

Who leads, who treats, what dose? European paediatric DTC practice –an EXPeRT survey

Michaela Kuhlen, Jelena Roganivic, Samuele Naviglio, Fredrik Baecklund, Rachel Bello, Tal Ben-Ami, Luca Bergamaschi, Ernest Bilic, Ewa Bien, Manuel João Brito, Alicia Castañeda, Maja Cesen Mazic, Nuno Jorge dos Reis Farinha, Aleksandra Jovanovska, Ronald de Krijger, Maria Debora de Pasquale, Rossella Elisei, Gema Grau Bolado, Gabriela Guillén, Magalie Haissaguerre, Dana Hartl, Jorge Huerta-Aragonés, Malgorzata A. Krawczyk, Livia Lamartina, Filipa Leite, Valeriano Leite, Ricardo López Almaraz, Nevena Manevska, Ludovic Mansuy, Evelina Miele, Elin Hallan Naderi, Thilde Nordmann Winther, Isabelle Oliver Petit, Zeynep Alev Özön, Marta Giorgia Podda, Apostolos Pourtsidis, Yves Reguerre, Maria Sandström, Dominik T. Schneider, Saniye Ekinici, Jasna Suput Omladic, Beata Sztangierska, Cecile Verite, Nicolas Waespe, Kee Howe Wong, Bilgehan Yalcin, Michael Abele, Gianni Bisogno, Daniel Orbach, Ines B. Brecht, Calogero Virgone, Antje Redlich

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1 Research Article

2 **Who Leads, Who Treats, What Dose? European Paediatric DTC Practice – an EXPeRT**
3 **survey**

4 Michaela Kuhlen^{1,2,3}, Jelena Roganivic⁴, Samuele Naviglio⁵, Fredrik Baecklund⁶, Rachel
5 Bello^{7,8}, Tal Ben-Ami⁹, Luca Bergamaschi¹⁰, Ernest Bilic¹¹, Ewa Bien¹², Manuel João Brito¹³,
6 Alicia Castañeda¹⁴, Maja Cesen Mazic¹⁵, Nuno Jorge dos Reis Farinha¹⁶, Aleksandra
7 Jovanovska¹⁷, Ronald de Krijger¹⁸, Maria Debora de Pasquale¹⁹, Rossella Elisei²⁰, Gema Grau
8 Bolado²¹, Gabriela Guillén²², Magalie Haissaguerre²³, Dana Hartl²⁴, Jorge Huerta-
9 Aragonés²⁵, Malgorzata A. Krawczyk^{12,26}, Livia Lamartina²⁷, Filipa Leite²⁸, Valeriano Leite²⁹,
10 Ricardo López Almaraz³⁰, Nevena Manevska³¹, Ludovic Mansuy³², Evelina Miele¹⁹, Elin
11 Hallan Naderi³³, Thilde Nordmann Winther³⁴, Isabelle Oliver Petit³⁵, Zeynep Alev Özön³⁶,
12 Marta Giorgia Podda¹⁰, Apostolos Pourtsidis³⁷, Yves Reguerre³⁸, Maria Sandström³⁹,
13 Dominik T. Schneider⁴⁰, Saniye Ekinci⁴¹, Jasna Suput Omladic⁴², Beata Sztangierska⁴³,
14 Cecile Verite⁴⁴, Nicolas Waespe^{45,46}, Kee Howe Wong⁴⁷, Bilgehan Yalcin⁴⁸, Michael Abele²⁷,
15 Gianni Bisogno^{49,50}, Daniel Orbach⁵¹, Ines B. Brecht²⁷, Calogero Virgone^{49,52}, Antje Redlich¹

16

17 ¹ Department of Paediatrics, Paediatric Haematology/Oncology, Otto-von-Guericke-
18 University, Leipziger Str. 44, Magdeburg-D 39120, Germany; antje.redlich@med.ovgu.de

19 ORCID 0000-0002-1732-1869

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- 1 ² Paediatrics and Adolescent Medicine, Faculty of Medicine, University of Augsburg,
2 Augsburg, Germany; michaela.kuhlen@uk-augsburg.de ORCID 0000-0003-4577-0503
- 3 ³ Bavarian Cancer Research Centre (BZKF), Stenglinstr. 2, Augsburg-D 86156, Germany
- 4 ⁴ Children's Hospital Zagreb, Department of Pediatric Oncology and Haematology, Klaićeva
5 16, Zagreb 10000, Croatia; jelena.roganovic02@gmail.com; ORCID 0000-0002-7960-6069
- 6 ⁵ Institute for Maternal and Child Health IRCCS "Burlo Garofolo," Trieste, Italy,
7 samuele.naviglio@burlo.trieste.it
- 8 ⁶ Pediatric Oncology Unit, Karolinska University Hospital, 171 64 Stockholm, Sweden;
9 fredrik.baecklund@regionstockholm.se ORCID 0000-0003-1333-2912
- 10 ⁷ The Jesse Z and Sara Lea Shafer Institute for Endocrinology and Diabetes, National Center
11 for Childhood Diabetes, Schneider Children's Medical Center of Israel, Petach Tikva, Israel
- 12 ⁸ Gray Faculty for Medical and Health Sciences, Tel Aviv University, Tel Aviv, Israel;
13 Rachelb2@clalit.org.il
- 14 ⁹ Paediatric Haematology/Oncology Unit, Kaplan Medical Centre, 7661041 Rehovot, Israel,
15 affiliated with Hadassah-Hebrew University Medical School, Jerusalem, Israel,
16 tal.ben.ami11@gmail.com ORCID 0000-0003-0017-6332
- 17 ¹⁰ Pediatric Oncology Unit, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan 20133,
18 Italy; luca.bergamaschi@istitutotumori.mi.it ORCID 0000-0003-2149-329X;
19 marta.podda@istitutotumori.mi.it ORCID 0000-0002-0855-2526

1 ¹¹ University of Zagreb, School of Medicine, Division of Pediatric Hematology and Oncology,
2 UHC Zagreb, Kispaticeva 12, 10000 Zagreb, Croatia; ernestbilic@gmail.com ORCID 0000-
3 0002-1909-118X

4 ¹² Department of Paediatrics, Haematology, and Oncology, Medical University of Gdansk,
5 Gdansk, 80-211, Poland; ebien@gumed.edu.pl ORCID 0000-0002-2091-2686;
6 mkrawczyk@gumed.edu.pl ORCID 0000-0001-7093-8975

7 ¹³ Pediatric Oncology, Centro Hospitalar e Universitario de Coimbra EPE, Hospital
8 Pediátrico, Coimbra, Portugal; mjbrito@ulscoimbra.min-saude.pt

9 ¹⁴ Pediatric Cancer Center Barcelona, Hospital Sant Joan de Déu. Barcelona, 08014, Spain;
10 alicia.castanedah@sjd.es

11 ¹⁵ University Children ´s Hospital Ljubljana, 1000 Ljubljana, Slovenia;
12 maja.cesenmazic@kclj.si ORCID 0000-0003-2434-8960

13 ¹⁶ Hospital Center of São João (CHSJ), 4200-319 Porto, Portugal;
14 nuno.reis.farinha@gmail.com

15 ¹⁷ Department of Hematology and Oncology, University Children `s Hospital, Faculty of
16 Medicine, Ss Cyril and Methodius University in Skopje, 1000 Skopje, North Macedonia;
17 jovanovska.a@gmail.co ORCID 0000-0003-2851-5228

18 ¹⁸ Princess Máxima Center for Paediatric Oncology, and Department of Pathology, University
19 Medical Center Utrecht, Utrecht 3584 CS, The Netherlands; r.r.dekrijger-
20 2@prinsesmaximacentrum.nl ORCID 0000-0001-6871-1296

