



Short Report

Thyroid Cancer Forum-UK (TCF-UK): a Free, Independent, Multidisciplinary Education Resource and Peer Support Organisation for Consultants

L. Moss

Velindre Cancer Centre, Cardiff, UK

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Context

Thyroid cancer is relatively rare and, as a result, each thyroid cancer multidisciplinary team deals with a relatively small number of new cases on an annual basis. In many centres, a single clinician specialises in the management of this disease, and there may be no conveniently located work colleague with whom to discuss difficult cases or controversial issues.

Background

Level 1 evidence from randomised controlled studies in thyroid cancer management is generally lacking. Therefore, the published US [1,2], UK [3] and European [4] consensus documents and guidelines are based primarily on retrospective studies and expert opinion. This results in considerable variation in practice, both nationally and internationally. In addition, all of these guidelines fail to help when dealing with the management of individual complex cases.

The objective for development of the Thyroid Cancer Forum-UK (TCF-UK) was to establish an electronic discussion forum for senior thyroid cancer specialists across the UK in order to facilitate patient management, service delivery, data collection and research.

Why, How, Who and What?

Why?

No national thyroid-cancer-specific organisation previously existed in the UK, so TCF-UK is unique in that it offers

a secure confidential information resource and support network for consultants and senior scientists specialising in thyroid cancer management.

Although this particular innovation is only applicable to a relatively small proportion of National Health Service (NHS) patients (1933 new UK cases in 2006 [5]), the organisation's membership base means that the vast majority of these UK thyroid cancer patients have the potential to benefit.

How it Started

In 2005, an informal letter and feedback form were sent to delegates who attended a national thyroid cancer meeting to assess the level of interest in an electronic information and support network. Further mail shots were sent to thyroid cancer multidisciplinary teams, and other specialists were approached through personal recommendations and poster advertising at national meetings. The targeted individuals were invited to comment on the proposal and asked if they would wish to participate. Widespread support and interest was received from across all disciplines. From the initial 106 letters posted, 90 responses (85%) were received; 89 of these were strongly in support of developing the forum (the other reply was from an individual no longer involved in thyroid cancer management).

All completed feedback forms were analysed for comments, and in view of the overwhelming positive response, it was decided to launch TCF-UK in July 2005. All e-mail addresses were registered, and information about how to use the forum was e-mailed to all registered individuals together with usernames and passwords.

Initially, the service only constituted an e-mail-based discussion forum. This was very easy to use but had limited

Author for correspondence: Laura Moss, Velindre Cancer Centre, Cardiff CF14 2TL, UK. Tel: 029-20316205; Fax: 029-20316267.

E-mail address: Laura.Moss@velindre-tr.wales.nhs.uk (L. Moss).

applications, and therefore restricted the options for TCF-UK development.

In 2007, TCF-UK changed from an e-mail-only discussion forum to a web-based organisation that allowed an increase in facilities. These additional features include a collection of seminal papers and a guideline library, secure databases for anaplastic thyroid cancer (ATC) and medullary thyroid cancer (MTC), and information on thyroid cancer for the general public with links to other patient-related information resources. Due to the complex requirements, the website is hosted and supported by a commercial information technology company.

Who?

Membership is only open to consultants and senior scientists. TCF-UK is multidisciplinary and includes oncology, surgery, endocrinology, pathology, radiology, nuclear medicine and basic scientists. The forum is free to registered users in order to encourage broader and continued participation of the UK thyroid cancer community. Introducing a registration fee, annual renewal fee or both would probably result in membership attrition, and as the emphasis and ethos of TCF-UK is to be inclusive and to encompass most UK senior clinicians, this would be counter productive.

TCF-UK is run by one clinician and is independent of the pharmaceutical industry, Royal colleges and other professional bodies in order to encourage a broad spectrum of membership and diverse opinions. Its multidisciplinary membership does, however, represent many professional bodies, including the British Thyroid Association, the British Association of Endocrine and Thyroid Surgeons, the British Nuclear Medicine Society and the National Cancer Research Institute Thyroid Cancer Subgroup.

Current membership of TCF-UK stands at 200, with just one withdrawal since its launch in July 2005. New members are continuing to register after recommendations from colleagues.

TCF-UK was originally implemented UK wide (plus Dublin), and forum users represent membership of all Welsh and Scottish cancer networks and at least 94% of English cancer networks.

What does it do?

Changing from an e-mail-only facility to a secure web-based facility has allowed the development of two national databases to collate information on the management of MTC and ATC, more elaborate and detailed discussion boards, and a library facility for members to access national and international guidelines, seminal papers and protocols.

The forum allows registered users to access the opinions and advice of its 200 senior colleagues, nationally and internationally, to discuss difficult cases, clinical management protocols and research ideas. Members regularly receive journal and conference abstracts, and meeting and educational course announcements via e-mail, and can also log in to the discussion forum website to access the

complete archive of papers, announcements and discussions.

TCF-UK therefore raises awareness of research areas and clinical trials, and disseminates information on forthcoming meetings and courses as well as published guidelines. It has allowed surveys of UK practice to be undertaken, and has the potential to collect national prospective data for MTC and ATC, the two rarer forms of thyroid cancer.

Two clinical oncology subgroup meetings have been hosted successfully, and a third meeting is scheduled. There is also information on the open access area of the website for the general public, with links to other information sources.

Database Development

No accurate national data currently exist on management of ATC and MTC in the UK. These are rare thyroid malignancies that can be difficult to manage. No individual clinician or multidisciplinary team treats very large numbers of these patients, so single-centre data are of limited use.

There was previously no mechanism for collecting data on management strategies and outcomes on a national basis. The proposed national datasets for thyroid cancer developed by the NHS Information Standards Board have concentrated on the more common differentiated thyroid cancers (papillary and follicular), the patient's original presentation, aetiological factors and initial treatment. The MTC and ATC databases, developed with the input of TCF-UK members, allow data collection in a wide range of data fields. MTC data fields include: biochemical marker trends; surgical details; radiotherapy use and techniques; imaging protocols; radioisotope use, including indications, isotope type, activity given, number of cycles and cumulative dose; chemotherapy use, including indications, agents and doses; somatostatin analogue use; clinical trials; and a comments section. ATC data fields include: tracheostomy and gastrostomy use; radiotherapy use and techniques; chemotherapy use, including indications, agents and doses; and a section enquiring about the clinician's opinion on whether any active intervention undertaken provided significant benefit to the patient, as this is usually a rapidly progressive disease where treatment fails to have much effect.

All data fields relating to treatments include fields on World Health Organization performance status, treatment response, treatment response evaluation methods and reasons for treatment discontinuation.

With the support and input of the members of TCF-UK, the potential exists to collect good-quality confidential patient data on MTC and ATC management. Such data will be invaluable in establishing the national patterns of disease presentation, investigation and management, and this in turn will help to improve the outcome for patients with these difficult-to-manage diseases.

Due to the patient database facilities, it is essential to have a secure website and to comply with the Data Protection Act principles of safe, secure, responsible data collection and storage. TCF-UK is therefore registered with

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