

# Managing Salivary Gland Cancers in Primary Care



[www.salivaryglandcancer.uk](http://www.salivaryglandcancer.uk)

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# Who we are



## Emma Kinloch

**BAHons (Oxon), MSc, MA**

- Investment Management: 20+ years experience in Europe and Asia.
- National Cancer Research Institute ('NCRI') Salivary Gland Cancer working group co-chair
- Adenoid Cystic Carcinoma Research Foundation ('ACCRF') Board member
- European Reference Networks, head and neck cancer domain Patient group representative
- Board member Head and Neck cancer Coalition
- Salivary Gland Cancer patient and founder of SGC UK

## Dr Robert Metcalf

**MB ChB, PhD, MRCP**

- Consultant Medical Oncologist (Salivary/Head and Neck Cancers) The Christie NHS FT, UK clinical leadership role for salivary gland cancer
- Honorary Reader, The University of Manchester
- National Cancer Research Institute ('NCRI') head and neck group member
- International Rare Cancers Initiative Salivary Group co-chair (UK)

## Dr Steve Churchill

**MB ChB, MRCGP, BMedSci (Hons.)**

- Salaried GP, Bodmin Road Health Centre
- GP with Specialist Interest and Clinical Research Physician in Medical Oncology (HPB and Head & Neck), The Christie NHS FT
- Primary Care Clinical Lead for Personalised Care, Greater Manchester Cancer Alliance
- Clinical Lead for Rapid Diagnosis of Cancer Programme at Manchester University NHS FT
- Clinical Lecturer and Academic Advisor, University of Manchester



# Disclosures

Dr Metcalf has previously received honoraria for advisory boards, research grants and meeting sponsorship from:

- Achilles Therapeutics
- AstraZeneca
- Ayala
- Bayer
- Bristol Myers Squibb
- Elevar
- Merck Sharp and Dohme
- Sanofi
- Roche



# Outline

- What are salivary gland cancers (SGCs)?
- What is SGC UK and what do we do?
- What are the challenges for primary care in diagnosing SGC?
- How can we support primary care clinicians to improve outcomes for patients with SGC?

# What would you do?

45-year-old man with a 2-week history of a hard, painless swelling in left parotid gland

- A – Urgent neck ultrasound
- B – Prescribe oral antibiotics
- C – Monitor and review in 2 weeks
- D – 2ww ENT referral

# The patient experience

Often asymptomatic or symptoms that are 'out of context' and easily explained by something else so missed as being cancer

- E.g. shooting pain and facial 'shimmering' due to teeth grinding for someone with a stressful job, rather than ACC invading the facial nerve

The 'diagnostic odyssey' it can often take multiple visits and referrals to get diagnosed – and that's when the GP is 'listening' - patients struggle sometimes to get heard

- E.g. several mouthguards made, prescribed steroids and two MRI scans a year apart before the cancer was diagnosed

There are many stories from patients on our webpage: [Our Stories - Salivary Gland Cancer UK](#)