- 1 ¹⁹ Oncohematology, Hemopoietic Transplantation, Cellular Therapies and Clinical Trials,
2 Bambino Gesù Children's Hospital, IRCCS, 00165 Rome, Italy; mdebora.depasquale@opbg.net
3 ORCID 0000-0003-1082-6810; evelina.miele@opbg.net ORCID 0000-0002-4747-1032
- 4 ²⁰ Endocrine Unit 2, Department of Clinical and Experimental Medicine, University Hospital
5 of Pisa, Pisa 56124, Italy; rossella.elisei@unipi.it ORCID 0000-0002-5333-9257
- 6 ²¹ Pediatric Endocrinology, Cruces Hospital, Barakaldo, 48093 Bizkaia, Spain;
7 mariagema.graubolado@osakidetza.eus
- 8 ²² Department of Pediatric Surgery, Hospital Universitari Vall d'Hebron, Barcelona 08035,
9 Spain; gabriela.guillen@vallhebron.cat ORCID 0000-0001-5632-2672
- 10 ²³ Department of Endocrinology and Endocrine Oncology, Haut-Lévêque Hospital,
11 University Hospital of Bordeaux, Pessac, France; magalie.haissaguerre@chu-bordeaux.fr
12 ORCID 0000-0001-5007-7602
- 13 ²⁴ Thyroid Surgery Unit, Department of Surgery and Anesthesiology, Gustave Roussy, 114
14 rue Edouard Vaillant, 94805 Villejuif, France; dana.hartl@gustaveroussy.fr ORCID 0000-
15 0003-1161-5628
- 16 ²⁵ Sección de Oncología y Hematología Pediátricas y del Adolescente, Servicio de Pediatría,
17 Hospital General Universitario Gregorio Marañón, Madrid, Spain;
18 jorge.huerta@salud.madrid.org
- 19 ²⁶ Paediatric Haematology/Oncology, Department of Paediatrics, University Hospital
20 Tuebingen, Tuebingen, Germany; michael.abele@med.uni-tuebingen.de ORCID 0000-
21 0002-9780-603X; ines.brecht@med.uni-tuebingen.de ORCID 0000-0001-7973-3300

1 ²⁷ Gustave Roussy, Département d’Imagerie Médicale, Service de Cancérologie
2 Endocrinienne, F-94805, VILLEJUIF, France; livia.lamartina@gustaveroussy.fr

3 ²⁸ Department of Pediatrics, Portuguese Oncology Institute of Porto, Porto, Portugal;
4 filipa.leite@ipoporto.min-saude.pt

5 ²⁹ Serviço de Endocrinologia, Instituto Português de Oncologia de Lisboa Francisco Gentil,
6 Rua Professor Lima Basto, 1099-023 Lisboa, Portugal; vleute@ipolisboa.min-saude.pt
7 ORCID 0000-0001-5479-7332

8 ³⁰ Paediatric Haematology and Oncology Unit, Hospital Universitario de Cruces, 48903
9 Barakaldo-Bizkaia, Spain; ricardo.lopezalmaz@osakidetza.eus ORCID 0000-0001-5521-
10 9892

11 ³¹ Institute of Pathophysiology and Nuclear Medicine, Faculty of Medicine, University of Ss
12 Cyril and Methodius, 1000 Skopje, North Macedonia; dr.nmanevska@gmail.com ORCID
13 0000-0001-7168-3775

14 ³² Department of Pediatric Hematology and Oncology, Children's University Hospital,
15 Nancy, France; lu.mansuy@chru-nancy.fr

16 ³³ Department of Head and Neck Oncology, Division of Cancer Medicine, Oslo University
17 Hospital/The Norwegian Radium Hospital; 0379 Oslo, Norway; elinad@ous-hf.no ORCID
18 0000-0002-0715-2272

19 ³⁴ Department of Paediatrics and Adolescent Medicine, Rigshospitalet, Copenhagen
20 University Hospital, Copenhagen, Denmark; thilde.nordmann.winther.02@regionh.dk

1 ³⁵ Endocrine Unit, Children Hospital, TSA 70034, 31059 Toulouse cedex, France;
2 oliver.i@chu-toulouse.fr

3 ³⁶ Pediatric Endocrinology, Faculty of Medicine, Hacettepe University, 06100-Ankara, Turkey
4 ³⁷ Pediatric and Adolescent Oncology Clinic, Children's Hospital MITERA, 6, Erythrou
5 Stavrou Str., 151 23, Marousi, Athens, Greece; ped.adol.onc@mitera.gr
6 apourtsidis@hygeia.gr ORCID 0000-0003-4031-6619

7 ³⁸ Paediatric Oncology and Haematology Unit, CHU Saint Denis de La Réunion, Bellepierre
8 97400, France; yves.reguerre@chu-reunion.fr

9 ³⁹ Department of Diagnostics and Interventions, Oncology, Umeå University, 901 85 Umeå,
10 Sweden; maria.sandstrom@umu.se ORCID 0009-0002-4328-8561

11 ⁴⁰ Clinic of Paediatrics, Klinikum Dortmund, University Witten/Herdecke, Dortmund,
12 Germany; dominik.schneider@klinikumdo.de ORCID 0000-0001-8153-1601

13 ⁴¹ Pediatric Surgery, Faculty of Medicine, Hacettepe University, 06100-Ankara, Turkey;
14 sekinci@hacettepe.edu.tr

15 ⁴² Clinical Department for Endocrinology, Diabetes and Metabolic Disease, University
16 Children's Hospital Ljubljana, 1000 Ljubljana, Slovenia; Jasna.suputomladic@kclj.si

17 ⁴³ Department of Pediatrics, Diabetology and Endocrinology, Medical University of Gdansk,
18 Gdansk, 80-211, Poland; bsztangierska@uck.gda.pl

19 ⁴⁴ Paediatric Oncology and Haematology Unit, CHU Bordeaux, 33076 Bordeaux, France;
20 cecile.verite@chu-bordeaux.fr

1 ⁴⁵ Division of Pediatric Hematology/Oncology, Department of Pediatrics, Inselspital, Bern
2 University Hospital, University of Bern, 3010 Bern, Switzerland; nicolas.waespe@unibe.ch;
3 ORCID 0000-0002-2271-8959

4 ⁴⁶ CANSEARCH research platform in pediatric oncology and hematology, Department of
5 Pediatrics, Gynecology and Obstetrics, University of Geneva, 1206 Geneva, Switzerland

6 ⁴⁷ Head & neck and thyroid oncology unit, Royal Marsden Hospital, London SW3 6JJ, United
7 Kingdom; Keehowe.wong@rmh.nhs.uk

8 ⁴⁸ Department of Pediatric Oncology, Faculty of Medicine, Hacettepe University, 06100-
9 Ankara, Turkey; bilgehanyalcin@yahoo.com ORCID 0000-0003-2840-0308

10 ⁴⁹ Department of Woman and Child's Health, University Padua, Padua, Italy

11 ⁵⁰ Pediatric Hematology Oncology Division, University Hospital of Padua, Padua, Italy;
12 gianni.bisogno@unipd.it ORCID 0000-0003-4462-5523

13 ⁵¹ SIREDO (Care, Innovation & Research in Childhood, Adolescent & Young-Adult Oncology)
14 Oncology Center, Institut Curie, 75005, Paris Sciences et Lettres University, Paris, France;
15 daniel.orbach@curie.fr ORCID 0000-0002-2520-139X

16 ⁵² Paediatric Surgery, University Hospital of Padua, Padua, Italy; calogero.virgone@unipd.it
17 ORCID 0000-0002-3651-9416

18

19 **Correspondence:** Michaela Kuhlen, Department of Paediatrics, Paediatric

20 Haematology/Oncology, Otto-von-Guericke-University, Leipziger Str. 44, Magdeburg-D

1 39120, Germany. Email: michaela.kuhlen@med.ovgu.de and Paediatrics and Adolescent
2 Medicine, University Medical Centre Augsburg, Stenglinstr. 2, 86156 Augsburg, Germany.
3 Phone: +49 821 400169307, Fax: +49 821 400179307. Email: michaela.kuhlen@uk-
4 augsburg.de

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15
16 **Abstract**

17 **Objective:** To map real-world management of paediatric differentiated thyroid carcinoma
18 (DTC) across Europe and identify targets for harmonisation.

