

## Introduction

GIST Cancer UK is a charity which represents the interests of those who have or had a GIST, and their family and friends (see [www/gistcancer.org.uk](http://www/gistcancer.org.uk)). GISTs are the most common form of sarcoma. This submission draws on evidence from a range of sources including our helpline, comments on our online forum and an activity held during a recent patient meeting specifically to inform this response. The latter involved around 60 people and focussed on two key aspects relevant to patients: diagnosis and treatment. This sample group had both negative and positive experiences as discussed below.

We have used the format suggested for responses from non-patients since there are wider policy issues which are relevant to us as a charity working in this area, although we do not have detailed knowledge of some aspects such as operational issues within the NHS.

## Health policy and sarcoma care (including data)

*Is national policy on health, including cancer and sarcoma (where you or your organisation is based, i.e. England, Scotland, Wales or Northern Ireland) delivering good or improving health outcomes for people with sarcoma, including addressing health inequalities? If not, how could policy be improved?*

Overall, since the foundation of the charity in 2009, national policy has provided good and improving health outcomes for those diagnosed with a GIST in the UK. This is the result of an improved understanding of GISTs and their treatment amongst healthcare professionals and their commitment to improving patient outcomes. More critical comments in this response should be viewed in the context of a good if somewhat inconsistent, overall picture.

The relevant National Institute for Clinical Excellence (NICE) guidelines are set out in [Improving outcomes for people with sarcoma](#) (2006) which emphasises amongst other aspects: the importance of prompt treatment, good communication between patients, their families and healthcare professionals, the importance of treatment being carried out by specialists through referral to a diagnostic clinic at, or linked to, a sarcoma treatment centre, the nature of the specialists who should make up a Sarcoma MDT and the support and rehabilitation that should be available after surgery. The British Sarcoma Group guidelines specifically for the management of GIST include sections on incidence, aetiology, diagnosis, including risk assessment, treatment and follow-up (see [www.nature.com/articles/s41416-024-02672-0](http://www.nature.com/articles/s41416-024-02672-0)) and were last reviewed and republished in 2024. Together these guidelines provide important reference points for patients and healthcare practitioners. The lack of a recent review of the NICE guidelines suggests to patients that this is not a priority area for the NHS.

Whilst most patients respond well to treatment, early diagnosis is important and there are some forms of GIST for which there is limited or no treatment. The effectiveness of the current arrangements for diagnosis are difficult to quantify since the GIST community is not made aware of key performance indicators or benchmarking data. If such data is available, it is not shared *routinely* with GIST Cancer UK although we have received presentations on such information in the past (see <https://www.gistcancer.org.uk/information/the-national-picture/>). Patients would welcome being able to see their cancer journey in the broader context that such data and analysis would provide.

None of the patients we surveyed reported that their views on any aspect of their diagnosis and treatment had been sought as part of their care package. Whilst we recognise that the number of GIST patients can be small on a local basis, aggregating for those with sarcomas would give meaningful data to inform future delivery. Furthermore, it is impossible to know if the expectation in the national guidelines that there is, for example, 'good communication

between patients, their families and healthcare professionals' is met if this is not measured and reported on.

We have not seen data relating to perceived health inequalities in relation to treatment since numbers and associated data are limited. Anecdotally, some patients report difficulties in accessing appropriate diagnosis and treatment depending on distance to a specialist centre and associated travel costs.

GIST Cancer UK has in place a range of support mechanisms for those diagnosed with a GIST which are highly valued by the community we represent. We rely on patients (and/or family and friends) finding their way to our website or being referred there by healthcare practitioners. Currently we estimate that only around 20% of those diagnosed formally register with us. For some this may be out of choice but for others clearer direction to their charity could lead to more immediate access to guidance and support. More could be done by medical teams to raise awareness of support from the GIST Cancer UK and other charities, at the time of diagnosis.

We would recommend:

- A review of the NICE 'Improving outcomes for people with sarcoma' guidelines which are now nearly 20 years old.
- More effective monitoring of the implementation of the guidelines including promptness of treatment and feedback from patients.
- The compilation of benchmarking data to enable comparisons of the effectiveness of treatments, as measured by patient outcomes, by centre and region and to enable comparison with similar data from other countries.
- The routine sharing of the outcomes of review and benchmarking with the patient community to reassure them that the UK is sector-leading in the treatment of sarcomas and GISTs in particular.
- Proactive referral of newly diagnosed patients to charities and patient groups for support.
- Closer working relationships between the NHS and relevant charities.

