

Patient Group Submission Form

The Scottish Medicines Consortium (SMC) is committed to working in partnership with patient groups to capture patient and carer experiences, and use them to inform decision-making.

Before you make a submission

Following a consultation with patient groups, we have changed the way you submit to SMC. You are now asked to complete a Patient Group Partner Registration Form before you make a submission. The registration form requests general information about your organisation. It only needs to be completed once and should save you time with any further submissions to SMC. If you have not already completed a registration form, please do this before you make your submission.

You can find the form here: www.scottishmedicines.org.uk/Public_Involvement

You will find it helpful to read our guide for Patient Group Partners, which gives details about the type of information you need to capture in the submission form. **Please read this before you make your submission and use it to help you complete each question.**

You can read the guide here: www.scottishmedicines.org.uk/Public_Involvement

Contact us

If you have any more questions after reading the guide, the SMC Public Involvement Team can support you throughout the submission process. You can email us at: hcis.SMCPublicInvolvement@nhs.net or phone: **0141 414 2403**. Please do not hesitate to get in touch, as we are here to help you.

Name of medicine:

Everolimus

Indication (what the medicine is used for):

Treatment of unresectable or metastatic, well differentiated non functional neuroendocrine tumours of gastrointestinal or lung origin in adults with progressive disease

Submission date:

31st October 2016

Name of organisation making submission:

The Ann Edgar Charitable Trust

Who is the main contact for submissions to SMC?

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- 1. Please provide details of any individuals who have had a significant role in preparing your submission and who have an interest to declare. (Please write no more than 300 words)**

NA

- 2. Please tell us how you gathered information about the experiences of patients and carers to help inform your submission. (Please write no more than 300 words)**

We undertook an online survey of our members, all of whom are affected by NETs in October 2016. The survey had 22 respondents, of these 68% were between 35 and 64 years of age with 32% over 65. 62% of respondents were female, and 38% male. The vast majority of those who completed the survey had a NET of gastrointestinal origin (86%).

One of our Trustees also undertook a focus group session held with a small group of GI NET patients/carers (6 in total) to discuss in detail the submission questions.

- 3.**

How does this condition affect the day-to-day lives of people living with it? (Please write no more than 400 words)

NETs have a significant effect on those with the diagnosis and their families. Our survey response demonstrated that the principal difficulties were living with the symptoms of the disease and the effect this has on employability and family life.

Living with the symptoms of NETs has a severe impact on working life, symptoms which are especially challenging include: reduction in energy level, diarrhoea, breathlessness, flushing, extreme fatigue/ tiredness and group noted that the effect of stress (even minor) on these symptoms can be significant. A number of respondents also cited emotional impacts of living with this rare tumour type as having a huge impact on their day to day life. One respondent noted that “making plans is difficult and I’ve had to give up work. It robs pieces of your life in multiple subtle ways” . The majority of respondents to the online survey (78%) and 100% of those who attended the focus group remarked that their NET has a considerable effect on their day to day life.

Many members of the group have had to stop working, given the difficulty in controlling their symptoms, and feel that this is a waste of their experience and their working lives have been cut dramatically. One member of the focus group commented “who would employ you?”.

One respondent summed up the condition as follows “I think of NETs as being like volcanoes ready to erupt and spew out nasty hormones at any time. Our tumours are trying to kill us in two ways – one by growing like other tumour types and the other by secretion of excess hormones. Even where tumours are non-secreting we have to live with the uncertainty every day which is extremely hard.”

4. How well are patients managing their condition with medicines which are currently available in NHSScotland? (Please write no more than 400 words)

There are very few treatment options available to treat patients with gastrointestinal or lung NETs at present. Of those respondents who had received some form of treatment it was noted that the effect of medicines/procedures available “don’t last”.