1 **Design:** Cross-sectional, web-based survey of centres providing paediatric DTC care.

2 **Methods:** One consolidated response per centre was requested from a clinician overseeing
3 paediatric DTC. The instrument covered centre profile/multidisciplinary tumour board
4 organisation; staging and guideline use; risk stratification and dynamic response;
5 diagnostics; surgery/lymph node management; radioiodine therapy (RAIT) policy and activity
6 selection; Thyroid-Stimulating Hormone targets, follow-up, shared-care/transition.
7 Analyses were descriptive at centre level.

8 **Results:** Forty-two centres from 18 countries participated. Among centres answering each
9 item, university/academic hospitals $\approx 75\%$; paediatric age cut-off ≤ 18 y $\approx 70\%$; dedicated
10 multidisciplinary tumour board (MDT) $\approx 60\%$. Staging systems varied and the primary
11 guidance was mixed ($\sim 30\%$), American Thyroid Association (ATA) 2015 ($\sim 25\text{--}30\%$), national
12 ($\sim 20\text{--}25\%$), or European Thyroid Association (ETA) 2022 ($\sim 10\text{--}15\%$). Dynamic response-to-
13 therapy categories were commonly used. For unilateral presumed low-risk disease,
14 hemithyroidectomy was the usual initial surgery in about two-thirds to three-quarters of
15 centres, total thyroidectomy was less frequent. For low-risk patients, RAIT policy split
16 between de-escalation ($\approx 55\%$) and risk-adapted use ($\approx 45\%$). When given, activity was
17 determined by weight, dosimetry, or fixed empiric approaches. Country-level patterns were
18 evident (ETA- vs ATA-leaning/national environments).

19 **Conclusions:** Across Europe, centres broadly endorse risk-adapted care but diverge at key
20 decision nodes—extent of surgery, formal risk framework, and RAIT in low-risk disease—
21 reflecting guidance plurality and organisational context. Leveraging existing infrastructures

1 offers pragmatic avenues to reduce unwarranted variation while generating paediatric-
2 specific evidence to refine recommendations.

3

4 **Significance statement**

5 We report the first pan-European view of real-world management of paediatric
6 differentiated thyroid carcinoma across 42 centres in 18 countries. Practice varies
7 systematically in three domains central to outcomes and late effects: surgical extent, use
8 of formal risk frameworks (ATA vs ETA vs national), and radioiodine therapy (RAIT) policy in
9 low-risk disease. Hemithyroidectomy is commonly preferred for unilateral presumed low
10 risk, while RAIT use splits between de-escalation and selective application. We provide a
11 concise ATA–ETA comparison and an illustrative MDT-anchored care pathway to help teams
12 situate their practice. These data identify targets for harmonisation and show how existing
13 European infrastructures (EXPERT, CPMS, and PARTNER) can support reference-board
14 decision-making and prospective outcome capture.

15

16 **Introduction**

17 Differentiated thyroid carcinoma (DTC) in children and adolescents is rare, yet its incidence
18 appears to be increasing, and patients require specialized, multidisciplinary care across
19 surgery, endocrinology, nuclear medicine, and paediatric oncology. (1-5) While survival is
20 excellent in most cases, optimizing long-term quality of life and minimizing late effects—

1 particularly those potentially related to radioactive iodine therapy (RAIT)—remain central
2 goals of contemporary management. (6-13) Within Europe, practice patterns for paediatric
3 DTC are perceived to vary substantially, including which specialties lead initial care, the
4 application of formal risk stratification, the extent of surgery including lymph-node
5 dissection, and indications and dosing strategies for RAIT. (14-16) These observations have
6 been echoed within the European Cooperative Study Group for Paediatric Rare Tumours
7 (EXPeRT) network and motivated the present survey.

8 Over the past decade, professional guidance has emerged for risk-adapted initial therapy
9 and dynamic response-to-therapy follow-up in paediatric DTC care. The American Thyroid
10 Association (ATA) 2015 paediatric guideline supports a selective, risk-adapted use of post-
11 operative RAIT, with surveillance without routine RAIT considered appropriate for many
12 patients at lower risk after surgery and post-operative assessment, while RAIT is
13 recommended for iodine-avid persistent or unresectable locoregional disease and distant
14 metastases, and may be considered in selected higher-risk presentations. (17) The
15 European Thyroid Association (ETA) 2022 paediatric guidance likewise endorses risk
16 stratification and multidisciplinary decision-making, but—reflecting acknowledged
17 paediatric evidence gaps—issues a broader low-strength suggestion that ^{131}I therapy can be
18 indicated after total thyroidectomy, while emphasizing individualized dosing and careful
19 weighing of potential late effects. (18) These differences, rooted in distinct interpretations of
20 a sparse paediatric evidence base rather than in opposing therapeutic goals, provide a
21 plausible substrate for heterogeneity of practice across Europe. (7, 19, 20) Mapping current

1 practice is therefore essential to identify gaps, prioritize harmonization efforts, and define
2 realistic targets for quality improvement across Europe.

3 To address this need, the EXPeRT Endocrine Working Group (21) designed a pan-European,
4 cross-sectional survey to capture how centres currently diagnose and treat newly diagnosed
5 paediatric DTC. We aimed to obtain one consolidated response per centre from clinicians
6 with oversight of paediatric DTC management, sampling EXPeRT institutions and affiliated
7 national society networks to achieve broad geographic coverage.

8 By delivering an up-to-date snapshot of paediatric DTC care across Europe, this survey seeks
9 to (i) quantify real-world variability, (ii) highlight areas of consensus and divergence relative
10 to contemporary recommendations, and (iii) inform practical next steps for EXPeRT-led
11 harmonisation, including shared pathways, centralized review options, and priorities for
12 prospective data collection/registry alignment. Ultimately, such a foundation is intended to
13 support safer, more consistent, and evidence-aligned care for children and adolescents with
14 DTC across diverse European health systems.

15

16 **Methods**

17 We conducted a cross-sectional, web-based survey of European centres caring for children
18 and adolescents with DTC. The survey was circulated to all EXPeRT members (86 members
19 across 26 countries) and disseminated via affiliated national societies. Additional snowball
20 dissemination was used to maximise geographic coverage. Because snowball reach could
21 not be precisely quantified, the exact number of centres contacted with this invitation

1 cannot be stated. One consolidated response was requested per centre, completed by a
2 clinician with oversight of paediatric DTC management. Where helpful for accuracy,
3 respondents could invite co-respondents from other disciplines at the same centre.

4 Eligible sites were hospitals providing any component of paediatric DTC care (paediatric or
5 adult endocrinology, paediatric oncology, surgery, nuclear medicine). The sampling frame
6 comprised EXPeRT group institutions and affiliated national societies, with snowball
7 sampling used to maximise geographic coverage. Centres reported their country.

8 The questionnaire was developed by members of the EXPeRT Endocrine Working Group
9 (M.K., J.R., A.R.), iteratively refined through internal piloting, and organised into the following
10 domains: (A) centre profile and multidisciplinary tumour board (MDT); (B) guideline use and
11 risk stratification; (C) diagnostic work-up; (D) surgery; (E) RAIT policy; (F) thyrotropin (TSH)
12 targets and follow-up; and (G) shared-care/transition and system enablers.

13 Responses were captured via Microsoft Forms® at the coordinating centre. Email addresses
14 were collected solely to facilitate authorship communication and were removed prior to
15 analysis. The analytical dataset contained no personal identifiers and no institution/centre
16 identifiers. Only country and professional specialty were retained. The primary outcomes
17 were centre-level practices in paediatric DTC.

