Global Patient Experience Map on DTC

Background information for DTC Patient Organizations in Canada, France, Germany, Italy, the Netherlands, Spain and UK

WHAT?

Thyroid Cancer Alliance (TCA) and Thyroid Federation International (TFI) with the support of IPSEN have initiated the creation of a "Patient Experience Map" (PEM) to globally support patients living with radioiodine refractory Differentiated Thyroid Cancer (DTC). This study will help the patient groups in understanding and managing their disease better. There is no commercial benefit to Ipsen in undertaking this, except to support TCA and TFI in this initiative.

The PEM takes into account the different phases of life with radioiodine refractory DTC including emotional and medical aspects of the disease.

It aims at supporting your community to better cope and live with the disease. Therefore, we would like to ask you to spread our invitation in your network.

HOW?

A fundamental component of the patient experience mapping process is the collection of information directly from patients living with radioiodine refractory DTC. Therefore, we plan to gather insights via an online-survey from patients living in Canada, France, Germany, Italy, the Netherlands, Spain and UK. The survey invitation and the survey questions will be in the local language of the respondents, who can answer in their local language as well.

Thanks to the patients' answers we will be able to identify gaps and difficulties that they face in dealing with your condition. Their testimony will allow us building an aggregated and anonymized global PEM. The participants will not be compensated for the time they spend participating in the survey. But thanks to them we will be able to support the DTC patient community to better cope and live with the disease. We furthermore plan to publish the survey results in the form of an article in a medical journal and make them available to the patient and scientific community.

The survey participants will be sent a link via email leading to the online survey and it will take 25 minutes only to complete the online questionnaire. Of course, any interested persons can receive the results of the survey as a processed article. TCA and TFI will keep you updated upon its availability.

WHO IS INVOLVED IN CREATING THE PEM AND ORGANZING THE SURVEY?

TCA, TFI and IPSEN are working with a specialist partner, PARTNERSEITZ, who will be preparing and creating the PEM. PARTNERSEITZ is a German agency specializing in patient engagement. PARTNERSEITZ helps companies to develop relevant patient services or programs and supports companies in their transformation to patient-centred organizations.

HOW MANY PARTICIPANTS PER SELECTED COUNTRY?

We plan to include 5 participants per country.

WHO MAY TAKE PART IN THE SURVEY?

It’s important that the interested participants meet the following criteria. The fulfilment of these criteria is a requirement for taking part in the survey.

- The participants are at least 18 years and not older than 75 years.
- They have received the diagnosis “Differentiated Thyroid Cancer” (DTC)
- They received both a first line and a second line systemic treatment after radioactive iodine therapy, i.e. your tumor returned a first time and they were treated (first line treatment) and their tumor returned for a second time and they were treated (second line treatment)
- They had their second line treatment reimbursed by their health insurance
- They have not been diagnosed with any other type of cancer besides DTC

The patients will be informed beforehand that their participation in the survey is not linked to any specific treatment and that it will cover all available treatments for the disease.

WHAT DO INTERESTED PARTICIPANTS NEED TO DO BEFORE RECEIVING THE SURVEY LINK?

Also, we ask the patients to sign two consent forms before their participation.
The first one provides information about the general conditions and the participation criteria and allows us to contact them to conduct the survey.
The second one specifies important details on the survey and the handling of patient’s personal data. His/Her/Their signature of the consent form is a requirement for taking part in the survey.
His/Her/Their consent of both forms is voluntary and can be revoked at any time without any disadvantage to them. There will be no negative consequences for interested patients if they decide not to participate in this survey.

CONTACT DETAILS

Do you have any questions?
Please contact Kathrin from PARTNERSEITZ: koenig@partnerseitz.de