## Data on Sarcoma Prevalence and Treatment:

*Does current data reporting and analysis on sarcoma prevalence, diagnosis and treatment, provide good information to plan, commission and deliver of high standards of patient care? If not, how could it be improved?*

We are not in a position to comment in detail on this question. Data issues are commented on in the previous response.

## Role of healthcare professionals in sarcoma diagnosis:

*(a) How effective are primary and secondary care at initially identifying and diagnosing people with a sarcoma?*

*(b) Do primary and secondary care require additional support, and if so, what form could this take?*

Diagnosis of GIST is problematic and there is no regular and routine screening for GIST cancer as part of other programmes (e.g. for bowel cancer). The rarity of the disease means that most GPs are unfamiliar with it and its possible symptoms which are often similar to those for other ailments. Patients may be 'lucky' and their GP may have some knowledge or refer rapidly to more knowledgeable secondary care specialists but this is rare and

misdiagnosis or delayed diagnosis is common. Some patients reported a period of two years between initially seeing a GP and being correctly diagnosed. In some instances, they report that they were informed of their diagnosis by email. Several patients reported that medical practitioners with whom they initially interacted informed them that GIST was not a cancer or that the nature of GISTs and their prognosis was poorly explained or insensitively handled. Diagnosis is a difficult time for patients who will, naturally, be feeling uncertain about their future and thus they may not be receptive to information and guidance provided at this time. Further work is required to ensure all patients receive an early diagnosis and that this is communicated in an effective and sensitive manner.

Patients often rely on their GP and do not know how to seek alternative views if misdiagnosis means their initial treatment is ineffective. Frequently patients report that GPs are unaware of specialist centres and were referred to local, non-specialist hospitals. Often they are treated at these centres and not referred to specialists (see section 4 below).

Post diagnosis, specialist care is provided mainly through specialist centres and GPs are largely unaware of how treatment might impact on other healthcare issues for which the patient might seek medical help.

Many patients are not routinely given advice from specialists on how to deal with the range of side-effects which occur when taking the main drugs: Imatinib, Sunitinib or Regorafenib. From a patient perspective it is difficult to know whether they should seek this advice from their MDT or GP. Many are unable to access NHS dental treatment easily, which is vital when on some of the common drugs.

We would recommend:

- That more emphasis is given, as part of routine GP training, to raising awareness of the symptoms of GIST, the process of referral to specialist centres and on the treatment of issues associated with the side-effects of drug treatment.
- That there is a more co-ordinated approach between MDTs and GPs when supporting patients post initial assessment and surgery where appropriate.
- That there is better guidance given to healthcare practitioners on how to give sensitive information at the time of diagnosis and that this is monitored.

#### 4) Sarcoma referral pathways and access to specialist sarcoma services:

*(a) To what extent do care pathways for people with sarcoma ensure they receive a timely onward referral to, and diagnosis and treatment, from a Specialist Sarcoma Centre; or do they create delays and unacceptable variation in access? If the latter, how could these be addressed?*

*(b) How does the centralised provision of specialised sarcoma services affect people's access to these services, e.g., for people in minority communities, who are on a low income or who live in underserved or rural areas?*

*(c) Some people with sarcoma are not referred to a Specialist Centre – what are the key reasons for this, and how does it impact their care?*

Significant numbers of patients reported that they were not referred to a GIST Specialist centre but were treated at a local hospital. Patients rely on the knowledge and experience of the oncologists and surgeons with whom they have contact and it is difficult for patients to challenge these authority figures. Some doctors seen in secondary healthcare settings refused to refer patients to specialist centres stating that they had the requisite expertise and experience. GIST specialist oncologists emphasise that detailed knowledge is required both for correct diagnosis and for the development of effective treatment plans. Patients reported limited awareness that specialist centres exist and that they have a right of referral or how to

access such a centre if this is refused locally. Many patients are not aware that they can ask for a second opinion, or if they do ask for one then this is not received well by the doctor that they are seeing affecting the vital patient/doctor relationship.