18 This professional-practice survey was conducted in accordance with the principles of the
19 Declaration of Helsinki. It collected no patient-level or personally identifiable data, targeting
20 instead institutional and professional practice patterns at the centre level. As a survey of

1 healthcare professionals collecting no patient identifiers, formal independent ethics
2 committee review was not required under applicable local and national regulations.

3

4 ***Statistical analysis***

5 Analyses were descriptive at the centre level. Categorical variables were reported as counts
6 and percentages. For single-choice items, percentages were calculated using the number
7 of responding centres for that item as the denominator. For multiple-choice items, each
8 option was coded separately, and its percentage was calculated over the number of
9 responding centres for that item. Because centres could select more than one option, the
10 percentages across options may sum to more than 100%. Missing item responses were
11 treated as missing and excluded from the denominator for that item.

12 To explore whether resource context relates to practice, we performed a descriptive
13 comparison using the Low Health-Expenditure Average Rate (LHEAR) country grouping as
14 defined by Roganovic et al. (22), which operationalises “low health-expenditure average
15 rate” countries for analyses of paediatric very rare tumour care in Europe. In our survey,
16 LHEAR countries were defined a priori as Croatia, Greece, North Macedonia, Poland, and
17 Turkey; all other participating countries were classified as other. This grouping was used
18 descriptive contrasts only.

19 Country-level summaries and the LHEAR vs other comparisons are presented descriptively.

20

1 **Results**

2 ***Participating centres and respondents***

3 We analysed 42 centres spanning 18 European countries including three centres with co-
4 respondents from other disciplines. Contributions were concentrated in France, Italy, Spain,
5 Germany, and Portugal, with additional centres from Central/Eastern and Northern Europe.
6 (Table 1)

7 Among the 42 respondents, 31 (73.8%), worked in university/academic hospitals, 5 (11.9%)
8 in tertiary paediatric hospitals, and 4 (9.5%) in adult hospitals with paediatric pathways. The
9 paediatric age cut-off was ≤ 15 years in 5/42 (11.9%), ≤ 18 years in 31/42 (73.8%), ≤ 25 years
10 in 1/42 (2.4%), and no strict cut-off in 5/42 (11.9%). Annual centre-level volume over the last
11 three years was 0–2 cases in 17/42 (40.5%), 3–5 in 9/42 (21.4%), 6–10 in 13/42 (31.0%), and
12 >10 in 3/42 (7.1%).

13 Respondents were predominantly paediatric oncologists (26/42, 61.9%), alongside
14 paediatric endocrinologists (5/42, 11.9%), adult endocrinologists (3/42, 7.1%), and
15 paediatric surgeons (2/42, 4.8%). The specialties most often leading initial management
16 were paediatric endocrinology (28/42, 66.7%), paediatric oncology (25/42, 59.5%), nuclear
17 medicine (13/42, 31.0%), adult endocrinology (12/42, 28.6%), endocrine/adult surgery
18 (11/42, 26.2%), and paediatric surgery (10/42, 23.8%).

19

20 ***Organisation of care***

1 A dedicated paediatric DTC MDT operated in 22/42 (52.4%) centres. Among those with an
2 MDT, scope was local in 17/22 (77.3%), regional in 1/22 (4.5%), and national in 4/22 (18.2%).
3 Meeting cadence ranged from weekly (12/22; 54.5%) and monthly (4/22; 18.2%) to ad hoc/on
4 demand/other (6/22; 27.3%). Alongside pathology and radiology, required attendees (where
5 specified) typically included endocrine/adult surgery (19/22; 86.4%), nuclear medicine and
6 paediatric oncology (each 17/22; 77.3%), paediatric surgery (15/22; 68.2%), paediatric
7 (13/22; 59.1%) and/or adult endocrinology (12/22; 54.5%), and other disciplines (5/22;
8 22.7%).

10 ***Diagnostic framework and risk-adaptation***

11 Centres most often used American Joint Committee on Cancer (AJCC)/Union Internationale
12 Contre le Cancer (UICC) Tumour Nodes Metastases (22/42, 52.4%), followed by ATA
13 paediatric 2015 (8/42, 19.0%), mixed systems (5/42, 11.9%), and ETA 2022 (3/42, 7.1%).
14 (Figure 1A)

15 The primary guideline informing care was a combination/mixed approach in 15/42 (35.7%)
16 and ATA 2015 in 11/42 (26.2%). (Figure 1B)

17 A formal risk-stratification system was reported by 36 centres, most commonly ATA 2015
18 (18/36, 50.0%) and ETA 2022 (10/36, 27.8%). (Figure 1C)

19 Dynamic response-to-therapy categories were used always in 16/42 (38.1%) and never in
20 9/42 (21.4%). (Figure 1D)

1 **Diagnostic work-up and molecular testing**

2 Neck ultrasound was universal (42/42, 100%) and fine-needle aspiration (FNA) was reported
3 in the standard pre-operative work-up by 39/42 (92.9%) centres. Thyroid function tests
4 (37/42, 88.1%) and thyroglobulin (TG)/anti-TG antibodies (31/42, 73.8%) were commonly
5 obtained. Use of cross-sectional imaging (computed tomography/magnetic resonance
6 imaging) was reported by 13/42 (31.0%) centres and PET scanning by 3/42 (7.1%), while
7 recurrent laryngeal nerve assessment was reported by 13/42 (31.0%) centres.

8 Regarding tumour genomics, somatic testing was reported selectively in 26/42 (61.9%),
9 routine in 11/42 (26.2%), and not performed in 5/42 (11.9%). Frequently cited targets
10 included *BRAF*, RAS pathway genes, *RET*, *NTRK*, and *ALK fusions*, and *TERT* promoter.

11 Germline testing for predisposition syndromes was selective in 24/42 (57.1%), routine in
12 14/42 (33.3%), and not used in 4/42 (9.5%).

13

14 **Surgery and lymph-node management**

15 For presumed unilateral low-risk disease, hemithyroidectomy was the usual initial surgery in
16 30/42 (71.4%), total thyroidectomy in 11/42 (26.2%), and other in 1/42 (2.4%). Indications for
17 central neck dissection (CND) were predominantly clinico-radiological nodal disease
18 (37/42, 88.1%) and intra-operative findings (35/42, 83.3%), as well as prophylactic in
19 intermediate and high-risk disease (23/42, 54.8%). Five centres (11.9%) also indicated using
20 CND in low-risk settings prophylactically. Lateral neck dissection (LND) followed a similar

1 pattern, triggered mainly by clinico-radiological evidence (41/42, 97.6%) and intra-operative
2 findings (33/42, 78.6%), with prophylactic LND uncommon (intermediate/high-risk 7/42,
3 16.7%; low-risk 1/42, 2.4%). Intraoperative nerve monitoring was used always in 28/42
4 (66.7%), often in 6/42 (14.3%), sometimes and rarely each in 3/42 (7.1%), and never in 2/42
5 (4.8%).

7 **Radioiodine (RAI) practice**

8 For low-risk patients without metastases, most centres reported never using RAI (16/42,
9 38.1%), selectively (13/42, 31.0%), or rarely (9/42, 21.4%). (Figure 2A)

10 The primary purpose when given was combined therapeutic/ablation (20/42, 47.6%) or
11 treatment of metastatic disease (18/42, 42.9%). (Figure 2B)

12 Activity selection varied across centres, including weight-based dosing (13/36, 36.1%),
13 dosimetry-guided (9/36, 25.0%), fixed empiric activities (7/36, 19.4%), and body surface
14 area-based dosing (5/36, 13.9%). (Figure 2C)

15 Common reasons to omit RAI (multi-response) included guideline recommendation (26/39,
16 66.7%), concerns about toxicity (16/39, 41.0%), lack of evidence for benefit (13/39, 33.3%),
17 and patient/family preference (6/39, 15.4%). (Figure 2D)

18 Long-term follow-up for potential RAI late effects was reported by most centres: 27/42
19 (64.3%) within routine paediatric oncology/endocrinology follow-up and 4/42 (9.5%) within
20 structured survivorship clinics, while 11/42 (26.2%) described limited or symptom-based

1 programmes. Among centres specifying which domains are monitored (n=31), the most
2 frequent were salivary-gland (21/31, 67.7%), pulmonary function and screening for
3 secondary malignancies (each 20/31, 64.5%), with additional attention to haematologic
4 (17/31, 54.8%) and gonadal/fertility (16/31, 51.6%) effects.

