

# THYROID CANCER ALLIANCE

## Information and support for patients on treatment with multikinase inhibitors (MKIs) – guidance for physicians and patient organisations

This document arises from the international patient-led workshop on “TKIs and what this means for patients” organised by the Thyroid Cancer Alliance and held in Paris, October 2014.

### Part 1: Information

---

Differentiated (papillary, follicular) thyroid cancer (DTC) is usually highly treatable and has a good prognosis. Radioactive iodine is often used in the treatment of DTC. However, in some cases, the cancer progresses and metastasises beyond surgical intervention and other treatments and may become resistant to radioactive iodine. In such cases, MKIs may be considered.

Surgery is the most important treatment for medullary thyroid cancer (MTC) and it can cure some localised forms of this disease. Radioactive iodine is not used in the treatment of MTC. When MTC has spread beyond the thyroid gland and other treatments do not work, MKIs may be considered.

#### a. WHEN should information be provided?

All thyroid cancer patients should be given a clear and understandable explanation of the expected clinical course of their thyroid

cancer and the available treatment options at their initial consultation. This often needs reinforcing in subsequent consultations to help and support patients.

#### b. WHAT information should be provided?

1.b.1. If a DTC patient is discovered to be radioiodine resistant or an MTC patient has disease that has spread beyond the neck, the following should be discussed:

- What does radioiodine resistance in DTC mean?
- What treatments, including targeted therapies, may be available and appropriate?
- Is the treatment curative?
- If palliative, what are the benefits in survival, symptom-free survival / progression-free survival or QOL?
- What are the side effects of treatment?
- What is the intended duration of treatment?
- How will the patient be monitored, how often, and what tests will be done?
- What is the availability of clinical trials?



- How can the patient access supportive care (patient organisations, community support)? See section 2b.
- What costs are involved if the patient has to (co)fund, as may be the case in some countries?

It should be made clear that the course of the disease varies greatly in individuals, that the disease may not progress for many years, if at all, and that there may be other options (surgery, radiotherapy, radioactive isotope therapy) before considering an MKI.

The information may need to be communicated over several consultations at different stages of the disease.

1.b.2. If a decision is made to consider/start treatment with an MKI, the decision to do so should be a shared decision between the patient and clinician.

Before starting treatment, the following should be discussed:

- What to expect and when.
- How to take the medication and when.
- What are the possible side effects and how can these be managed? See section 1d.
- Who is the patient's primary medical team contact? See section 2.a.
- How to access supportive care (patient organisations, community support). See section 2b.

### **c. HOW should the information be provided?**

At each stage, information should first be given verbally in the clinical setting by the patient's specialist consultant clinician, who will ideally be supported by a specialist clinical nurse.

The patient should be encouraged to bring a family member or friend to their consultations for support and to take notes.

The patient and the clinical team should together discuss the quality of life (QOL) the patient may expect if the disease progresses, and this should take account of the patient's own QOL goals. This should be discussed regularly, always taking account of what the patient hopes to achieve and whether these goals have changed.

Care should be taken to listen to and adapt the consultation to the patient's own needs and learning speed.

Patients may need time to absorb the information, so it is recommended that they are provided with written information endorsed by the clinical team to take home and read. The information provided to the patient may also include recommendations about other information resources that have been found to be reliable, such as: films/DVDs, recommended websites, and patient stories and testimonials.

Patients should be provided with contact details (telephone, email) so that they can ask the primary contact clinician or a specialist nurse if they have any questions after the consultation.

Patients should also be provided with contact information about support groups and patient organisations that may be able to provide further information and emotional support. See section 2b.

Written informed consent should be taken by a clinician experienced in MKI treatment according to the current recommended legal guidance in the country in which treatment is being provided (e.g. UK guidance following Montgomery –v– Lanarkshire Health Board 2015).



#### **d. Management of side-effects of MKIs**

Patients should be given clear written information about possible side effects of MKIs, including:

- What side effects may occur
- What to do to minimise them
- What the medical team can do to lessen them
- How to report them and to whom
- The importance of reporting side effects promptly

Where possible, patients should be able to contact a clinical nurse specialist who is part of the clinical team.

Treatment will usually be initiated at a specialist (tertiary) centre. If it is overseen locally, at a distance from the specialist centre, good communication between the two centres is crucial.

### **Part 2: Support**

---

#### **a. WHO should be the patient's primary contact person?**

Given the variations in national and regional practice, the primary contact person may be:

- An oncologist
- An endocrinologist
- A clinical nurse specialist or nurse practitioner with a specialist interest in the management of advanced thyroid cancer

#### **b. What role can patient organisations play in supporting patients on MKI treatment?**

- Patient organisations can develop patient information materials, jointly with clinicians, and give feedback to the medical community on the patient perspective.

