

7. Does the impact assessment fairly reflect the likely activity, budget and service impact?

(Required)

- Yes
 No

If you selected 'No', please tell us what is inaccurate?

We are only able to comment on this assessment in relation to how it impacts on GIST cancer patients who from the statistics contained in this document represent **18.42%** of the population in the UK.

For GIST patients the existing pathway **K4.1 defines the aim of the service is: To improve outcomes for all patients with sarcoma by ensuring that all patients will be referred to specialised sarcoma services.**

We fully support this aim but are concerned that in the case of GIST cancer, specialist skills also exist in locations outside of these specialised sarcoma centres to an expert level, with GI oncology specialists. Please can the specification be more finely tuned to include sites such as these and recognise their expertise more officially e.g. Addenbrookes hospital has an expert GIST MDT in Cambridge. Exclusion of centres such as this from this specification will have a negative impact on the service delivered to GIST patients.

We think that there are sufficient numbers of GIST patient numbers in England to justify a recognised **GIST treatment network** to be published for both the NHS and patients to see exactly where they should be going and that this should include both Sarcoma and GI oncology GIST experts who have agreed lines of communication.

L3 Implementation. We request that when the Sarcoma Advisory Group (SAG) is convened that it includes a recognised senior UK GIST specialist to provide the primary source of clinical opinion for GIST for the network. As a significant percentage of the patient population (700 p.a. / 18.42%) we feel that this should be clearly mandated.

8 Does the document describe the key standards of care and quality standards you would expect for this service?

(Required)

- Yes
 No

If you selected 'No', what is missing or should be amended?

Assuming that this question refers to the Service Specification we are keen to understand how the relationship between the SAG and the designated MDT members will work. e.g. how will the SAG interface with bodies such as AUGIS and other organ specific surgeons and GI Oncologists to streamline their joint activities? From a GIST perspective we need assurance that the surgeon with the best site specific expertise is involved in their removal.

We agree that patients with GIST should be “discussed” with a Sarcoma MDT because we want to ensure a consistently good service, offering the most up to-date treatment options and best advice for GIST patients. We understand that most of the clinical trials for GIST are run by sarcoma centres and we are keen to ensure that GIST patients from all parts of the country are alerted and have access to GIST clinical trials that are available.

It will be very easy for offence to be taken within the different disciplines who see it as their responsibility to manage patients from a cancer site specific perspective to suddenly have the Sarcoma Specialists dictating how things should be. Paying attention to disease specific and patient age specific expertise is essential to ensure that current specialisation is preserved.

We think that there are sufficient numbers of GIST patients in England to justify a recognised **National GIST treatment network** to be published for both the NHS and patients to see exactly where they should be going and that this should include both Sarcoma and GI oncology GIST experts to ensure key quality of care for GIST patients.

9 Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that we have described?

We fully support the overall aims for GIST patients to be referred to specialists but are concerned that in the case of GIST cancer these specifications are mandating arbitrary figures about minimum numbers of new patient to determine specialist capability and that this number is too high. GIST patients do need to be treated by specialists who have recognised experience of GIST cancer management and who are treating significant numbers but they also want to be treated in centres that are near to where they live.

A minimum number of 24 new patients would mean for example that none of the specialist centres in the West Country would meet the criteria (Bristol, Exeter & Plymouth). It is also noticeable that the specialist Sarcoma centres listed do not include any site on the South Coast. It should not be necessary for those patients who don't need systemic or really specialist treatment to travel long distances. The important thing is that patients receive proper specialist GIST treatment and guidance.

We think that there are sufficient numbers of GIST patients in England to justify a recognised **National GIST treatment network** to be published for both the NHS and patients to see exactly where they should be going and that this should include both Sarcoma and GI oncology GIST experts who have agreed lines of communication..

10 Are there any changes or additions you think need to be made to this document, and why?

We would like to see the following changes/additions made to the service specification:

1. Please refer to **GIST** by its internationally recognised name “**GastroIntestinal Stromal Tumour**” rather than by a new name created to incorporate the word “sarcoma”. This change is confusing.
2. This document quotes UK statistics. It would be more accurate to **quote English statistics** as it relates to NHS England’s service.
3. Please include “Management of GIST cancer will be in accordance with **The National GIST Guidelines**”.
4. Please include that GIST patients "**should be referred at the earliest possible stage, to prevent unnecessarily aggressive surgery which can seriously affect subsequent QoL**".
5. Please modify 1.1.5 to accommodate the relevant **GIST expert centres**, such as Addenbrookes.
6. Please modify dot point 7 of 3.1.2 so that it reads “to support patients through an allocated key workers who has specialist knowledge of **their type** of sarcoma and their treatments”.
7. Sarcoma Advisory Groups (**SAG’s**) to include **specialist GIST experts**.
8. **MDT’s to identify GIST specific research leads**
9. The medical management of **GIST patients by specialists with experience in the management of GIST with an annual minimum of 10+ new cases**. (N.B cumulative numbers at this level make for a not insignificant number quite quickly).
10. **PAWS-GIST** needs to be explained correctly. It stands for:
Paediatric, Adolescent, Wild-type & Syndromic - **GIST.**
11. Please include the **reference to PAWS-GIST patient management in both the GIST section and the rarer subset section** and be very much more specific about what and where it is www.pawsgistclinic.org.uk.
12. **Please include the National GIST Tissue Bank** and support that all patients undergoing surgery are invited to donate their tissue to the bank fresh from the operation along with blood to encourage more research. (The bank will be relocating to The Royal Marsden during 2016 and will have a website reference there).

Before completing the survey you must declare any financial or other interests in any specialised services.

GIST Support UK (registered charity No. 1129219) is the only charity focusing solely on the support of GIST patients in the UK.

We are supported in our work by specific grants from Pfizer and unrestricted educational grants from Novartis, together with charitable donations from patients, carers, and a wider support community who are aiming to raise funds that can be used to improve treatment and find a cure for GIST cancer.