TEAMEd
Thyroid Eye Disease Amsterdam Declaration
Implementation Group UK

First Report – May 2014
Executive Summary
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1. Background – the Amsterdam Declaration

Thyroid Eye Disease (also known as Graves’ Orbitopathy [GO]) is a disfiguring condition that affects an estimated 50,000-100,000 people in the UK. Recent advances in our understanding of the predisposing factors and treatment have made it possible to reduce the incidence and severity of this disease but evidence suggests that this is not occurring in many parts of the UK.

In response to similar concerns in many countries, The Amsterdam Declaration (AD) to improve prevention, care and access to care for thyroid eye disease (TED) was signed by 86 national and international professional and patient-led organisations in 2009-10. The targets set by the AD include:

• halving the time from presentation to diagnosis,
• halving the time from diagnosis to referral to a centre of excellence,
• optimal treatment of thyroid disease including appropriate use of radioiodine, avoidance of hypothyroidism and vigorous anti-smoking measures in patients at risk of or with thyroid eye disease.

2. The UK Thyroid Eye Disease Amsterdam Declaration Implementation Group (TEAMeD)

The UK Thyroid Eye Disease Amsterdam Declaration Implementation Group (TEAMeD) was formed in 2010 to take forward this initiative in the UK and comprises representatives of all the key stakeholder organisations: The Royal College of Physicians, The British Thyroid Foundation, Royal College of Ophthalmologists, Scottish Ophthalmological Club, Society for Endocrinology, British OculoPlastic Surgery Society, British Thyroid Association, and the Thyroid Eye Disease Charitable Trust.

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<th>Group</th>
<th>Representative</th>
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<tr>
<td>British Thyroid Foundation</td>
<td>Mrs Janis Hickey, Mr Geoffrey E Rose, Mr Peter Foley (patient member)</td>
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<td>Thyroid Eye Disease Charitable Trust</td>
<td>Prof Colin Dayan (Chair), Mrs Julie McLaren (patient member)</td>
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<td>Royal College of Ophthalmologists</td>
<td>Mrs Jane Dickinson, replaced by Mr Dan Ezra, January 2014</td>
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<td>Society for Endocrinology</td>
<td>Dr Petros Perros</td>
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<td>Scottish Ophthalmological Club</td>
<td>Mrs Carrie McEwen</td>
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3. The First TEAMeD report

This is the first TEAMeD report and describes progress so far and the plans for completion of other work streams over the next two years. Work to date includes a survey of recently diagnosed patients, a web survey of the specialist clinics for TED, analysis of referral rates for specialist procedures in TED care (orbital decompression), a clinical tool for detection and referral of TED in endocrine clinics and development of a smoking advice tool for use in clinics.

4. Key points arising from the work of TEAMeD so far

- There remains a significant delay (mean of five months) from the onset of symptoms to making the diagnosis with much variation between individuals (0-216 months). However this represents some improvement on previous rates (> 6 months, Estcourt et al 2009).
- Many patients are not seen in specialist clinics: only 50% of patients are referred to a specialist clinic and only 20% are seen in a joint clinic. This is insufficient but also represents an improvement on previous rates (Estcourt et al 2009 – 25% attending a specialist clinic)
- Once referred, patients appear to be seen promptly in a specialist clinic (median delay to first appointment – 2 months).
- Awareness of smoking risks (making the disease more likely to occur, more severe and more resistant to treatment) once thyroid eye disease is diagnosed seems high, though smoking rates among patients who are newly referred to tertiary centres is still high.
- More than 30 centres in the UK treat moderate and severe thyroid eye disease.
- Of these, around 38% have clinics conducted jointly between an ophthalmologist and an endocrinologist. Patient activity varies widely across centres – 65% of centres see less than two severe cases of TED per year and 61% (47/77) of all severe cases were seen in three centres
- TEAMeD has published a review of decompression rates by PCT which also suggests that the provision of specialist procedures and rates of referral for TED specialist care for patients varies widely (more than 30-fold) by region.
- An advice leaflet on the risks of smoking based on the principles of information sharing and specifically designed for patients with TED was drafted by the Group. It contains practical advice and promotes shared decision making. It is available from http://www.btf-thyroid.org/index.php/campaigns/teamed/thyroid-eye-disease-teamed

5. Conclusions so far

These findings suggest that care of patients with TED in specialist centres has improved in recent years. However, there is potential to further reduce delays in diagnosis, and to increase the number of patients seen in specialist clinics. The provision of specialist clinics,
joint working with endocrinology, and reducing inequalities in workload, maintenance of specialist expertise and access to specialist services by region could also be improved.

6. Future work of TEAMeD

Ongoing workstreams include an audit of the use of radioiodine in thyrotoxcosis across endocrine units, the development of best practice guidelines for referral of patients to specialist centres, a baseline audit of rates of optic neuropathy due to TED (severe disease) and an audit of the journey taken by patients arriving in specialist clinics. These workstreams are scheduled for completion in 2015/6.

TEAMeD is also leading a national group for defining specifications of centrally commissioned specialised services in England. In combination with best practice guidelines for referral and provision of specialist clinics and the implementation of measures to reduce the incidence rates of significant TED (appropriate use of radioiodine, early smoking advice), there is significant potential to achieve the goals set by the Amsterdam Declaration.

TEAMeD has organised a meeting for May 2014 in Newcastle, which will bring together UK and European experts on TED, patients, carers and the public, in order to prioritise and promote research in this area.

7. References:


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May 2014

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