QOMS Salivary Gland Cancers registry – Protocol

PROJECT DETAILS

Project Title: QOMS Salivary Gland Cancers registry (SGC)

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Funding: British Association of Oral and Maxillofacial Surgeons (BAOMS)

INTRODUCTION

Salivary glands are divided into major (parotid, submandibular and sublingual) and minor glands. The latter includes up to 1,000 glands distributed throughout the oral mucosa, palate, uvula, floor of the mouth, posterior tongue, retromolar and peritonsillar areas, pharynx, larynx and paranasal sinuses.

In the UK, salivary gland tumours are rare. Most are benign (between 6.2 and 7.2 per 100 000 people pa), and the incidence of malign tumours is around 8 or 9 per 1m people pa, which represents < 800 primary malignant neoplasms pa. Salivary tumours are uncommon in children (< 19 years of age), but a greater proportion (20–30%) of them are malignant. Although, overall, tumours are more common in the parotid, the incidence of malignancy increases with decreasing gland size (15% parotid tumours are malignant, 35% for submandibular glands, 85% sublingual glands, and 50% for minor salivary glands).

Clinically, salivary gland tumours present either as a simple palpable lump (well-defined, discrete, and mobile) or a lump with significant accompanying symptoms (pain, rapid growth, fixity to surrounding structures, nerve involvement or neck metastasis), with the latter suggestive of malignancy. Salivary gland cancers present a range of histological and clinical behaviours. The most common type overall is adenoid cystic carcinoma, followed by mucoepidermoid carcinoma for the parotid glands and acinic cell carcinoma. Unfortunately, most tumours are generally slow growing, and patients must be followed up for 10 years or more before one is confident of the natural history of the histological entity. In most instances, this information is not available as the clinical behaviour of many subtypes is still to be identified.

Source: Sood et al. J Laryngol Otol. 2016;130(S2):S142-S149. doi: 10.1017/S0022215116000566. Management of Salivary Gland Tumours: United Kingdom National Multidisciplinary Guidelines

QOMS

The Quality and Outcomes in Oral and Maxillofacial Surgery (QOMS) project is the quality improvement and clinical effectiveness programme for Oral and Maxillofacial Surgery (OMFS), initiated by the British Association of Oral and Maxillofacial Surgeons (BAOMS).

QOMS operates a series of clinical registries across several OMFS subspecialties (oral and dentoalveolar surgery, trauma, oncology, reconstruction, non-melanoma skin cancers and orthognathic surgery) either as audits / service evaluations to measure the quality of care provided to patients or as disease- or procedure-specific registries to look at medium to long-term patient outcomes to guide recommendations for patient treatment and management. QOMS is already running an audit / service evaluation for oncology & reconstruction.

The SGC registry is run independently from the Oncology & Reconstruction (OR) registry as it will be dedicated solely to salivary gland cancers but patients affected by this type of cancer might also be included in the (more general) OR registry when their treatment falls into the remit of the OR registry.

RATIONALE, AIM & EXPECTED BENEFITS

The rarity and histological diversity of these tumours mean that there is a lack of strong evidence to provide recommendations for their management. In addition, their long natural history also render randomised control trials (RCT) for salivary gland cancers not feasible. The next best level of evidence after RCT is observational evidence based on a registry data.

A registry specific to salivary gland cancers in the head and neck allows for the collation of real-world data can lead to benefits for patients, surgeons, participating institutions, and commissioners. Their overarching aim is to measure and improve quality of care. This can be achieved by better understanding the natural history of these tumours, generating future research hypothesis, raising awareness of this type of cancers, assessing and informing clinicians and patients about the effectiveness of current treatments, their safety and tolerability profiles, providing a faster diagnosis and design care pathways.

When a registry also includes the collection of patient reported outcomes (PRO), it can improve communication between patients and healthcare professionals. From a clinician's perspective, PRO are relatively easy to collect and address in a one-to-one conversation with a patient. The challenge

arises one tries to sense of the outcomes reported by different patients in different ways. The use of standardised PRO measures (PROM) can help.

The registry will initially concentrate on the SGC in the head and neck regions. It is hoped that with time, the registry should expand its remit to not only include other surgical/medical specialties (ENT, Oncology) but also expand its dataset to include non-head-and-neck adenoid cystic carcinomas.

