



**pan-Canadian Oncology Drug Review
Patient Advocacy Group Feedback on a pCODR
Expert Review Committee Initial
Recommendation**

**Sorafenib (Nexavar) for Differentiated Thyroid
Cancer**

Thyroid Cancer Canada

July 16, 2015

Feedback on pERC Initial Recommendation

Name of the drug indication(s): Sorafenib (Nexavar)

Name of registered patient advocacy: Thyroid Cancer Canada

**pCODR may contact this person if comments require clarification. Contact information will not be included in any public posting of this document by pCODR.*

1.1 Comments on the Initial Recommendation

- a) Please indicate if the patient advocacy group agrees or disagrees with the initial recommendation:

agrees agrees in part disagree

It was made very clear to us that when faced with disease that has 100% chance of progressing to death, and without other options, patients would choose this therapy over no therapy. Patients interviewed also indicated that the side-effects that they did experience, did NOT impact their quality of life, and would choose this therapy over no therapy.

- b) Notwithstanding the feedback provided in part a) above, please indicate if the patient advocacy group would support this initial recommendation proceeding to final pERC recommendation ("early conversion"), which would occur within 2(two) business days of the end of the consultation period.

Support conversion to final recommendation. Do not support conversion to final recommendation.
 Recommendation does not require reconsideration by pERC. Recommendation should be reconsidered by pERC.

- c) Please provide feedback on the initial recommendation. Is the initial recommendation or are the components of the recommendation (e.g., clinical and economic evidence) clearly worded? Is the intent clear? Are the reasons clear?

Page Number	Section Title	Paragraph, Line Number	Comments and Suggested Changes to Improve Clarity

1.2 Comments Related to Patient Advocacy Group Input

Page Number	Section Title	Paragraph, Line Number	Comments related to initial patient advocacy group input
5	Patient Based Values	Paragraph 2 (Patient Values on	The recommendation states: "The patients noted that substantial adverse events also

Page Number	Section Title	Paragraph, Line Number	Comments related to initial patient advocacy group input
		Treatment):, last line	<p>impacted their quality of life significantly"</p> <p>We feel that this statement is not an accurate reflection of how the patients we interviewed felt about their experience, nor how this perspective was presented in our submission.</p> <p>We request that the committee review the evidence we provided in Section 3.2:</p> <p>Paragraph 1 "The impact of the treatment on the disease"</p> <ul style="list-style-type: none"> - "Both patients indicated that their quality of life while taking this treatment was good, despite some negative side effects" <p>Paragraph 2 "Assessing risks associated with the treatment"</p> <ul style="list-style-type: none"> - "Both patients were made aware of the possible risks [...] both felt that the potential benefit outweighed any possible risk". Both patients provided feedback with a very high degree of understanding and clarity about the potential effects of the therapy, and described the effects with a very high level of awareness of how they impacted the physical and psychosocial aspects of their lives. <p>Paragraph 5 "Adverse effects and symptoms"</p> <ul style="list-style-type: none"> - All symptoms identified by both patients were "Manageable as long as the treatment was effective". - "Neither patient was able to identify an adverse effect or symptom that had a serious negative impact on her personal quality of life, nor on the quality of life of her caregiver/loved ones". <p>Paragraph 10 "The social impact of the treatment"</p> <ul style="list-style-type: none"> - Both patients expressed that while the treatment did put restrictions on some aspects of their day to day life, they had "a good quality of life and indicated that the therapy had no serious negative impact on the spending time with loved ones,

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			<p>maintaining friendships” . Both patients felt “the benefits of the medication greatly outweighed any negative impact of the side effects” .</p> <p>Both patients described the experience of negative effects, and the changes they had to make to their life to manage these effects, both concluding that none of the changes amounted to reducing their quality of life and their ability to enjoy the additional time that they were given to live because of this therapy.</p> <p>Both patients and the clinician that we interviewed provided quotes, included in the last paragraph under “The Social Impact of Treatment” , emphasising how important having this treatment was to them.</p>

1.3 Additional Comments About the Initial Recommendation Document

Please provide any additional comments:

Page Number	Section Title	Paragraph, Line Number	Additional Comments