

National Assembly for Wales

[Health and Social Care Committee](#)

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from GIST Support UK – CDP 24



www.gistsupportuk.com

Registered Charity No: 1129219



Submission from GIST Support UK to the Inquiry into progress made on implementing the Welsh Government's Cancer Delivery Plan

1. GIST Support UK is a UK wide charity set up to inform and support GIST patients and their carers. It is entirely run by volunteers who are either patients or carers themselves. Gastro Intestinal Stromal tumour (GIST) is an extremely rare cancer – specifically, a sarcoma. Incidence is around 15 per million, and it affects people from all walks of life and all ethnic backgrounds. The majority are over 60 on diagnosis.
2. Diagnosis is difficult as there are few presenting symptoms, and the rarity of the disease means that most General Practitioner (GPs) will never see one in their working careers. Thus diagnosis is often incidental while the patient is having imaging for another condition or for general screening, or an emergency if undiagnosed until tumour rupture or other major consequence of having a large abdominal tumour. CT scans remain the major tool for making an initial diagnosis, so that easy and early access to CTs and other imaging modalities is crucial if rare tumours are to be detected early! Good outcomes depend on early diagnosis.
3. Patients with rare diseases also often have few treatment options, as there is a smaller return on investment when the patient pool is small, thus the cost of drug development is proportionally greater. In addition, it is harder (and much more costly) to run clinical trials when there are fewer available patients. Finally, even when a drug receives marketing registration, it is sometimes deemed uneconomic to undergo a NICE technology appraisal. Witness Bayer's regorafenib, an effective drug for GIST when other options have failed,

which is not to be appraised by NICE due to economics. The intention is to rely on the Cancer Drugs Fund in England for those handful of patients who have been failed by the available therapies. Therefore patients with rare diseases are at a major disadvantage:

Disadvantages to all patients with rare disease:

Difficulties getting diagnosis, Few treatments, Few specialists

4. Access to Drugs:

Drugs which are not NICE approved are sometimes funded through the English Cancer Drugs fund where clinically indicated. Welsh patients are denied those drugs as Wales does not have an equivalent fund.

Welsh patients who are on the English border highlight the post code lottery from the two health care systems of Wales and England and we see this as an inequitable service to the detriment of patients

Evidence: The Specialist MDT hosted at Wrexham Meallor Hospital **includes** patients from Countess of Chester Hospital. Patients are subject to a postcode lottery which relates to a number of drugs in upper GI and liver cancer. This disadvantage to Welsh GIST patients includes lack of access to imatinib (at the higher dose not yet approved by NICE, or as adjuvant therapy) and regorafenib.

5. Access to imaging:

Welsh UGI Patients who attend the MDT at The Shrewsbury and Telford Hospital NHS Trust who require imaging scans have these undertaken at Stoke providing they are registered with a GP based in England. For the majority of Welsh patients referred to the MDT who are registered with a GP based in Wales, scans are undertaken in Cardiff, approximately 120 miles away. This can give cause considerable delay and inconvenience to those patients.

6. Access to Follow Up:

Shropshire patients who have undergone neoadjuvant chemotherapy routinely have a second PET scan but there is no funding available for the patients with a GP based in Wales to access this.

7. Future potential access to PAWS clinic for Welsh patients:

The new national Paediatric, Wild Type and Syndromic GIST Clinic in England at Addenbrookes Hospital, Cambridge opened in March 2014, and it would be a great advantage to Welsh patients if they could be referred there for an overview of their medical position (with the intention that their ongoing medical care continues with their usual providers). This would potentially greatly benefit TYA (teenage and young adults) with GIST, as this is an extremely rare condition in young people.

8. Further evidence of disadvantages to Welsh patients:

We have patients who elect to be treated at major cancer centres in England in order to get the therapies they need. They travel as needed for appointments. Not sure how this is funded.

These actions speak eloquently of disadvantages felt by Welsh patients over English patients.