RECOMMENDATIONS

- Ultrasound guided fine needle aspiration cytology is recommended for all salivary tumours and cytology should be reported by an expert histopathologist. (R)
- Adjuvant radiotherapy (RT) following surgery is recommended for all malignant submandibular tumours except in cases of small, low-grade tumours that have been completely excised. (R)
- In the event of intra-operative tumour spillage, most cases need long-term follow-up for clinical observation only. These should be raised in the multidisciplinary team to discuss the merits of adjuvant RT. (G)
- As a general principle, if the facial nerve function is normal pre-operatively then every attempt to preserve facial nerve function should be made during parotidectomy and if the facial nerve is divided intra-operatively then immediate microsurgical repair (with an interposition nerve graft if required) should be considered. (G)
- Neck dissection is recommended in all cases of malignant parotid tumours except for low-grade small tumours. (R)
- Where malignant parotid tumours lie in close proximity to the facial nerve there should be a low threshold for adjuvant RT. (G)
- Adjuvant RT should be considered in high grade or large tumours or in cases where there is incomplete or close resection margin. (R)
- Adjuvant RT should be prescribed on the basis of clinical factors in addition to histology and grade, e.g., stage, pre-operative facial weakness, positive margins, peri-neural invasion and extracapsular spread. (R)
- It should be recognised that the clinical behaviour rather than the histology of a tumour provides a better treatment guide and it is important to consider clinical factors in addition to histology and grade when planning treatment.

Source: Sood et al. J Laryngol Otol. 2016;130(S2):S142-S149. doi: 10.1017/S0022215116000566. Management of Salivary Gland Tumours: United Kingdom National Multidisciplinary Guidelines

INFORMATION GOVERNANCE

The SGC registry will follow the same principles of Information Governance as the other QOMS registries.

- The SGC registry is NOT a research project but an audit / service evaluation, it therefore does not require ethical approval (see Appendix 1).
- Collection of patient identifiable information: Yes
- Data will be collected with seeking patient consent. A patient information leaflet is available in Appendix 2.
- Data collection will be done directly either by dedicated members of staff (data coordinators) or by surgeons.

- Data is collected and stored in an instance of the Research Electronic Data Capture (REDCap) system, hosted and managed by the Barts Cancer Research UK Centre (BCC), Queen Mary University of London (QMUL).
  The Barts CR-UK Centre (BCC) has a valid NHS Digital DSPT toolkit (EE133904-ECC04) and is ISO 27001 certified (Cert. No. 225111).
- Data processing: see data flow in Appendix 3.
- Data retention: 10 years after the end of collection of follow-up data. Data retention for the registry will be reviewed on a regular basis.
- Population: Patients **currently treated for or newly diagnosed** with a (primary) salivary gland cancer. Patients diagnosed with secondary cancers or recurrence of salivary gland cancers are also included.
- Data access is under access control policy:
  - Local clinical lead(s) of participating departments will be given full access (including patient identifiable information) to the records entered in the registry for their own institution only. They will be able to view, edit and download that data to use it locally.
  - Access to the whole dataset is limited to the designated data manager (Fabien Puglia), who is a non-clinical member of the QOMS team. Other members of the QOMS team will only have access to anonymised information.
- Access to the central dataset by any party (individuals/institutions) will require a formal request, via the online data request form. Applicant must demonstrate that they will adhere to relevant information governance regulatory framework. Applications will be reviewed by the SGC working team (as described in SOP).

DATA COLLECTION PROCESS

Consent: The consent process will be set up online. The patient information leaflet will be available both printed and electronic. A copy of the signed consent form will be sent to the patient's email when a valid email address has been provided.

Clinical data: Data collection will be done directly either by dedicated members of staff (data coordinators) or by surgeons. Each user will be provided with a unique username and password to access the online registry. User's access to data will be limited to data collected in a user's institution.

Follow-up and Patient Reported Outcomes (PROs): Patients will followed up yearly until the registry ends or they decide to opt-out. Patient will be contacted yearly to complete a patient reported outcome measures (PROMs).

Imaging and biological samples: Any imaging or biological samples collected as part of patient's diagnosis, treatment or follow-up, will be made available to be reviewed by a panel of expert and used for secondary research. No new samples will be collected as part of the registry.