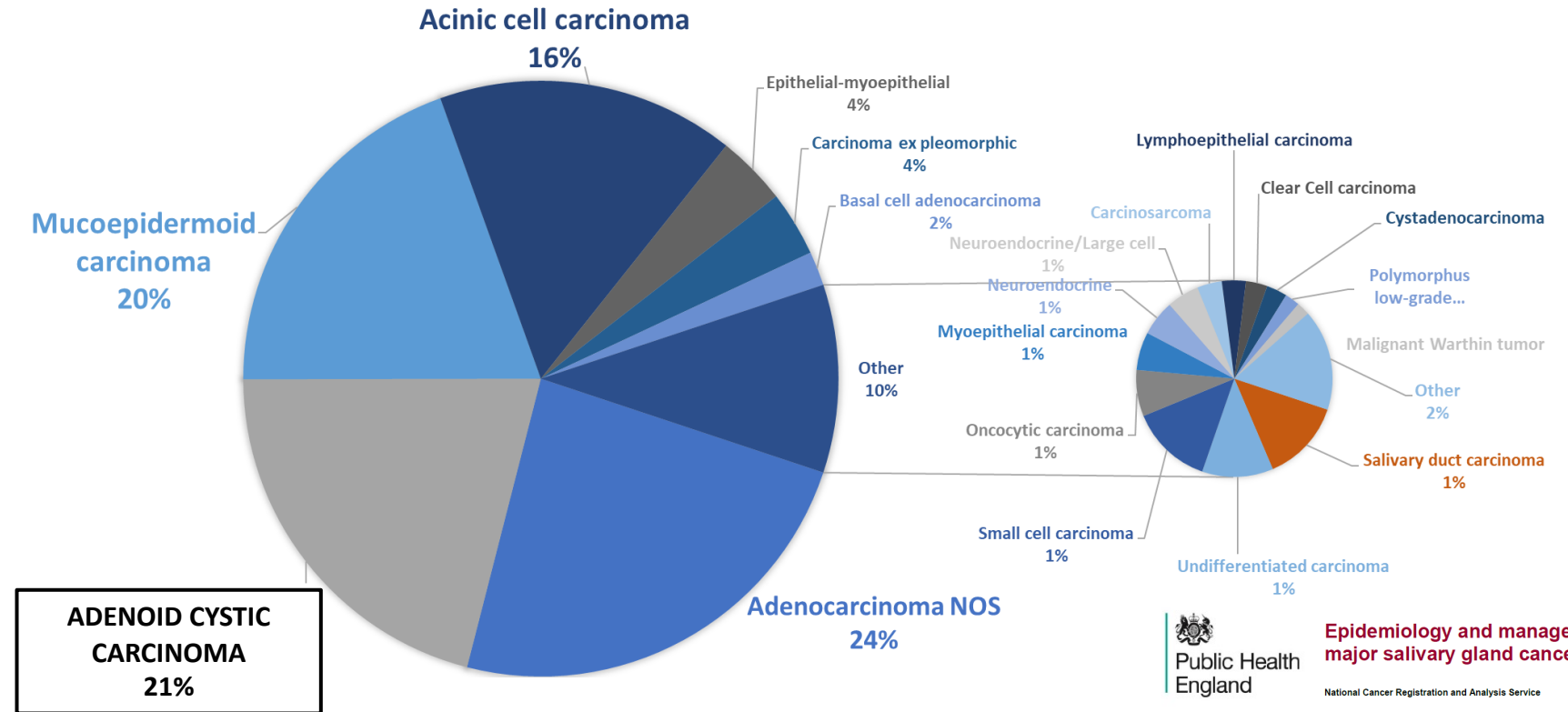
# What are Salivary Gland Cancers?

