

Thyroid Cancer Forum-UK

Data collection

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www.thyroid-cancer-forum-uk.org



Why?



- No national thyroid cancer specific organisation in UK
- Complex cases not covered by 'guidelines'
- Launched 2005

Who?: Membership

- Free and independent
- Consultants and senior scientists
- >210 members (oncology, surgery, endocrinology, nuclear medicine, pathology, radiology...)
- UK (covers >94% English cancer networks and 100% Scottish and Welsh cancer networks)
- International: Australia, Belgium, Canada, Czech Republic, Holland, Panama, Republic of Ireland, USA

What does it do?

- Access wider opinion for difficult clinical scenarios
- Circulate journal abstracts
- Raise awareness of research areas, clinical trials
- Notification of meetings, guidelines, courses
- Survey UK practice
- National prospective data collection for MTC and ATC

Database: Why?

- No accurate national data on the management of ATC and MTC
- Nobody treats very large numbers of these patients
- No other mechanism of collecting data on management strategies and outcomes nationally

Database: How?

TCF-UK members consulted on

- Concept
- Method of collection
- Data fields

Thyroid cancer patient organisations
consulted

- Website, newsletters
- Proactive patients

Collecting patient data

- As TCF-UK is not part of the NHS, automatic patient data entry is not allowed under the DPA unless patient gives their consent
- Registered with Information Commission Office
- Data being collected in accordance with DPA

- Consent can be verbal
- Patient information leaflet available in website article library to download
- Patient data is only available to the member who enters it and the TCF-UK administrator. Securely stored

Personal data

Includes

- Initials
- DOB
- Gender
- Hospital number

Does not include

- Full name
- Address
- Sexuality, religion

MTC: Data fields

- Presentation
- Biochemistry
- Surgery details: primary, nodes, extent, recurrences, mets
- RT: adjuvant, therapeutic, palliative, dose, technique
- FU protocol: ? Routine imaging planned
- Recurrence: site, how diagnosed

MTC: Data fields

- Radioisotope therapy: isotope, activity, regime, evaluation method, outcome
- Chemotherapy: indication, regime, response
- Somatostatin analogues
- Clinical trial
- Other

ATC: Data fields

- Presentation
- Diagnosis method
- Surgery
- Tracheostomy
- Gastrostomy, NG tube
- RT: radical, palliative, dose, technique
- Chemotherapy: intent, regime, outcomes
- Trials
- Hindsight: did the treatment offered provide significant benefit/palliation?
- Comments

Problems

- Voluntary not mandatory data entry
- Time: busy work schedules
- Funding

Possible ways to increase data entry

- ? Mandatory requirement
- ? Other professional groups to be approached to help with data entry
- ? Researcher to travel to cancer centres and input data
- ? Registry study

Thank you

For more information please contact me
at

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