

Report on the UK Head and Neck Sarcoma (HNS) Survey of professionals – Where do we go from here ?

Head and Neck Sarcomas (HNS) are a rare and diverse group of tumours with multiple histological subtypes of both bone and soft tissue. They have a variety of clinical presentations and often involve complex multimodality treatment. Management pathways across the UK can vary for this disease. The Scottish Sarcoma Network (SSN) and British Sarcoma Group (BSG), in collaboration with British Association of Head and Neck Oncologists (BAHNO) conducted a survey to better understand the pathways for the management of Head and Neck sarcomas in patients over 16 years of age.

The Survey questionnaire was designed by a steering group consisting of Head and Neck and Sarcoma UK Specialists from all relevant clinical disciplines. Namely, ENT surgeons, Maxillofacial surgeons, Head and Neck Oncologists and Sarcoma Oncologists (*Appendix 1*). Details on the survey questionnaire are found in *Appendix 2*. The survey questionnaire received endorsement by the British Sarcoma Group (BSG) and the British Association of Head and Neck Oncology (BAHNO).

The survey was communicated to head and neck and sarcoma specialists through professional networks, such as NCRI Head and Neck CSG, BSG and BAHNO and nominated “champions” through the steering group. In Scotland the survey was conducted through the National Sarcoma Managed Clinical Network (SSN) and the three regional (North, South East and West) Head and Neck Cancer managed clinical networks.

No funding was associated with this piece of work. No HRA approval required as this was a service evaluation project. This is the first time a survey of professionals on this subject is done. Limitations of this service evaluation include limited amount of responses, associated biases, however given how niche this clinical entity is, we decided there is value in reporting our results.

The key findings from the survey have been presented at the BSG 2020 Conference and are summarised below:

- 94 Consultants across the UK who managed H& N sarcomas participated in the survey, including ENT(19%) and maxillo-facial surgeons(23%), Plastic surgeons (2%) and, Oncologists (46%: clinical and medical, specialising in sarcomas and/or Head and Neck). Consultants from other sub-specialties in sarcoma care(eg Radiologists and pathologists) were not represented in the survey.
- **Geographical Response distribution:** 23% of the responses came from Scotland and 4% from Northern Ireland, 71% from England and 1% from Wales.
- **Volume of practice:** 12% responded in their centre they treat over 40 sarcomas per year, 37% between 10-39 cases and 52% less than ten.
- **Management pathways for Head and Neck soft tissue sarcomas(HNSTS):** 61%(n= 56) of the responders indicated there is a clear management pathway for HNSTS, 13%(n=12) indicated there is no clear pathway and 23%(n=21) were unsure.
- **Management pathways for Head and Neck bone sarcomas (HNBS):** 59%(n=55) of the responders indicated there is a clear management pathway for bone head and neck sarcomas, 10%(n=9) indicated there is no clear pathway 30%(n=28) were unsure.

- **Cross MDT collaboration and input:** Majority (86%) of the responders indicated that Patients with head and neck sarcomas are being discussed at both head and neck and sarcoma MDTs. 3% responded there is a dedicated Head and Neck Sarcoma MDT in their center.
- **Pathology review by sarcoma specialist for HNS:** Majority (87%) of the respondents indicated that pathology is reported by a Specialist Sarcoma Pathologists. 12% of the responders reported they were not sure.
- **72% of the responders report they refer a HNS case to a specialist centre for discussion.**
- **CNS input provision:** It was felt that Clinical Nurse Specialist provision is good either from a head and neck CNS, or a sarcoma CNS or both .
- **Dietetic/SALT input provision:** Similarly respondents felt that Allied Health Professional provision is good for Dietetics and Speech and Language Therapy but poor for psychosocial support .
- When asked whether they would support some form of supra-regional/ national head and neck, the majority of respondents said they would support this although sarcoma MDT is supported, although there were concerns raised about whether this was feasible.
- What are the current issues with the management of HNS in the UK: 88% of the responders indicated there is need for national consensus guidelines.

The BSG is currently updating the clinical guidelines for both bone and soft tissue sarcoma and a subsection relating to head and neck sarcomas will be incorporated into those manuscripts alongside a stand-alone guideline document specific to head and neck sarcomas.