DATASET

Clinical dataset

Item	Item
Part 1: Demographics to postop pathology	Perineural invasion
Patient's identifier (NHS, CHI...)	Intraneural invasion
Sex	Neural invasion distant to the main tumour?
Date of birth	**Part 2: Radiotherapy**
Age	Radiotherapy intent
History of radiation therapy to head and neck	RT modality
History of previous salivary gland cancer	Indicate dose / fractionation
Family history of salivary gland cancer	Technique
Is the disease presentation a primary or a recurrent/metastatic tumour?	Field
Tumour location	Neoadjuvant agents
Cranial nerve deficit	Neoadjuvant cycles
Skin involvement	Response
Imaging	Concurrent agents
Diagnostic tissue sampling.	Concurrent cycles
Taxonomy (suspected following FNA/Biopsy)	Palliative agents
Histological Grade	Palliative cycles
Clinical staging	Best response
Surgery	Indicate agents
Lymphadenectomy	Were they
Taxonomy (Final Histology)	Hormonal therapy
For poorly differentiated carcinoma	Were they
Histological Grade	Cycles
Pathologic staging	Best response
Location of involved/positive lymph nodes Matrix would work there	**Part 3: Follow-up** (To be completed at the following time 12, 24, 36, 48, 60, 84 & 120 months)
Closest margin (mm) *(For major glands only)*	Did the [X-month visit] take place?
Lateral margin (mm) *(For minor glands only)*	Patient's status
Deep margin (mm) *(For minor glands only)*	Date of follow-up
Immune-histochemical tests and results	(If patient died), DOD
Any molecular tests performed	Recurrence
Other histological features present	Date of diagnosis
Lymphovascular invasion	Treatment

Patient reported outcomes

The tool selected to collect patient-reported outcomes is the University of Washington Quality of Life Questionnaire (UW-QOL v4). The UW-QOL v4 is a 16-question questionnaire, with Q1 to 12 covering the following domains (pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder, taste, saliva, mood and anxiety) and a question about concerns and two more general items. Patients are asked to provide for each items answers typical of the last seven days.

PATIENT AND PUBLIC INVOLVEMENT

A patient and public involvement meeting was organised by Emma Kinloch through the patient network of the Salivary Gland Cancer UK Charity. A group of 9 patients and carers with Emma Kinloch (chair), Michael Ho and Fabien Puglia met online on July 6th, 2022. Prior to the meeting, the project protocol was shared with the group to be used as a starting points for discussions.

The aims of the meeting was for patients and carers to:

(1) Demonstrate that they were satisfied with the rationale, objectives and processes of the registry and

(2) Provide feedback to the working group on the registry form (e.g., scope of the dataset) and content (e.g., readability of the patient information leaflet).

In summary, patients and carers thought that creating a Salivary Gland Cancers registry is positive and could see the benefits to patients, healthcare professionals and commissioners. A summary of the feedback from the group is provided in Appendix 4.

DATA OWNERSHIP

Participating organisations will retain the ownership of the data they entered, while the ownership of the central dataset will be BAOMS. BAOMS will curate data on behalf of participating organisations.

