retention, UTI; other non-infective complications: delirium, fall, psychosis, suicide; or other infective complications: septicaemia, C. Difficile, COVID, MRSA...)

Infective  Non-infective  No

Indicate the Clavien-Dindo grade of the most severe complication(s)

GRADE I GRADE IIIa GRADE IVa GRADE V GRADE II GRADE IIIb GRADE IVb

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Collected by:

## Flap outcomes within 30 days of index surgery

To complete **ONLY** for patients who had a free or pedicled flap

### Flap outcome

- Complete success
- Partial success with loss of some components of the flap, but no secondary reconstruction or prosthesis not required
- Partial failure requiring a second flap (free or pedicled) to rehabilitate defect
- Partial failure requiring prosthesis to address residual defect
- Complete flap failure requiring a second flap (free or pedicled) to rehabilitate it
- Complete flap failure requiring prosthesis to address it
- Complete flap failure requiring no further reconstructive or prosthetic rehabilitation
- Failure to establish reconstruction

### If partial failure, indicate reason for flap failure

- Arterial failure  Venous failure  Uncertain/other causes - e.g. microcirculatory

### If failure to establish reconstruction, indicate the reason for flap failure

- Flap harvest attempted but abandoned because of unfavourable anatomy - e.g. inadequacy of vascularity or perforators
- Flap harvested but abandoned because of failure to perfuse before release from donor site, or inadequacy of the recipient vessels available
- Flap harvested and transferred to recipient site but abandoned/discarded because of failure to perfuse after attempted anastomosis to recipient vessels

## Resection margins

Are the margins...? Clear  Involved / incomplete resection

Was further surgical treatment required?  Y  N

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Collected by:

## Further surgical treatment

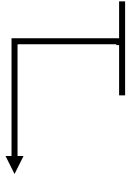
Date of first surgical treatment (further)

D	D	M	M	Y	Y
---	---	---	---	---	---

Surgery details

- Enucleation
- Enucleation + Carnoys solution
- Enucleation + bony curettage (with bur)
- Rim resection (mandible or maxilla)
- Segmental resection or maxillectomy
- Other (provide details)

Other surgery details



Was reconstruction required?  Y  N

What was used for reconstruction? Implant  Free flap  Pedicled flap

Flap used for mandible reconstruction

Flap used for maxilla reconstruction

Treatment details

- Single stage resection (and reconstruction) \*
- Decompression followed by enucleation \*
- Other (provide details)

Other

Date of final surgical treatment (further)

D	D	M	M	Y	Y
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## Comment

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Collected by:

## Annual follow-up

Date of current status

D	D	M	M	Y	Y
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Current status

Treatment completed and tumour free

New tumour identified

Treatment completed - residual disease monitored

Recurrence of previously treated tumour

Residual disease - adjuvant treatment required

## New tumour

Date of new tumour detected

D	D	M	M	Y	Y
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Site

Mandible

Maxilla

Subsite

Incisor

Molar

Incisor

Molar

Premolar

Posterior jaw

Premolar

Posterior jaw

Treatment for new tumour

 Y N

If yes, If a new tumour has been detected, start a new record for the patient

## Recurrence

Date of recurrence

D	D	M	M	Y	Y
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Site

Mandible

Maxilla

Subsite

Incisor

Molar

Incisor

Molar

Premolar

Posterior jaw

Premolar

Posterior jaw