UK CANCER REGISTRY DATA – ALL SALIVARY GLAND CANCERS 4 YEARS TO 2013

n = 3,675

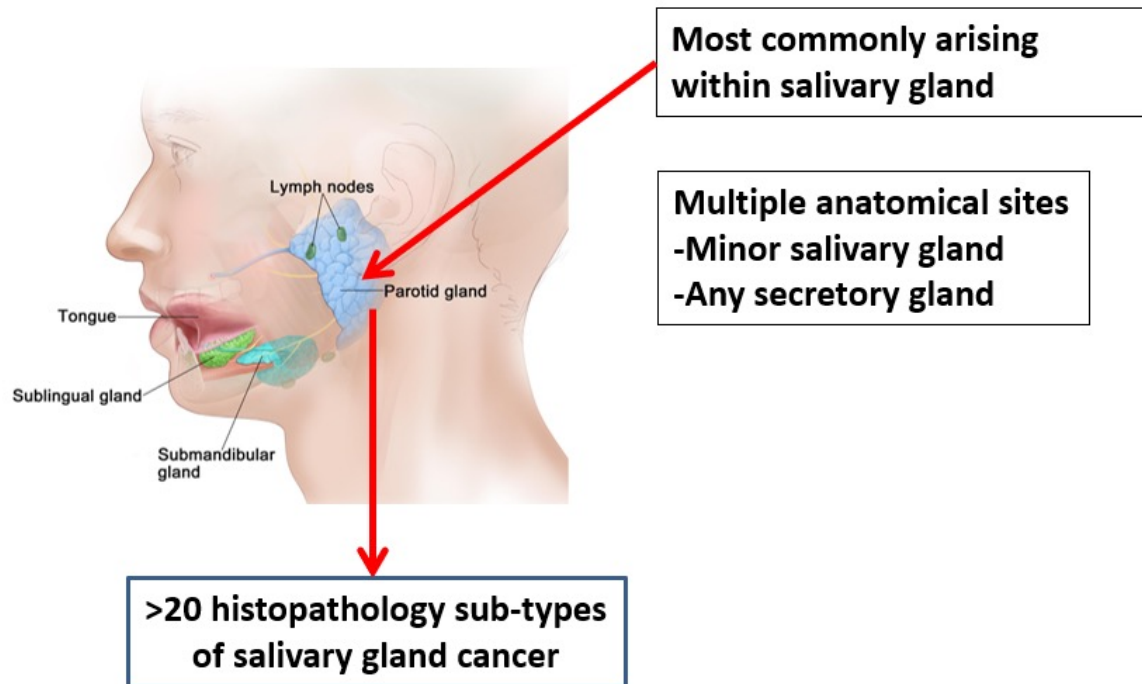
## CHALLENGES

- >20 sub-types
- Small absolute case numbers
- Research progress is decades behind more common cancers
- 6 out of 7 salivary gland tumours are benign





# Our initial focus was adenoid cystic carcinoma (ACC)



## What is ACC?

- ACC is a cancer of salivary gland and other secretory glands
- **Distant recurrence** occurs on most despite surgery/radiotherapy at diagnosis
- There are **no effective drug therapies**

## Primary unmet need

- Develop new and effective drug therapies
- We have identified 12 key challenges

# And what is challenging?

No identified risk factors lead to late diagnosis

Limited treatment options

Living with and beyond, often with metastatic disease and late effects

Research and access to trials

- Low patient numbers
- Knowing about them
- Tumours occur across anatomical sites
- Access to genomic profiling

Urgent healthcare problem

# Meeting the unmet needs in the UK and beyond



In April 2019 Salivary Gland Cancer UK ("SGC UK") was launched

[Setting up a charity for an "orphan" cancer - The BMJ](#)

Collaboration and coproduction to build an active patient and research community:

- Understand the biology of SGC's, advance research, develop new treatments
- Provide peer support & reliable information to patients and carers
- Develop a network of people affected by, treating and interested in SGC's to move it all forwards



# What's been achieved

- **Regular Patient and Clinician gatherings**
  - Deep dives into research developments, treatments and processes e.g. ASCO updates, carbon ion therapy and the challenges of diagnosis for SGC
  - Videos and podcasts, Youtube channel
- **Expanded network to include 'orphaned' cancer types/patients**
  - E.g. Acinic cell carcinoma, secretory carcinoma, MEC
  - International – Indonesia to Indiana
  - Patient stories
- **Providing reliable information for patients through collaborative work**
  - Return to work guide
  - Genomics leaflets, gene profiling
- **International work**
  - ESMO Guidelines for Salivary Gland Cancers
  - Registries: STARTER EURACAN project
  - Rare Cancers Initiative ('IRCI') for collaborative clinical trials
- **Awareness**
  - Social media on twitter / FB / Insta



# 8 Aims for SGC UK

*- identified through patient/clinician co-production*

## **1. To build support and information networks** to:

1a. Bring together those living with salivary gland cancers, giving them access to the latest information on their disease, and mutual support networks

1b. Raise awareness of salivary gland cancers, their symptoms and treatments amongst the general public and the clinical community

1c. Bring together the patient, clinical and research communities to help drive forward research and improvements in treatments

2. Support advances in the understanding of the experience of living with and beyond these cancers, and the development of interventions to improve this experience

## **3. Improve the rate of early diagnosis for salivary gland cancers**

## **4. Optimise the pathways to diagnosis**



# 8 Aims for SGC UK

**5. Support the development of standardised guidelines for the management and surveillance of individual salivary gland cancers.**

6. Understand the effectiveness of different types of radiotherapy for specific salivary gland cancers.

7. Support the development of surgical and radiotherapy treatments to deliver improved survivorship and quality-of-life post-treatment for salivary gland cancer patients.

8. Support the development of standard drug treatments for salivary gland cancers to improve life expectancy and survivorship by:

8a. Supporting research into the biology of individual salivary gland cancers.

8b. Supporting translational research that turns this knowledge into effective treatments.

8c. Developing and pushing forward drug trials to test the effectiveness of both existing drugs, and those specifically developed to target a particular salivary gland cancer.