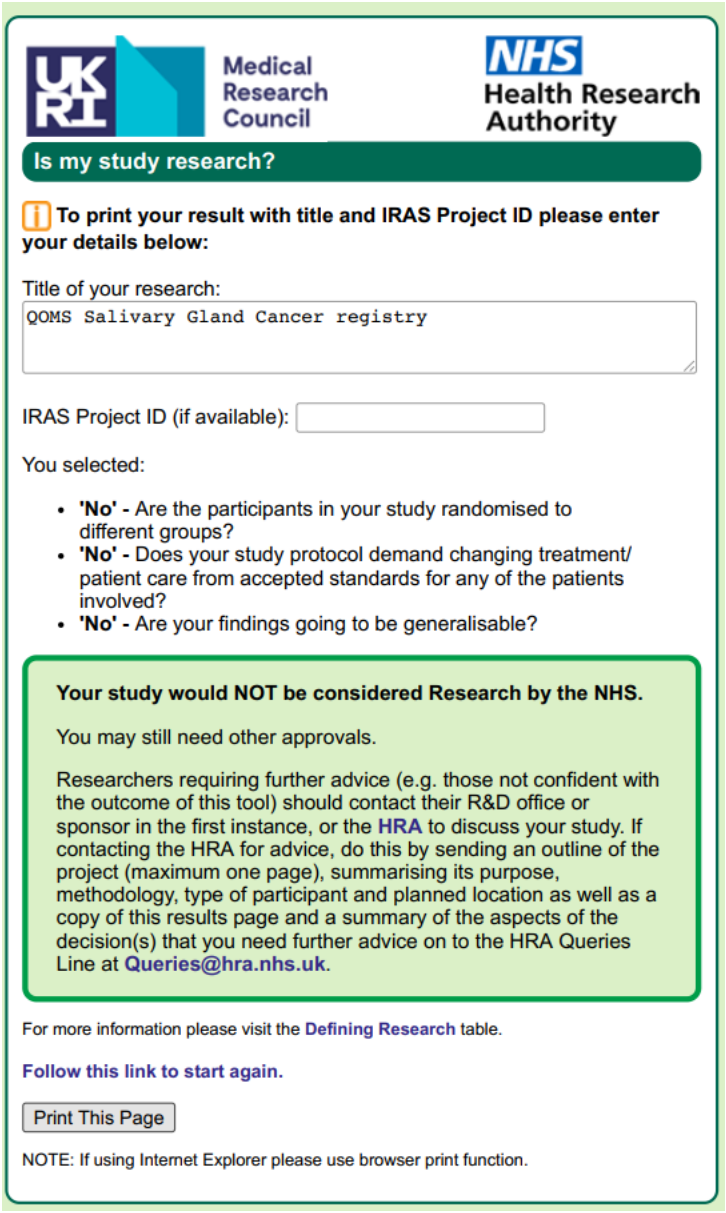
PUBLICATION POLICY

The British Journal of Oral and Maxillofacial Surgery (BJOMS) will have first refusal of any peer reviewed output from this initiative.

Individuals responsible for collecting data will be acknowledged as “collaborators” and listed in publications.

APPENDICES

APPENDIX 1. HRA MRC TOOL KIT "IS MY STUDY RESEARCH?"



Medical Research Council

NHS Health Research Authority

Is my study research?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

QOMS Salivary Gland Cancer registry

IRAS Project ID (if available):

You selected:

- **'No' -** Are the participants in your study randomised to different groups?
- **'No' -** Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'No' -** Are your findings going to be generalisable?

Your study would NOT be considered Research by the NHS.

You may still need other approvals.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the **HRA** to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of this results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at **Queries@hra.nhs.uk**.

For more information please visit the **Defining Research** table.

Follow this link to start again.

Print This Page

NOTE: If using Internet Explorer please use browser print function.

APPENDIX 2A. PATIENT INFORMATION LEAFLET

Version 1.2 Date: 04/04/2023

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:

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

APPENDIX 2B. CONSENT FORM

Version 1.2 Date: 04/04/2023

Consent form for patients aged 16 years and above, deemed to have capacity to consent

Before signing this consent form, please read carefully the accompanying patient information leaflet (version: XX, Date: DD/MM/YYYY) and ask questions to your clinical team. Once you are satisfied, please complete the consent form below to show whether or not you consent to the collection of your personal information and sign this form.

Please **initial** the boxes below

1.	I confirm that I have read and understand the patient information leaflet (version XX, date: DD/MM/YYYY) describing the registry and potentially associated work and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2.	I am fully aware that the project collects personal information about me and that I will remain anonymous.	☐
4.	I understand that I have the right to withdraw my consent at any time without giving a reason and that my care will not be affected.	☐
5.	I agree to having my personal health data stored in this database at the Barts' Cancer Centre	☐
6.	I agree to have images and samples of my blood/tissue collected from any procedures that would have been undertaken as part of my treatment, to be accessed for review and secondary research.	☐
7.	I understand and agree that data from the study can be used in future research and that data would be completely anonymised.	☐
8.	I am fully aware that data collected will be stored securely, safely and in accordance with Data Protection Act (2018) and the General Data Protection Regulation (GDPR).	☐
9.	a. I AGREE to take part in this project and for my information to be collected.	☐
	b. I DO NOT AGREE to take part in this project and for my information to be collected	☐