6 ***TSH targets and follow-up***

7 TSH goals were risk-adapted: for low-risk disease, most centres aimed to keep values within-
8 the reference range (0.5–2.0 mU/L; 27/41, 65.9%); for intermediate-risk, mild suppression
9 (0.1–0.5 mU/L) was most common (24/41, 58.5%); and for high-risk, full suppression (<0.1
10 mU/L) predominated (36/41, 87.8%). (Figure 3)

11 Routine clinical/biochemical surveillance intervals were every 3 months in year 1 (30/42,
12 71.4%) and every 6 months in year 2 (29/42, 69.0%) and 3 (22/42, 52.4%).

13 Shared-care with local providers was reported by 13/42 (31.0%) centres, while 29/42 (69.0%)
14 continued follow-up exclusively within the treating centre. Among centres specifying
15 transition/discharge criteria (n=13), the most common trigger was age (e.g., 18 years) in 8/13
16 (61.5%), followed by sustained excellent response (e.g., after ≥ 3 years) in 4/13 (30.8%). A
17 minority indicated that patients are never discharged (2/13, 15.4%) or transition after a
18 stable intermediate response (1/13, 7.7%), or transition on patient preference (1/13, 7.7%).

20 ***National frameworks and access to targeted therapies***

1 A centralised/national board for paediatric DTC was available in 14/42 (33.3%).

2 Targeted therapies were widely accessible: on-site in 32/35 (91.4%), with additional access
3 via clinical trials or referral (each 8/35, 22.9%). Reported agents spanned *RET* and *NTRK*
4 inhibitors, *BRAF/MEK* inhibitors, and multikinase inhibitors. Targeted therapies were
5 currently not available in 2/42 (4.8%) centres and 5/42 (11.9%) centres indicated that such
6 cases were not treated.

7
8 **Country-level variation** (countries with ≥ 3 centres)

9 Across the five countries with at least three responding centres (n=33 total), adoption of a
10 formal risk framework showed patterned differences. France was ETA-leaning (ETA 3/7, ATA
11 1/7), Italy reported no ATA use (ETA 3/5), Spain was ATA-leaning (ATA 3/5; ETA 2/5), Germany
12 was predominantly *other* (*other* 3/4), and Portugal was mixed (ATA 1/4; ETA 1/4). Overall,
13 pooling these countries and considering only centres naming either ATA or ETA (n=22), usage
14 was evenly split: ATA 11/22 (50%) and ETA 11/22 (50%). (Figure 4A)

15 For unilateral presumed low-risk disease, hemithyroidectomy predominated overall (23/33,
16 69.7%), with total thyroidectomy in 9/33 (27.3%) and other approaches in 1/33 (3.0%). By
17 country, France was mainly hemithyroidectomy (5/7); Italy was mixed (3 hemithyroidectomy,
18 2 total); Spain (4/5) and Germany (3/4) favoured hemithyroidectomy; and Portugal was
19 evenly split (2 hemithyroidectomy, 2 total). (Figure 4B)

1 Policies for RAI in low-risk patients were roughly split between de-escalation (*never/rarely*
2 18/33, 54.5%) and *selective/routine* use (15/33, 45.5%). De-escalation predominated in Italy
3 (3 *never*, 1 *rarely*) and Portugal (3 *never*, 1 *rarely*). France and Spain leaned toward
4 *selective/routine* use, while Germany showed mixed policies. (Full country counts shown in
5 Figure 4C)

7 **Centres in countries with low health-expenditure average rates (LHEAR)**

8 To explore resource context, we contrasted centres from LHEAR countries (n=6) with other
9 European centres (n=36). (Figure 5) LHEAR sites reported fewer MDTs (MDT present 2/6,
10 33.3% vs 20/36, 55.6%), but similar or greater uptake of risk-adapted concepts: any RAI use
11 in low-risk (4/6, 66.7% vs 22/36, 61.1%; *never* RAI 2/6, 33.3% vs 14/36, 38.9%), dynamic
12 response used *always/often* (4/6, 66.7% vs 21/36, 58.3%), and dosimetry-guided activity
13 when RAI is given (1/6, 16.7% vs 8/36, 22.2%). For initial surgery in presumed unilateral low-
14 risk disease, hemithyroidectomy was the usual approach in 3/6 (50.0%) LHEAR centres
15 versus 28/36 (77.8%) in others. Notably, ATA 2015 was far more frequently the formal risk-
16 stratification system in LHEAR (5/6, 83.3%) than elsewhere (13/36, 36.1%), while ETA 2022
17 was less common (1/6, 16.7% vs 9/36, 25.0%). The RAI policy mix also differed: among
18 LHEAR centres the distribution was *never* 2, *rarely* 0, *selectively* 4, *routinely* 0, whereas other
19 countries showed *never* 14, *rarely* 9, *selectively* 9, *routinely* 4. Taken together—and
20 acknowledging the small LHEAR sample—these contrasts suggest organizational gaps (MDT

1 availability) alongside broad application of risk-adapted care, with a stronger ATA orientation
2 in LHEAR settings.

3
4 Taken together, these findings are summarised schematically in Figure 6, which illustrates
5 the reported sequence from diagnostic evaluation through MDT-based treatment decisions
6 to follow-up.

8 **Discussion**

9 This pan-European survey demonstrates substantial heterogeneity in how paediatric DTC is
10 staged, risk-stratified, and treated across centres and countries. Variation was most evident
11 in the choice of formal risk framework (ATA vs ETA vs national/institutional), (17, 18) the
12 extent of initial thyroid surgery, and policies for post-operative RAIT in presumed low-risk
13 disease. These findings are consistent with a broader structural reality in paediatric thyroid
14 oncology: excellent survival, limited paediatric-specific evidence, and non-identical
15 guidance frameworks that reasonably interpret the same evidence base differently. (14, 17,
16 18)

17 Several interacting forces explain this variation. Guideline plurality is the most direct driver:
18 ATA 2015 and ETA 2022 reach different default conclusions for RAIT in low-risk disease
19 despite sharing the same limited evidence base. (17, 18) National regulatory context adds a
20 further layer, as radiation-protection regulations for minors, dosimetry access, and

1 reimbursement structures differ across jurisdictions. (The 2013/59/Euratom Directive
2 (<https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32013L0059>, accessed
3 on 13 April 2026) Organisational factors—case volume, MDT composition, and specialty
4 leadership—shape which framework becomes the institutional default. Historical training
5 trajectories contribute inertia, as institutional protocols often lag guideline cycles. Finally,
6 genuine evidentiary gaps mean that for key decision nodes, clinicians reasonably weigh
7 competing risks differently. Variation therefore reflects convergence of these forces in a low-
8 incidence disease with limited paediatric-specific data.