- They can provide the “narrative” by publishing patient stories and testimonials.
- They can lobby/advocate for patients’ needs to be met, i.e. funding (access to drugs), social work, welfare rights, legal advice.
- They can provide support through holding support meetings and by one-to-one contact (telephone or face to face).
- In some instances the patient organisation may be able to introduce patients to a “buddy” who is going through or has gone through treatment and can talk to the patient either by telephone or face to face.\*
- They can raise awareness among patients and the public.

\*There are differing views on whether it is appropriate to assign an individual a face-to-face or telephone buddy. There may be different expectations and practices in different countries.

#### **c. Encouraging feedback**

The clinical team should be encouraged to listen to patients and to regularly seek their opinions and feedback.

Patients should be made to feel comfortable about speaking up and giving feedback about the management of their disease.

There should be a good two-way communication between patient and medical team based on mutual trust.

#### **d. When treatment ends**

Treatment with an MKI can provide patients with a progression-free period to enable them to accomplish their goals, but it is not curative.

When treatment ends, the clinical team and the patient should review together the path ahead, with an emphasis on being realistic.



If there are other options to be explored, such as a second MKI or participation in a clinical trial, these should be reviewed carefully together.

The clinical team should assess the patient's psychological well-being at each stage.

#### **e. The psychological and physical impact**

The availability of psychological services is vital if the patient needs to access these.

Support should also take into consideration the needs of the patient's family: "When you have cancer, the whole family has cancer."

If there are no further treatment options, the emphasis should be on providing the best supportive care by controlling the symptoms and caring for the patient in the community setting, providing holistic care and minimising distress to patients and families as much as possible.

**APPENDIX 1:** Information for patients with advanced differentiated thyroid cancer

**APPENDIX 2:** Information for patients with advanced medullary thyroid cancer

#### **List of workshop participants**

Perea, Soledad R.1, 2; Armstrong, Nicola15; Bartès, Beate6; Brose, Marcia S.9; Elisai, Rossella11; Farnell, Kate4; Grey, Joanna7; Harmer, Clive13; Hobrough, Helen5; Luster,

Markus14; Mallick, Ujjal15; McGarry, Mary12; Moss, Laura16; Palazzo, Fausto17; Porrey, Marika8; Pitoia, Fabian A.18; Schlumberger, Martin10; Taylor, Judith1; Villar, Carmen1, 3

1. Thyroid Cancer Alliance, Diss, Norfolk, United Kingdom. 2. ACTIRA, Buenos Aires, Argentina. 3. AECAT, Madrid, Spain. 4. Butterfly Thyroid Cancer Trust, Newcastle, United Kingdom. 5. Thyroid Cancer Support Group Wales, Cardiff, United Kingdom. 6. Vivre sans Thyroïde, Paris, France. 7. Association for Multiple Endocrine Neoplasm Disorders, Tunbridge Wells, United Kingdom. 8. Schildklier Organisaties Nederland (SON), Amersfoort, Netherlands. 9. Otorhinolaryngology: Head and Neck Surgery, University of Pennsylvania, Philadelphia, PA, United States. 10. Centre de Lutte Contre le Cancer (CLCC) de Villejuif, Institut Gustave Roussy, Villejuif, France. 11. University of Pisa, Pisa, Italy. 12. Thyroid Cancer Support Group Ireland, Dublin, Ireland. 13. Clinical Oncologist, London, United Kingdom. 14. University of Marburg, Marburg, Germany. 15. Freeman Hospital, Newcastle Upon Tyne, United Kingdom. 16. Velindre Cancer Centre, Cardiff, United Kingdom. 17. Hammersmith Hospital & Imperial College, London, United Kingdom. 18. Hospital de Clínicas - University of Buenos Aires, Buenos Aires, Argentina.

Copies of the patient leaflets are available in English, French, German and Spanish on request from:

Thyroid Cancer Alliance  
PO Box 359 | Diss, Norfolk  
IP22 2NX  
United Kingdom

Leaflets are also available online:

**[www.thyroidcanceralliance.org](http://www.thyroidcanceralliance.org)**  
**[www.thyroidcancerpatientinfo.org](http://www.thyroidcancerpatientinfo.org)**

Voluntary donations to help with printing and postage are welcome. Please contact **[info@thyroidcanceralliance.org](mailto:info@thyroidcanceralliance.org)**

© Thyroid Cancer Alliance May 2016

This information is prepared by the Thyroid Cancer Alliance, which is an international network of national thyroid cancer patient support organisations working together to provide support and information to those affected by the disease throughout the world. It is an outcome of a patient-led workshop on 'TKIs and what this means to patients,' which was held in Paris, October 2014. Please note, this information does not replace the information provided by your doctor. Always ask your clinical team if there is anything that is not clear to you.

This workshop and the follow-up meeting in Orlando, FL in October 2015 were supported by Bayer.

**[www.thyroidcanceralliance.org](http://www.thyroidcanceralliance.org)**