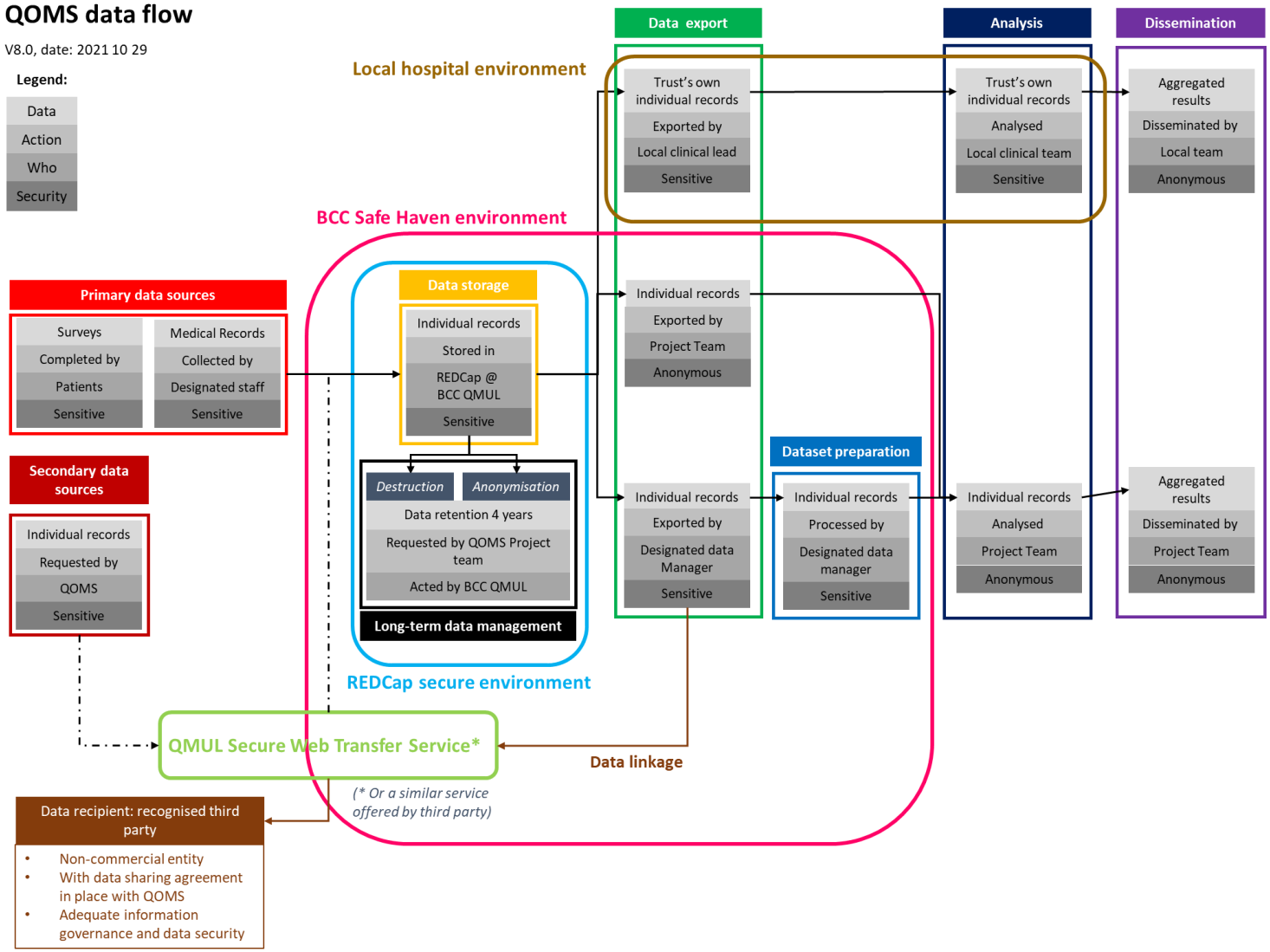
_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Name of the person taking consent	Signature	Date

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

BAOMS | 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

One copy of this form should be given to the patients, one copy kept in the patient's note and the original copy kept by the treating team.