# Example patient journey

- August 2016 – patient found submandibular lump
- October 2016 – ultrasound scan reported as no abnormality detected
- January 2017 – persistent symptoms, MRI scan showed mass in the floor of mouth
- January 2017 – ultrasound guided biopsy confirmed adenoid cystic carcinoma
- February 2017 – staging CT scan showed lung metastases
- March 2017 – chemoradiotherapy with concurrent cisplatin with partial response
- 2017-2021 – slowly progressive disease
- August 2021 – extensive disease progression, commenced palliative Lenvatinib (off-licence)
- January 2022 – progressive disease, seen in early phase trials clinic and added to active waitlist
- August 2022 – Commenced STA551 monotherapy (as part of STA101JG Phase 1 trial)

# Treatments and Prognosis

## Localised disease

- Surgery +/- adjuvant radiotherapy

## Inoperable/metastatic disease

- No licensed treatments
- Options include chemotherapy, radiotherapy, surveillance
- Newer targeted treatments
- Early phase trials

## Prognosis highly variable

# Challenges for Primary Care



Rare disease

Vague symptoms

Lack of continuity

No clear guidelines

Remote consultations

# Diagnostic approach

Examine, examine, examine...

- Caution with remote consultations

Fixed, hard, immobile lumps

Persistent unexplained symptoms

- Altered sensation, altered speech/mastication

Early referral

## Oral cancer

- 1.8.2 Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for oral cancer in people with either:
- unexplained ulceration in the oral cavity lasting for more than 3 weeks **or**
  - a persistent and unexplained lump in the neck. **[2015]**
- 1.8.3 Consider an [urgent](#) referral (for an appointment within 2 weeks) for assessment for possible oral cancer by a dentist in people who have either:
- a lump on the lip or in the oral cavity **or**
  - a red or red and white patch in the oral cavity [consistent with](#) erythroplakia or erythroleukoplakia. **[2015]**
- 1.8.4 Consider a suspected cancer pathway referral by the dentist (for an appointment within 2 weeks) for oral cancer in people when assessed by a dentist as having either:
- a lump on the lip or in the oral cavity consistent with oral cancer **or**
  - a red or red and white patch in the oral cavity consistent with erythroplakia or erythroleukoplakia. **[2015]**

## Laryngeal cancer

- 1.8.1 Consider a [suspected cancer pathway referral](#) (for an appointment within 2 weeks) for laryngeal cancer in people aged 45 and over with:
- [persistent unexplained](#) hoarseness **or**
  - an unexplained lump in the neck. **[2015]**

## Thyroid cancer

- 1.8.5 Consider a suspected cancer pathway referral (for an appointment within 2 weeks) for thyroid cancer in people with an unexplained thyroid lump. **[2015]**

# NG 12



# Management of a salivary gland lump

- If there is a parotid or submandibular gland swelling that is persistent and/or unexplained:
  - Arrange urgent referral (for an appointment within 2 weeks) to an ear, nose, and throat surgeon.
- If there is a suspected [salivary gland calculus](#):
  - Arrange referral to an ear, nose, and throat surgeon or maxillofacial surgeon, depending on local service provision, the urgency depending on clinical judgement.

## Basis for recommendation

^ [Hide](#)

The recommendations on management of salivary gland swellings are based on the UK publication *Management of salivary gland tumours: United Kingdom national multidisciplinary guidelines* [[Sood, 2016](#)] and expert opinion in review articles on salivary gland disorders [[Wilson, 2014](#)] and on salivary gland tumours [[Mantravadi, 2019](#)].



# NICE CKS



# How can we help?



Establish NG12 guidelines

Primary care education

Engaged patient group

# What would you do now?

45-year-old man with a 2-week history of a hard, painless swelling in left parotid gland

- A – Urgent neck ultrasound
- B – Prescribe oral antibiotics
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# Take-home messages

- Salivary gland cancer is rare
- Diagnosis often takes a long time
- **Early diagnosis leads to better outcomes**
- Treatment options are very limited
- **Current guidelines do not support early diagnosis**
- We are here to help

# Thank you for listening

(and for all you do)



[www.salivaryglandcancer.uk](http://www.salivaryglandcancer.uk)

## Any questions?

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