A number of patients who responded to the survey have been on various medications, or received other treatments (e.g. RFA / embolisation for liver metastases) since their diagnosis. The majority have received somatostatin analogue injections which they noted have significant complications, specifically pain at injection site with a number of people now having painful lumps where injections have been given over a course of years/months. In addition the inconvenience of having to see nurse/GP every few weeks for injection or in some cases travelling to the hospital for regular injections has a major impact on their day to day living.

5.

Would this medicine be expected to improve the patient’s quality of life and experience of care, and if so, how? (Please write no more than 400 words)

An effective treatment that made a difference to symptoms of NETs would have a huge effect and impact on the day to day lives of people with NETs. The AECT cannot comment on the clinical effectiveness of everolimus (only one patient who responded to the survey had received the medication as part of clinical trial). However, we note from the published clinical trials that the medication demonstrated a survival benefit without significant side effects.

The vast majority of respondents (90%) commented that if additional medicines were available to manage NETs this would be of huge benefit to them/their family, especially given the lack of options available at present. Important factors of any new medicine which were noted by patients were: improved quality of life, prolonged survival / improvement in prognosis and symptom control.

Furthermore the group commented that the lack of “debilitating side effects” was important however it was noted that the side effects weren’t felt to be that important if the medicine improved quality of life.

Regarding the possible side effects of this new medication, which were outlined in the information provided, the group did not have significant concerns.

6. How would treating a patient with this medicine impact the patient’s family or carers? (Please write no more than 400 words)

For those patients who currently have no treatment option available to them a new effective medicine for NETs would have a huge impact on their family/carers. One member of the group noted that it would “reduce stress on the family” as living with NETs “affects everyone” in the family.

There is a significant impact on partners/family members of a person with a NET. Often the impact of symptoms, e.g. extreme fatigue, means that a lot of responsibility can land on partner who may have to take time out from work to look after kids, grandkids (for example) even although the person with NETs is there.

Respondents also commented that there was a huge amount of worry for family members regarding how the person with NETs will be feeling day to day, given the unpredictability of the disease.

7.

Are there any disadvantages of the new medicine compared to current standard treatments? (Please write no more than 400 words)

The AECT feel they cannot comment directly on any disadvantages of the medicine. Side effects of any new medication are of concern to patients; however, the focus group considered the side effects of everolimus contained within the information summary and did not have any concerns.

The group did however have a positive response to the fact that everolimus is an oral treatment, a number of whom have previously received SSA injections. The benefit of taking a tablet over injections was noted, especially as this would allow people to “take control of your life back”, i.e. taking a tablet was straightforward and done in own home without taking time off from work etc. This would allow people to get their “normality back”. The group agreed they had often “felt guilty taking time out” for going to hospital for treatment given the impact this had on others (colleagues, family members etc.).

8. Please summarise the key points of your submission in no more than 200 words:

NETs are rare tumours which are often slow growing with a late diagnosis. The symptoms which affect patients are significant and have an extremely debilitating effect on patients’ quality of life, specifically in the ability to continue with working life.

Given the frequency of late diagnosis, the majority of this patient group have advanced disease at presentation, which means that although they are aware there are new treatments in the pipeline which may result in a cure such as immunotherapy these are realistically some time off. In the meantime the holy grail is stable disease. For many patients the idea that there is some hope that the disease will be halted for some time is a fantastic result.

At present there are very few treatment options available for treatment of NETs which provide symptom control, thereby improving quality of life, and prolong life. In our view, having additional treatment options, in this case in the form of everolimus, would be extremely beneficial to patients with NETs, particularly to those who have exhausted all other options available to them.

(This is the information that will be used in the published Detailed Advice Document (DAD) summary of Patient Group Submissions. It will also be used during the presentation at the SMC committee meeting. It is very important that you concisely capture the key messages of your submission here.)

9. Do you consent for a summary of your submission to be included in the Detailed Advice Document for this medicine?

Yes

No

Thank you for completing this form.

Please email it to: hcis.SMCPublicInvolvement@nhs.net

If you are unable to email this form to us, please send by post to the address below:

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