Dr Ioanna Nixon, on behalf of SSN and BSG

Dr Lindsay Campbell, on behalf of SSN

Mr Andrew Hayes, on behalf of BSG

Appendix 1

Steering Group

Dr Ioanna Nixon, Consultant Clinical Oncologist, Head and Neck/Sarcoma, Glasgow

Dr Aisha Miah, Consultant Clinical Oncologist, Sarcoma, London

Dr Fiona Cowie, Consultant Clinical Oncologist, Sarcoma, Glasgow

Mr Jeremy McMahon, OMFS Surgeon, Glasgow

Mr Stuart Winter, ENT Surgeon, Oxford

Dr Bernadette Foran, Consultant Clinical Oncologist, Head and Neck, Sheffield

Dr David Thomson, Consultant Clinical Oncologist, Manchester

Prof Peter Brennan, OMFS surgeon, Southampton

Professor Jim McCaul, OMFS and MCN Lead for HNC in the West of Scotland, Glasgow

Appendix 2

Survey Questionnaire

- 1. You are**
 - OMFS Surgeon
 - ENT Surgeon
 - Base of Skull Surgeon
 - Medical Oncologist(H&N)
 - Medical Oncologist(Sarcoma)
 - Clinical Oncologist(H&N)
 - Clinical Oncologist(Sarcoma)
 - Other
- 2. Your practice is based in**
 - England
 - Scotland
 - Wales
 - N. Ireland
- 3. What is your primary hospital base?**
 - General hospital
 - Specialised Centre(bone and soft tissue sarcoma)
 - Specialised centre(soft tissue sarcoma), University Hospital
 - Other.
- 4. Do you treat Head and Neck Sarcomas in your centre with (choose all applicable)**
 - Surgery
 - Chemotherapy
 - Radiotherapy
- 5. If yes, how many Head and Neck sarcomas are treated in your centre per year?**
- 6. Is there a specific Head and Neck Soft Tissue Sarcoma pathway established in your centre?**
 - Yes
 - No
 - Unsure
 - Other
- 7. Is there a specific Head and Neck Bone Sarcoma pathway established in your centre?**
 - Yes
 - No
 - Unsure
 - Other
- 8. If a Head and Neck Sarcoma (Bone or Soft Tissue) case presents, where is it discussed?**
 - At Head and Neck MDT
 - At sarcoma MDT
 - At both Head and Neck and Sarcoma MDT
 - at dedicated Head and Neck Sarcoma MDT
 - Other

9. Are all Head and Neck sarcomas discussed at a sarcoma MDT at diagnosis?

Yes No Unsure Other

10. Are all Head and Neck sarcomas discussed at a sarcoma MDT after surgery?

Yes No Unsure Other

11. Surgery is performed at:

a Head and Neck Centre

a Head and Neck centre following discussion at the Sarcoma MDT

a sarcoma Centre

Not sure

other

12. Final pathology is reviewed by a sarcoma specialist

yes always. Occasionally No Not sure. Other

13. Head and Neck sarcoma patients who require chemotherapy are treated by:

Head and Neck oncologist

Head and Neck oncologist following discussion with sarcoma oncologist

Sarcoma oncologist

Other

14. Do Head and Neck sarcoma patients have designated key worker support?

Yes, Head and Neck CNS.

Yes, Sarcoma CNS

Both Head and Neck and Sarcoma CNS

no

not sure

other

15. If oncological treatment is delivered by sarcoma oncologist, do these patients have access to a multidisciplinary team (SALT, dietician).

Yes No Unsure Other

16. Head and Neck sarcoma patients requiring radiotherapy are treated by:

Head and Neck Clinical oncologist Sarcoma Clinical Oncologist

17. In your opinion, given the heterogeneity and rarity of these tumours, should we have a designated MDT for challenging cases?

Yes No Unsure Other

18. If yes, would monthly meetings be sufficient?

19. When you come across a Head and Neck Sarcoma case, do you refer to a specialist centre for discussion?

Yes No Unsure Other

What are the current issues with the treatment of Head and Neck Sarcomas

20. Is the treatment pathway clear?

Yes No Unsure Other

21. are the treatment decisions communicated in a timely manner?

Yes No Unsure Other

22. Do we need to provide national consensus guidelines?

Yes No Unsure Other

23. Who should perform surgery?

Head and Neck surgeon Dedicated Centre Dedicated Team Unsure. Other

24. Is there adequate access to a multidisciplinary team for these patients?

Yes No Unsure Other

25. Is there a Head and Neck Sarcoma Lead in your centre?

Yes. No