9 Two contemporary pillars frame practice in Europe. The ATA 2015 paediatric guideline
10 formalises risk tiers and permits de-escalation, including omission of RAI in many low-risk
11 children to limit late effects without compromising disease control. (17) The ETA 2022
12 recommendations are likewise risk-aware and MDT-centred but—explicitly citing very low
13 paediatric evidence—issue weak suggestions and adopt a more conservative default for RAI
14 after total thyroidectomy. (18) A concise comparison of convergences and divergences is
15 provided in Supplementary Table S1. Both frameworks share the goals of excellent control
16 and minimising late effects. Their principal divergence lies in the routine use of remnant
17 ablation in low-risk disease, where definitive paediatric trials are lacking. (7, 14, 17-20, 23,
18 24)

19 Country-level patterns were coherent with this backdrop: among nations with ≥ 3 centres,
20 frameworks ranged from ETA-leaning (e.g., France, Italy) to Spain more ATA-leaning and
21 Germany mainly using national/institutional schemas. For unilateral presumed low-risk
22 disease, hemithyroidectomy predominated overall, though its uptake varied by country.

1 Policies for RAI in low risk split between de-escalation and risk-adapted use: Italy and
2 Portugal favoured de-escalation, Spain reported any use in all centres, and France/Germany
3 lay between these poles. Taken together, these differences mirror guideline anchoring and
4 national/institutional board customs rather than case-mix alone.

5 Within Europe, national adaptation offers useful perspective. The Dutch position statement
6 employed a structured AGREE-based process anchored to ATA 2015 to provide an
7 accessible multidisciplinary pathway aimed at harmonisation and centralisation, while
8 emphasising European regulatory context, late-effect minimisation, and the need for
9 algorithms that evolve with emerging data. (14) Our results—showing divergent use of risk
10 frameworks and RAI thresholds—underscore the value of such context-sensitive adaptation
11 and its potential scalability.

12 Although this is a survey rather than a guideline, several practice signals emerge that may
13 help reduce unwarranted variation while new evidence accrues. First, because a substantial
14 fraction of paediatric nodules are malignant, structured referral pathways for paediatric
15 thyroid nodules and systematic high-quality thyroid ultrasound with cervical lymph-node
16 mapping are likely to standardise pre-operative staging and inform the extent of surgery. (17,
17 18) Second, multidisciplinary decision-making at diagnosis and again post-operatively
18 appears central to how European centres operationalise risk-adapted care. In many
19 programmes, a minimum MDT quorum includes paediatric endocrinology/oncology, thyroid
20 pathology, expert thyroid radiology, paediatric surgery, and a high-volume thyroid cancer
21 surgeon. Concentrated surgical expertise is associated with fewer complications and more
22 complete nodal management in thyroidectomy. (25-28) Third, the post-operative MDT

1 provides a consistent forum to reassess risk, decide on RAI (or its omission), select
2 activity/dosimetry approaches, and plan surveillance balancing recurrence risk and late-
3 effect burden. To illustrate these steps, we include an example pathway from presentation
4 to follow-up (Figure 6), reflecting common sequences reported by centres.

5 The EXPeRT infrastructure can enable pragmatic harmonisation without foreclosing clinical
6 judgement. (21) Through the European Reference Network (ERN) for Paediatric Cancer
7 (PaedCan), the EXPeRT Clinical Patient Management System (CPMS) offers a platform for
8 cross-border case discussions, particularly valuable for complex or rare cases, and helps
9 delineate zones of equivalence (where ATA- and ETA-concordant choices are both
10 reasonable) versus zones of preference many centres favour (e.g., omitting RAI in clearly
11 low-risk disease). (29) Building on this, the development of national MDTs is essential to
12 ensure consistent, locally coordinated care following shared principles—as demonstrated
13 by the German MET reference program and the Dutch national recommendations. (6, 14) In
14 parallel, the European Standard Clinical Practice (ESCP) initiative under ERN PaedCan can
15 use the results of this survey to develop a dedicated ESPC document on paediatric thyroid
16 carcinoma, incorporating harmonised definitions of complete remission and recurrence as
17 recently established by international Delphi consensus. (21, 30, 31) The Paediatric Rare
18 Tumours Network–European Registry (PARTNER) Registry—endorsed by the European
19 Society for Paediatric Oncology (SIOPE) and already including paediatric thyroid
20 carcinoma—serves as the established platform to implement a minimum dataset and core
21 outcomes (surgical extent, nodal management, RAI intent/activity method, dynamic
22 response-to-therapy categories, late-effect domains) to benchmark care. (32) Prospective

1 data accrual through this registry will first establish precise, stratum-specific recurrence
2 rates across Europe—a prerequisite for, and potential run-in to, a future randomised trial
3 addressing the most contested question in low-risk disease: RAIT versus active surveillance
4 after total thyroidectomy. Power estimates (assumed recurrence rate without RAIT in low-
5 risk disease: ~10-15% at 5 years; assumed reduction with RAIT: ~5% points) suggest that
6 ~300-400 patients per arm would be required, implying a feasible 5-7 year recruitment
7 window across an EXPeRT/PARTNER network given current European incidence (~200-250
8 new cases/year across Europe; approximately 40-50% low-risk).

9 10 ***Strengths and limitations***

11 Strengths include the broad geographic participation across diverse health systems, the
12 centre-level granularity, and the coverage from diagnostics to survivorship. Limitations
13 include modest numbers within some countries, which makes the findings susceptible to
14 centre effects, reliance on self-reported data without case-level validation, and a possible
15 responder bias toward more engaged or specialised programmes. The study was descriptive
16 and therefore did not support causal inference. In addition, because most respondents were
17 paediatric oncologists, centres in which paediatric thyroid cancer care is primarily led by
18 paediatric endocrinologists or adult disciplines are likely underrepresented. Although the
19 survey was disseminated broadly across EXPeRT and affiliated networks, the exact
20 denominator of centres exposed to the invitation cannot be defined because snowball
21 dissemination was used. Nonetheless, the consistency of country-level patterns and their

1 alignment with known guidance differences in guidance support the external validity of the
2 main signals.

3

4 ***Interpretation***

5 European centres broadly endorse risk-adapted principles yet diverge at decision nodes that
6 matter—particularly the extent of surgery and RAI use in low-risk disease—reflecting
7 guidance plurality and organisational context. Presenting a succinct ATA–ETA comparison
8 (Supplementary Table S1) and an illustrative care pathway (Figure 7) may help teams situate
9 their local practice while EXPeRT/CPMS-enabled consultation and prospective,
10 standardised data capture (PARTNER) build the paediatric-specific evidence needed for
11 future consensus.

12

13 **Conclusion**

14 Across Europe, paediatric DTC management shows broad uptake of risk-adapted principles
15 but marked heterogeneity in execution—particularly around staging/guideline choice and
16 RAI indications/dosing.

17 To reduce unwarranted variation and late-effect exposure while preserving excellent
18 outcomes, we propose: (i) consensus harmonisation of European paediatric DTC pathways
19 that reconcile current guidance; (ii) reference-board infrastructure for complex decisions

1 and equitable access to expertise; and (iii) prospective data collection to inform future
2 iterations of paediatric-specific recommendations.

3 These steps would bring paediatric DTC closer to the protocolised standards typical of other
4 paediatric oncology diseases.

5

6 **Conflict of Interest**

7 Nicolas Waespe reports educational talk, advisory board and travel reimbursement from
8 Swedish Orphan Biovitrum AB; advisory board and travel reimbursement from NovoNordisk;
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10 to the content of this manuscript.

11 The authors declare that there is no conflict of interest that could be perceived as prejudicing
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13

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11 **Data Availability Statement**

12 This study analysed a professional practice survey without patient-level data. Centre
13 identifiers were de-identified; only country was retained. The full questionnaire is provided
14 in the Supplement. Aggregate, de-identified summaries (tables/figures) are included in the
15 manuscript; additional centre-level aggregates are available from the corresponding author
16 on reasonable request. No datasets were deposited in a public repository.

18 **Author's Contribution**

1 The manuscript was conceptualized and coordinated by Michaela Kuhlen and Antje
2 Redlich. All authors contributed to the survey and the final manuscript, approved its
3 content, and agreed to its submission for publication.

