This vision does not represent government policy but provides useful insight into how sarcoma services might develop over the next 5 years

Annex I

Sarcoma 2015

Epidemiology

1. There are around 50 different types of sarcoma, generally categorised as soft tissue or bone sarcomas. There are around 3000 new cases of soft tissue sarcoma reported in the UK each year and around 500 bone sarcomas. This is likely to be an underestimate of the true incidence. It is expected that the incidence will increase further by 2015 as a result of better diagnosis leading to more accurate identification and reporting and an aging population (some sarcomas are more common in older people although not all).

2. Progress is being made to determine the true level of sarcoma via the National Cancer Intelligence Network. There is now clear information on the numbers of bone sarcoma patients, but there is still a lack of clarity about soft tissue sarcoma patient numbers. This needs to be addressed as a priority.

IOG implementation

3. The key priority for people with sarcoma or potential sarcoma is that the Improving Outcomes Guidance (IOG) is fully implemented across the country. The IOG is not currently fully implemented so steps must be taken to ensure this happens as soon as possible. In the Networks where it has been implemented, it appears to be working well.

4. By 2015, commissioners should be ensuring that all sarcoma services are fully IOG-compliant.

Prevention

5. There will be no significant developments to our knowledge or practice of how to prevent sarcoma by 2015.

Screening

6. There will be no role for national screening programmes for sarcoma by 2015. However, people with neurofibromatosis (a genetic condition where people develop multiple, benign tumours of nerve tissues) and their families are at increased risk of developing sarcoma and should be assessed at regular intervals.

7. By 2015 referral pathways to neurofibromatosis services should be clearly identified with agreed protocols for sarcoma detection in operation and audited between specialist neurofibromatosis services. Neurofibromatosis services should have identified referral pathways to nominated sarcoma treatment centres.

Raising Awareness/ Improving referral

8. With the exception of some soft tissue sarcomas, it is unlikely that potential sarcomas will be picked up as part of 2 week wait referrals. Most patients who are diagnosed with sarcoma report having made multiple GP visits before being referred to a specialist. However, a GP is unlikely to see many sarcomas in their career and even when they do they can be difficult to recognise. Support should be given to GPs to make more accurate and timely referrals. For example:
    i. easier access to cross sectional imaging such as ultrasound, MRI and CT;

ii. measuring lumps on first presentation so that there is a baseline to assess any growth;
iii. prospectively auditing current referral guidelines for suspected sarcoma to identify effectiveness; and
iv. the NCRI Primary Care Clinical Studies Development Group should identify methods by which further evidence could be gained including the development of intervention studies to improve the time to diagnosis of patients with sarcoma. For example, it is uncommon for teenagers and young people to visit a GP many times in a year so increased appointments might trigger further consideration of signs and symptoms in this group.

9. Patients with suspected sarcoma should always be referred to recognised sarcoma diagnostic/treatment centres.

10. By 2015:
    i. the role of GP referral guidelines should have been evaluated and updated if appropriate; and
    ii. more work should be carried out to develop and implement more effective strategies – any intervention studies (not sarcoma-specific) that NCRI may have in the pipeline should be supported to inform this work, for example, studies proposed by the NCRI's teenage & young adult clinical studies development group.

<u>Diagnostics</u>

11. The diagnostic stage in the patient pathway has the potential to produce the most improvement in services for people with sarcoma. Cross sectional imaging (ultrasound, CT or MRI) is key to diagnosing sarcoma and in the past long waiting times to access these tests may have deterred GPs from requesting such investigations. There remains a need to increase ultrasound capacity, however, diagnostic capacity for both CT and MRI has increased and this has the potential to lead to earlier diagnosis of some sarcomas but more radiographers and radiologists are needed. Molecular diagnostics will also evolve over the next 5 years and diagnostic services will need to modernise in line with this.

12. By 2015:
    i. the threshold for suspicion leading to a GP referral for cross sectional imaging should be lower - advice (not necessarily sarcoma specific) needs to be produced to support GP referral for cross sectional imaging;
    ii. the dedicated sarcoma diagnostic centres, required in the IOG, should have been up and running for several years with the additional specialist radiologists and histopathologists needed to support them - by 2015 these centres should have been evaluated to see if they have been effective in accurately diagnosing sarcoma and any findings acted upon;
    iii. histological material from all patients with sarcoma should be analysed in centres with access to appropriate molecular diagnostic services. Such centres should be adequately resourced; and

iv. all centres dealing with sarcomas should store fresh tissue for future research and comply with the HTA, and offer patients the opportunity to enter national sarcoma studies.