For some patients, the location of specialist centres can be an issue since distance and hence travel can be problematic. When patients seek independent advice, it's not clear how they should contact the specialist centres themselves.

The position is somewhat complicated by the fact that, in-line with the guidance, some 'non-specialist' hospitals have close working relationships with specialist centres effectively operating as satellite sites. This means that there is a greater geographical coverage of support but, as far as we are aware, there is no updated and easily accessible record of these satellite centres. This makes it difficult for patients to know if they are receiving the appropriate level of support. Satellites appear to be as the result of personal contacts between clinicians rather than as part of any strategic approach to enabling the easy access to specialist support necessary across the nation.

Patients with GISTs which do not respond to standard drug treatment can be supported by the PAWS-GIST clinic (<https://www.pawsgistclinic.org.uk/>). This provides a personalised care plan on the basis of input from specialists in the field and is much valued by the patients who take part and their families. Referral relies on oncologists knowing of its existence or of patients finding their way there through the GIST Cancer UK or PAWS-GIST websites. We regularly have contact with patients who might benefit from the clinics but who are unaware of their existence. Furthermore, it is unclear to GIST Cancer UK whether there is a long-term commitment from the NHS to the continued support for this valuable and beneficial initiative. The specialists working at the clinic contribute to the growing evidence-base on effective action for difficult to treat patients.

The effective treatment of GISTs including the interpretation of scans and correct drug treatment all require specialist knowledge and more needs to be done to ensure that patients' treatment is overseen by GIST specialists as detailed in the guidelines. We would recommend:

- The formal establishment of recognised satellite centres in a strategic manner so that, as far as possible, no patient is more than an hour's travel from a specialist or recognised satellite centre.
- The routine publishing of centres and any agreed satellites including contact details.
- The formal establishment of PAWS-GIST clinics to optimise patient treatment and to their continued support and promotion amongst patients and healthcare practitioners.
- If they do not exist, then the establishment of similar clinics to optimise patient treatment for other rare sarcomas.
- The right of independent advice for patients where they wish to question treatment decisions provided locally and its effective communication to patients.

## 5) Public awareness and knowledge of sarcoma:

*(a) Does the general population have a good basic understanding about what sarcoma is and when they should seek medical advice?*

*(b) What more could government, the NHS and charities do to improve education and awareness of sarcoma?*

Since there are no simple symptoms of a GIST, and it is rare, any actions taken to raise awareness amongst the general population are likely to be ineffective and not cost-effective. We believe it is better to focus resources and training on primary and secondary healthcare practitioners.

## 6) NHS workforce planning and training for sarcoma care:

*To what extent does NHS workforce planning and training ensure that Specialist Sarcoma Centres are sufficiently resourced to deliver good or improving health outcomes for people with sarcoma?*

We are not in a position to comment meaningfully on this question.

## 7) Research and new treatments:

*(a) Is there sufficient funding for research into sarcoma, the development of new treatments and equitable access for people with sarcoma to clinical trials?*

*(b) Can more be done by government agencies, universities, charities, or the pharmaceutical industry to achieve faster progress in this area?*

GIST Cancer UK supports research through direct funding and in conjunction with Sarcoma UK. It has established a Medical Advisory Board to support this endeavour and funds the National GIST BioBank to provide researchers with access to tissue samples. Currently a range of projects are supported but future developments will depend on our ability to access new funding streams. Traditional sources of funding, including Pharma, are increasingly more difficult to access.

Whilst we would welcome more research and research funding in this area, this is problematic for a number of reasons. Low patient numbers mean that this is not a priority area for many pharmaceutical companies particularly as current drugs are effective for many patients and given the expense of novel drug development. Academics have their own specialist areas of research which may or may not have an immediate practical focus. Engagement of specialist consultants in establishing priority areas and reviewing research bids whilst vital, is problematic given pressures on their time. GIST Cancer UK would not want to stifle novel and innovative research, however, current research is largely ad hoc and poorly coordinated.

The National GIST BioBank has sufficient samples of some GIST mutations but the coordination of sample collection to ensure a full range of tissue samples is reliant on the knowledge of local consultants. As a result, many patients undergoing surgery are not informed of the possibility and importance of tissue collection. Given that only certain mutations are now required, more could be done at the point of initial assessment to ask patients with the rarer sub-types to provide a sample for the Biobank so that there is a full range of samples available to researchers.