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7

8 **Figure legends**

9 **Figure 1. Diagnostic framework and risk-adaptation across European centres.**

10 (A) Staging system used. (B) Primary guideline informing care. (C) Formal risk-stratification
11 among respondents. (D) Use of dynamic response-to-therapy categories.

12 Values are centre counts with percentages.

13 **Figure 2. Radioiodine (RAI) practice.**

14 (A) Use of RAI in low-risk patients without metastases. (B) Primary purpose when RAI is given.
15 (C) How administered activity is determined. (D) Reasons to omit RAI (multiple response;
16 percentages calculated over responding centres).

17 Values are centre counts with percentages.

18 **Figure 3. Thyrotropin (TSH) suppression targets by risk group. (n=41 centres)**

19 **Figure 4. Country-level variation.**

20 (A) Formal risk-stratification by country (ATA vs ETA vs other). (B) Initial surgical approach in
21 presumed low-risk disease by country (Hemi- vs total thyroidectomy vs other). (C)
22 Radioiodine policy in low-risk disease by country.

23 Values are centre counts.

1 Abbreviations: ATA, American Thyroid Association; ETA, European Thyroid Association; RAI,
2 radioactive iodine.

3 **Figure 5. LHEAR versus other European countries: organisational and practice features.**

4 Side-by-side bars comparing LHEAR countries (Croatia, Greece, North Macedonia, Poland,
5 Turkey) with other European countries across five metrics: MDT presence, RAI use in low-risk
6 disease, hemithyroidectomy for presumed unilateral low-risk disease, and ATA 2015 and ETA
7 2022 risk stratification.

8 Bars show percentages of centres.

9 Abbreviations: LHEAR, low health-expenditure average rate; MDT, multidisciplinary tumour
10 board; RAI, radioiodine.

11 **Figure 6. Illustrative MDT-anchored care pathway for paediatric differentiated thyroid**
12 **carcinoma.**

13 From initial presentation, children undergo high-quality thyroid ultrasound with systematic
14 cervical lymph-node assessment, followed by multidisciplinary tumour board (MDT) review.

15 Depending on imaging and clinical context, pathways include watchful waiting, fine-needle
16 aspiration, or (hemi-)thyroidectomy. Post-operative MDT re-assessment integrates

17 pathology and dynamic risk to determine whether to omit or offer radioiodine (RAI) and to set
18 risk-adapted follow-up (surveillance and late-effects monitoring). The pathway is illustrative

19 and intended to reflect common steps reported by participating centres.

20

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1 **Table Legends**

2 **Table 1. Centre and respondent characteristics. Total centres: n=42; countries: n=18**

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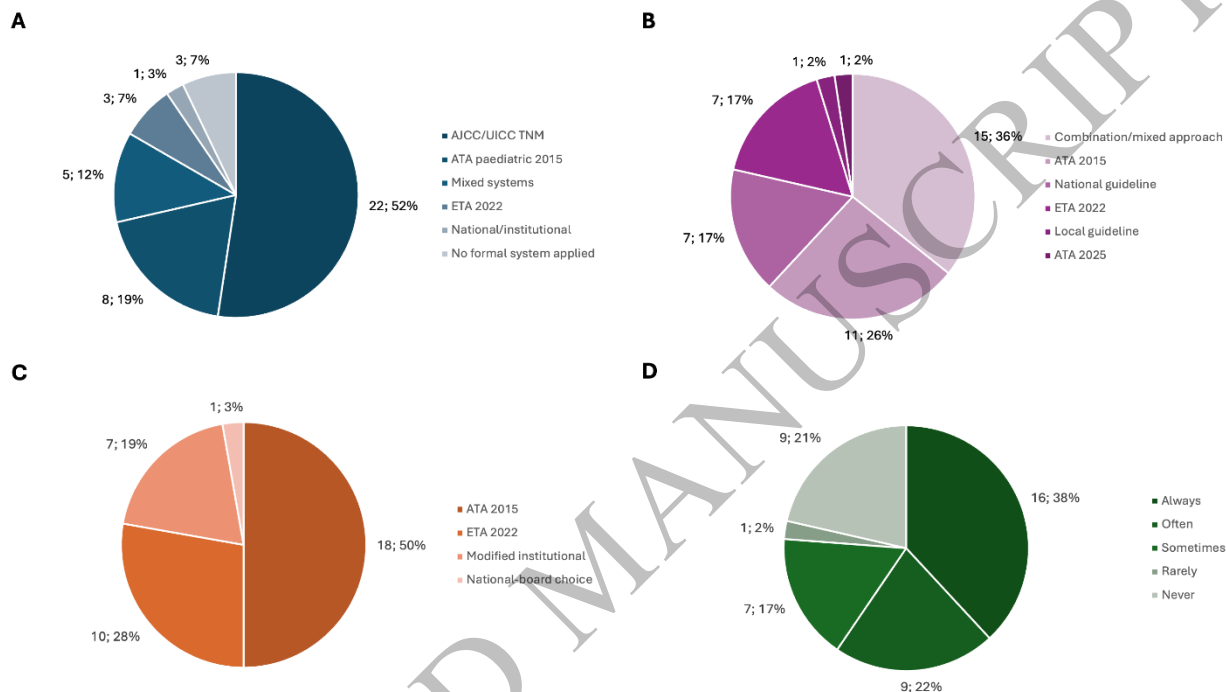


Figure 1
165x93 mm (x DPI)

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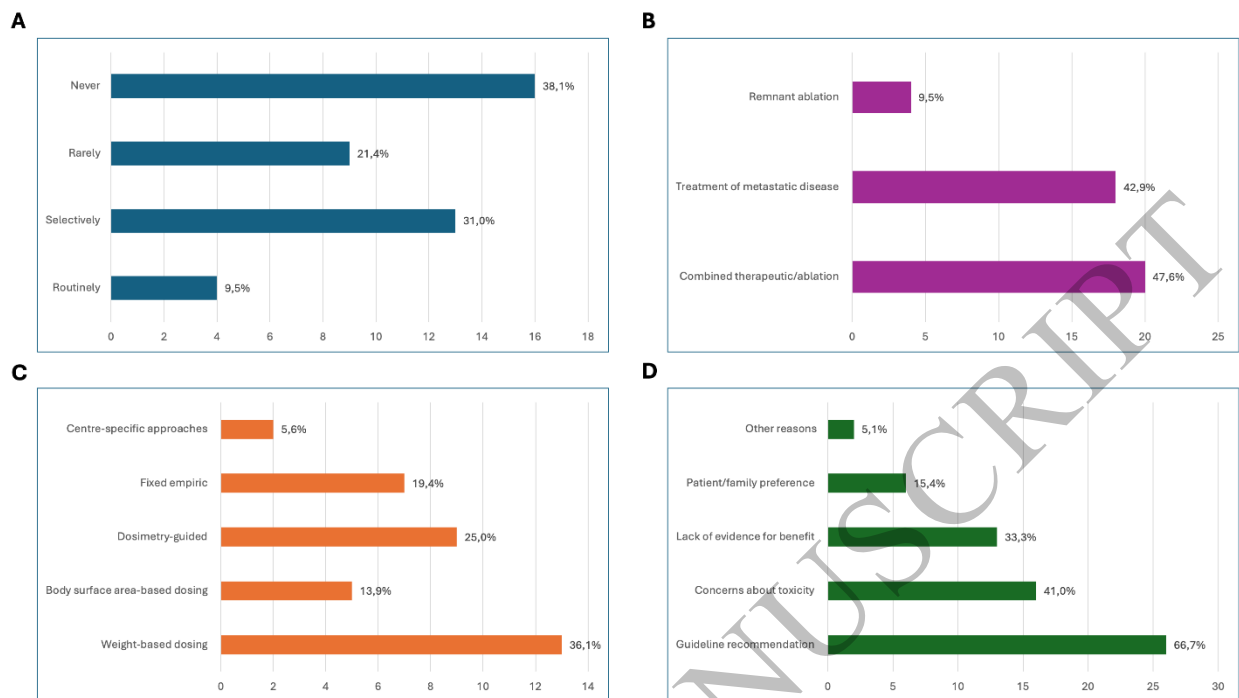