Treatment

13. Some outcomes for bone sarcomas are currently inferior in the UK compared with other European countries.

14. National commissioning is appropriate for most sarcomas. It should be undertaken using the series of clinical guidelines currently under development by the British Sarcoma Group that provide a guide to required standards. National commissioning does not currently relate to retroperitoneal sarcoma and there remains a need for clearer structures for this type of sarcoma.

15. The key to treating soft tissue sarcomas is that evaluation and treatment decisions are undertaken by an experienced specialist multidisciplinary team. Surgery will continue to be the main treatment for this group of sarcomas but newer techniques for treating liver and lung metastases will become more important. Centralisation in line with the IOG is supported but may need to go further for some of the rarer sarcomas (such as retroperitoneal sarcoma and GIST) which provide significant management problems. Best results are likely if these sarcomas are managed in recognised centres where sufficient cases are treated to ensure that experience is adequate – this will require setting up supra regional centres as set out in the IOG.

16. Plans for a single national multi-centre MDT for Ewing's sarcoma are welcome and its development should be supported.

17. Training and succession planning are key elements in securing high quality services in the future. Training requirements provide another strong argument for further centralisation of sarcoma surgery and treatment.

18. Over the next 5 years there will be an increasing role for conformal radiotherapy, IMRT and proton therapy in the treatment of sarcoma. The latter is particularly useful in certain sites of the body where the tumour is lying very close to critical structures. It is also likely that, as radiotherapy capacity expands, there will be increasing use of pre-operative radiotherapy. In addition, it is likely that there will be an increase in treatment possibilities from a variety of new drugs. These developments in treatment will improve the prognosis of many patients but will also present funding challenges.

19. A key way of improving patients' experience of treatment for sarcoma is through prompt (ideally immediate) reporting of test results, in particular scans. Slow reporting of scans is a significant cause of patient stress and anxiety.

20. There has been a very welcome increase in the number of first and second line research studies for metastatic disease, as well as the new surgical study for GIST and plans for new approaches in the treatment of soft tissue sarcomas. Patients should be encouraged to enter appropriate clinical trials.

21. By 2015:

i. momentum should be maintained in sarcoma research;
ii. outcomes of treatment of bone sarcomas should be equal or superior to those achieved in the US and other European countries. This will require greater centralisation of bone sarcomas for treatment other than surgery as well as the establishment and evaluation of nationally coordinated mechanisms for planning local therapy decisions for bone sarcomas such as Ewing's sarcoma;
iii. there needs to be increased radiotherapy capacity across the country including access to new radiotherapy techniques such as conformal radiotherapy and IMRT;
iv. there should be a national proton facility with capacity to treat certain sarcomas. In the interim the centrally facilitated scheme should ensure fair access to proton facilities abroad;
v. the Cancer Drugs Fund and the introduction of Value-Based Pricing should help address the challenges sarcoma patients have sometimes experienced when trying to access drugs. This will need to be kept under close review;
vi. all sarcoma treatment centres should have defined strategies for training key staff and succession planning for core MDT members; and
vii. national multidisciplinary audits of NCG-commissioned services (National Commissioning Group) for bone sarcomas should be regularly undertaken and results published. An equivalent national audit for soft tissue sarcoma should also be up and running.

Supportive & Palliative Care

22. By 2015 there should be:

i. greater co-ordination of a patient's care, ensuring that specialist centres and health and social services work together in a seamless way, for example, to ensure that patients have the equipment and support they need to return home;
ii. provision of specialist prostheses (eg. prosthetic limbs) for children, teenagers and young adults which take account of an individual's needs and lifestyle preferences. For example, the provision of both a walking and a sports limb if needed. At the moment prostheses tend to be aimed at older patients when a significant number of sarcoma patients are children and young adults;
iii. more clinical nurse specialists (CNSs) especially if they are to take on the key worker role envisaged in the IOG; and
iv. a high standard of care available in all hospitals that may treat cancer patients who develop febrile neutropenia.

Follow up

23. There are some sarcoma groups where justification of longer term follow up is clear (eg. bone sarcomas) but for others the evidence is less clear and there is no national consensus on the duration of follow-up particularly for low-grade tumours. The overriding principle should be that the needs of the patient should be placed at the heart of any decision over follow-up, rather than considerations about service organisation. A national study looking at follow up is underway, with results due in 2012.

24.By 2015:

i. findings from the study looking at follow up for sarcoma patients should have been considered and acted upon;
ii. number of non-sarcoma specific actions also need to have taken place;
iii. collection of information about what patients think of, and want from, follow up both in terms of short term (possible reoccurrence) and longer term (late effects of treatment and late recurrence) follow up;
iv. an evaluation of existing international guidelines on follow-up;
v. development of a risk stratification model for follow-up, which should be standard practice and in regular use; and
vi. development of different models of follow-up including clear routes back to specialist MDTs where follow-up is led elsewhere.

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