We recommend:

- Consultants and academics (and potentially Pharma) are involved in identifying areas for research which are likely to have the most benefit for patients for whom existing drug treatments are not effective. This would provide a non-exclusive basis for calls for research funding helping to guide research developments.
- Continued funding of the GIST BioBank being undertaken by the NHS possibly as an extension of existing similar Biobank initiatives.
- Proactive targeting of patients with rare mutations to ensure the Biobank has a full range of samples.

## 8) Genomic testing in sarcoma care:

*(a) To what extent is genomic testing being offered by Specialist Sarcoma Centres to people with sarcoma to assist with diagnosis and treatment?*



*(b) If it is not always being offered, what barriers need to be addressed to ensure equitable access for people with sarcoma?*

Genomic testing is important in the treatment of GISTs because some mutations are not responsive to standard drug treatments. Patients report that access to genomic testing depends on their centre of treatment and is not consistent across Sarcoma Centres, satellite centres and those treated in other secondary healthcare settings. In our sample, only one-third reported that their GIST had been genomically tested. This is an area which appears unmonitored, yet a lack of testing could lead to the inefficient use of NHS resources.

Patient understanding of the importance of genomic testing and its implications for their treatment is also problematic. As with diagnosis, as noted above, test results often come at a difficult time for patients. Busy consultants are variable in their ability to communicate the implications and the formal record that patients receive, whilst it provides the essential genomic details, does not provide an interpretation, in lay terms, nor set out in writing the implications for the optimum treatment pathway.

We recommend:

- Genomic testing should be standard for all patients with a GIST.
- Better and fuller communication with patients regarding the implications of the outcomes of their genomic test should be provided.

## 9) Coordination of physical and mental healthcare

*Is there effective provision of support within the NHS for the physical and mental healthcare needs of people with sarcoma; or is there more that could be done to ensure continuity of care?*

Being diagnosed with a cancer can have a significant impact on mental health particularly when there is no simple treatment, metastasis or a return of cancer. Patients often feel isolated and may not be aware of pathways for self-referral. The need for mental health support may not be apparent at time of diagnosis but develop as patients become more aware of their prognosis and of the side-effects of some drug treatments. Patients who fall into these categories need to be regularly asked about their need for support rather than relying on self-referral. Furthermore, access to support varies depending on location.

We recommend:

- A more proactive and integrated approach to mental health support particularly aimed at those likely to be in greatest need.

## 10) Recovery, long-term support and palliative care:

*(a) Is there adequate NHS support to help people with their recovery from sarcoma, or to deal with managing long-term health impacts?*

*(b) Is follow-up monitoring effective at supporting people if sarcoma recurs, or how could it be improved?*

*(c) Is palliative care well integrated into the sarcoma care pathway, or are there ways in which it could be improved?*

Patients report very different periods of adjuvant treatment with imatinib. Whilst there may be good reasons for this linked, for example, to the nature of the genetic mutation or the mitotic rate, it can raise concerns particularly when patients discuss treatments with others. Follow-up monitoring is generally reported as effective but there can be significant differences in terms of how often scans are provided and patients report concerns about the

risks involved in having regular scans. Patients should be clear about the nature and frequency of long-term monitoring of their condition and of the rationale behind such plans.

There are currently only 3 treatments for GIST Cancer licensed by NICE in the UK, as opposed to Europe and the USA where others are available. Increasingly more patients are reaching a point where there is no further treatment available to them. Such patients report that they are not offered treatments which could enhance their life expectancy such as secondary surgery, radiotherapy or ablation as a matter of course. Patients should be made aware of options available to them should a particular drug stop working and what the possible alternative treatments are. All such patients should be informed of clinical trials for new treatments and referred to the PAWS-GIST clinic where appropriate. Currently this depends on the knowledge of their MDT and appears variable depending on location. Information about relevant trials should come routinely through the MDT rather than patients having to constantly monitor external websites.

We recommend:

- Greater clarity and consistency in the reasons for, and length of, drug treatment, in the provision of monitoring scans and the possibilities of alternative treatment.
  - Pro-active communication by the NHS with patients regarding clinical trials.
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