Figure 2
165x93 mm (x DPI)

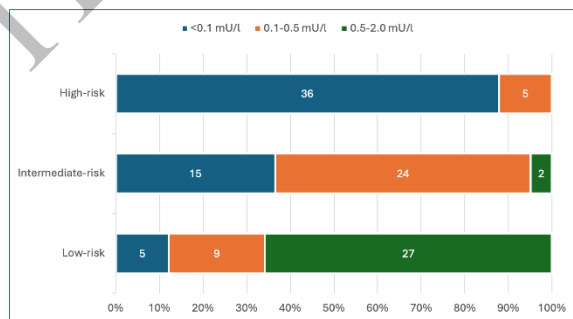


Figure 3
165x93 mm (x DPI)

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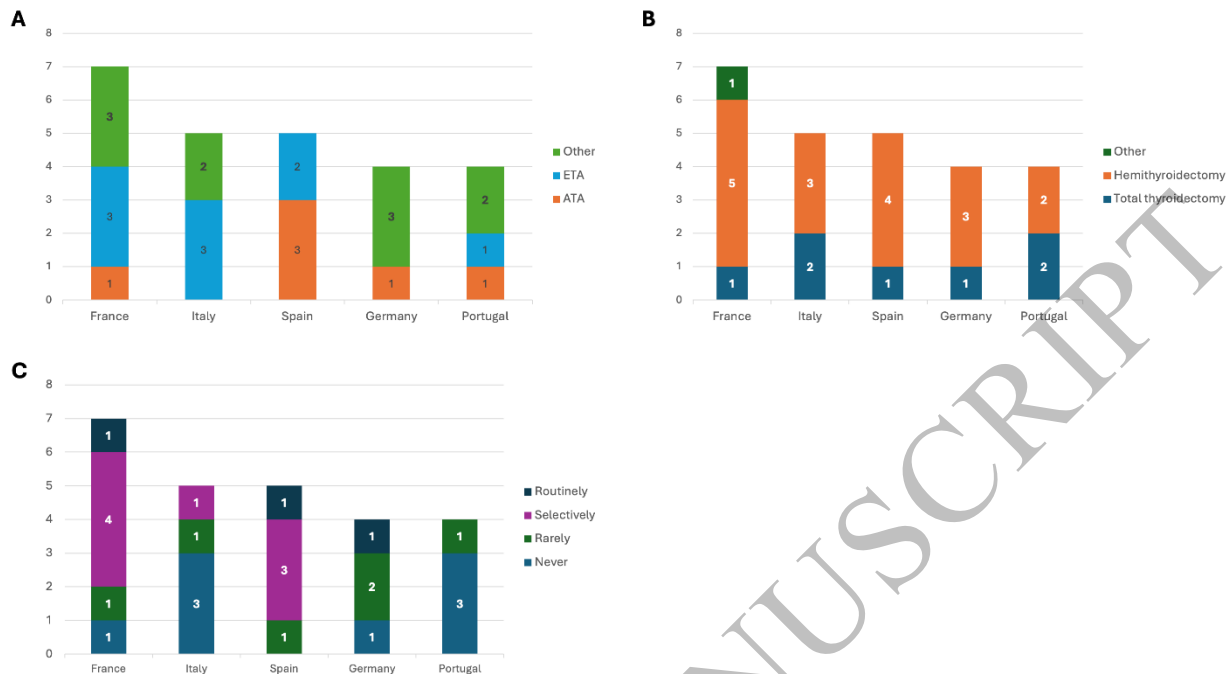


Figure 4
165x93 mm (x DPI)

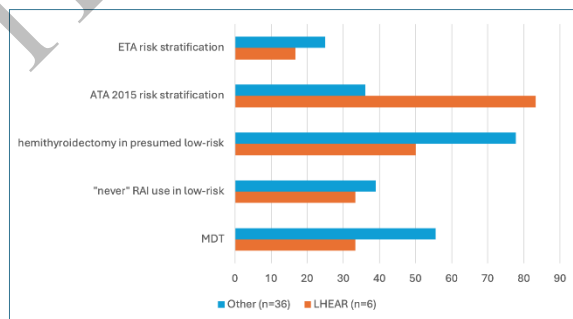


Figure 5
165x93 mm (x DPI)

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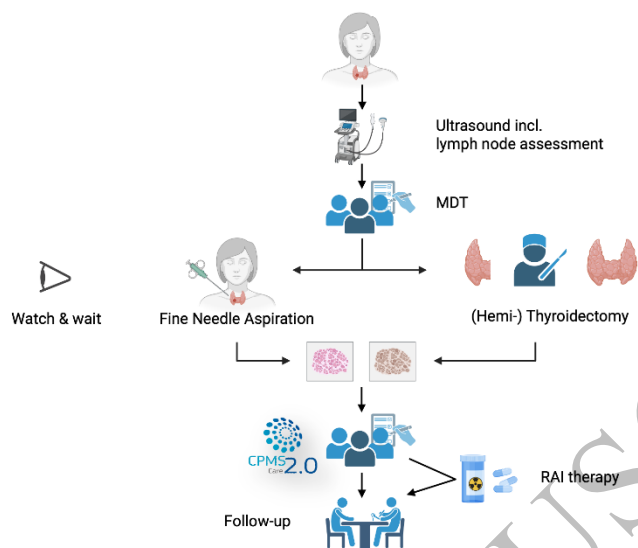


Figure 6
165x93 mm (x DPI)

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Table 1. Centre and respondent characteristics. Total centres: n=42; countries: n=18

Category / Item	n	%
Countries		
France	7	16.7
Italy	5	11.9
Spain	5	11.9
Germany	4	9.5
Portugal	4	9.5
Croatia	2	4.8
Israel	2	4.8
Sweden	2	4.8
Switzerland	2	4.8
Denmark	1	2.4

Greece	1	2.4
Netherlands	1	2.4
North Macedonia	1	2.4
Norway	1	2.4
Poland	1	2.4
Slovenia	1	2.4
Turkey	1	2.4
United Kingdom	1	2.4
Institution type		
University/academic hospital	31	73.8
Tertiary paediatric hospital	5	11.9
Adult hospital with paediatric pathways/service	4	9.5
Adult Cancer Centre with Paediatric Oncology Unit and paediatric pathways	1	2.4
Secondary or regional paediatric hospital	1	2.4
Paediatric age cut-off		
≤ 15 years	5	11.9
≤ 18 years	31	73.8
≤ 25 years	1	2.4
No strict age cut-off (depends on case / referral pattern)	5	11.9
Annual paediatric DTC volume (last 3 years)		
0-2	17	40.5
3-5	9	21.4
6-10	13	31.0
>10	3	7.1
Respondent primary profession/discipline		
Paediatric oncologist*	26	61.9
Paediatric endocrinologist	5	11.9

Adult endocrinologist	3	7.1
Paediatric surgeon	2	4.8
Endocrine/adult surgeon	1	2.4
Adult internal medicine	1	2.4
Adult oncologist	1	2.4
Clinical oncologist	1	2.4
Nuclear medicine physician	1	2.4
Pathologist	1	2.4

Specialties leading initial management (multiple response)

Paediatric endocrinology	28	66.7
Paediatric oncology	25	59.5
Nuclear medicine	13	31.0
Adult endocrinology	12	28.6
Endocrine/adult surgery	11	26.2
Paediatric surgery	10	23.8
Otorhinolaryngology (ear, nose, and throat/head and neck surgery)	1	2.4
Clinical oncology	1	2.4

1 *In four instances, a single centre-level response was jointly submitted by clinicians from multiple disciplines
2 at the same centre.

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