APPENDIX 3. DATA FLOW



APPENDIX 4. PATIENT AND PUBLIC INVOLVEMENT PANEL DISCUSSIONS

Area of concerns / discussions	Discussion points	Answers / Action points
Aims of the registry	Possibility of quality improvement (e.g., postcode lottery) is there a mechanism in place to address disparity?	As part of the wider QOMS project, there is already a head and neck Oncology & Reconstruction (OR) registry. QOMS-OR patients with SGC are included in this OR registry which mainly aims to measure the quality of care provided (see BAOMS website for details). It could be used to complement the SGC registry by providing data about location. There are two caveats – (1) the OR registry is focused on head and neck/oral and maxillofacial cancers and (2) Patients are captured prospectively, with aim to improve quality – measuring hospital length of stay and unplanned reoperations… postcode is collected and then converted to enable evaluation of geographical factors which might affect treatment outcomes.
Aims of the registry	Is one of the aims to produce guidelines for SGC guidelines in the UK?	BAHNO produces treatment guidelines at regular intervals to provide contemporary best practice guidance. As the SGC registry matures, it will hopefully feed into the process by the provision of data on treatment related outcomes.
Outreach	Do we plan to reach out Reaching to other patient groups, local HN support group, healthcare professional categories (e.g., SaLT)?	The intention of the working group is to disseminate information and publicise this registry to the MDT colleagues through representatives in each organisation.
Potential benefits	Lack of continuity in treatment pathways and care plan (e.g. between different treatment institutions, management based on tumour location rather than type)	We hope that the development and introduction of this registry will improve awareness for these rare tumours amongst health professionals, through regional MDTs. Increased awareness and communication could generate early improvement in patient care and experience. This could be achieved by local MDT teams arranging educational sessions during the Annual Head and Neck Cancer Awareness Week.
Potential benefits	Lack of awareness/knowledge of healthcare professionals (dentists, surgeons…) which can significantly delay referral, final diagnosis and treatment	
Potential benefits	Lack of awareness of patients about SGC and treatment options	This could be achieved by local MDT teams arranging educational and patient/public engagement sessions during the Annual Head and Neck Cancer Awareness Week. BAOMS QOMS will disseminate suitable information through the social media.
Project expansion	Collaboration with other specialties and associations (e.g. ENT-UK, BAHNO and BASO)	The registry was initially developed by oral and maxillofacial (OMF) surgeons. We are actively engaging BAHNO, ENT-UK and BASO to endorse and collaborate in this initiative.
Project expansion	Collaboration with non-UK based registries / initiatives	We have already discussed the possibility of taking part to EURACAN and are aware of other initiatives (e.g. in the US). At the appropriate time in the roll-out of this project, we will reach out to other potential stakeholders.
Registry content	To include patient morbidity questions – how treatment (especially radiotherapy) affected patients (hearing,	We are looking into including some or all of these items to the registry through a PROMS component.

	eyesight, jaw opening, muscle tension in face and neck, shoulders, speech, psychological impacts)	
Registry content	Does the registry capture cases where a tumour is not located in the head and neck region?	The registry was developed by oral and maxillofacial surgeons and focuses on tumours in the head and neck region treated surgically, however we will actively encourage and support registration of non-head and neck tumours e.g. adenoid cystic carcinoma. As the registry progresses and grows, we will expand its remit to include non-HN tumours and non-surgical treatment / alternative treatment modalities. Non-surgical treatment could be due to MDT recommendation based on tumour factors (location, size), patient factors (co-morbidities) or patient choice.
Registry content	Does the registry capture cases where a SGC tumour is not treated surgically?	
Registry content	Are SGC biomarkers available?	This information will be recorded for centres which report these findings in their pathology reports (e.g. Ki-67/MIB-1, HER2, MYB rearrangement…).
Registry content	Length of follow-up from surgery	10 years is a minimum and would probably necessitate lifelong follow-up. This is particularly relevant in younger patients who may want to have families in the future. We will change the patient information leaflet and protocol to leave it more open ended.
Registry content	Where patients are treated	SGC treatment is mostly centralised in the UK however the affected patients can present through various avenues and diagnostic tests are still being done in various secondary care settings.
Registry content	Does the registry capture time from diagnosis to treatment?	Yes
Registry content	Possibility to capture patients who went abroad to get treated	If the patients have some or part of their diagnostic work-up and/or care in the UK and consent to inclusion in this registry then they will be included in this registry.
Registry content	Capture of change of diagnosis, esp. from benign tumour to SGC. To decrease “diagnostic shock” and improve process for patient to get ready for surgery, consent, avoid 2 episodes of surgery? Referral to subspecialists. Are there some more reliable test that could / should be performed?	Yes these information will be collected in the SGC registry and linked with PROMs outcomes to help us understand its impact on the patient’s experience better.