



Clinical Practice Snapshot

Adrenal Tumours

FINAL VERSION, 240903

Common Data Elements Adrenal Tumour Diagnosis specification

- a. Clinical diagnosis [Radio button, one selection]
- Primary aldosteronism Pheochromocytoma
 Cushing Incidentaloma
 ACC Other
 Metastasis
(If 'Other', answer question b)
- b. Other clinical diagnosis [Free text; string]
-
- c. Date of clinical diagnosis [Date, dd/mm/yy format; after DoB]
-
- d. Pathologic diagnosis [Radio button, one selection]
- ACC
 Pheochromocytoma
 Metastasis
 Adenoma
 Other
(If 'ACC', 'Metastasis' or 'Pheochromocytoma', show Clinical Practice Snapshot)
(If 'Metastasis', answer question 2a-2f and 3e in Clinical Practice Snapshot)
(If 'ACC', answer question 2g, 3a, 5i-5l in Clinical Practice Snapshot)
(If 'Pheochromocytoma', answer question 3d)
(If 'Other', answer question e)
- e. Other pathologic diagnosis [Free text; string]
-
- f. Date of pathologic diagnosis [Date, dd/mm/yy format; after DoB]
-

Clinical Practice Snapshot

1. Please update the common data elements. *(Changes might have occurred in patient status/hospital or treatment/genetics/diagnosis etc.)* [Radio button, one selection]
- I have changed nothing
 I have added previously unknown information
2. Diagnosis: [Radio button, one selection]
- a. Specify type of metastasis [Radio button, one selection]
- Melanoma Other
 Lung cancer Unknown
 Renal cancer
(If 'Other', answer question 2b)
- b. Other type of metastasis [Free text; string]
-
- c. Date of diagnosis of primary tumour [Date, dd/mm/yy format; after DoB]
-
- d. TNM classification primary tumour: T [Free text; string]
-
- e. TNM classification primary tumour: N [Free text; string]
-

- f. TNM classification primary tumour: M [Free text; string]
- g. Hormone, tumour or systemic cancer-related symptoms at presentation (for S-GRAS score, see helptext for more information) [Radio button, one selection]
 Yes No
3. Previous treatment:
- a. Neo-adjuvant treatment ACC performed: [Radio button, one selection]
 No
 Yes
 Unknown
(If 'Yes', answer question 3b)
- b. Which neo-adjuvant treatment was given? [Checkbox, multiple selection]
 Mitotane
 Chemotherapy
 Other neo-adjuvant treatment
 Unknown
(If 'Other neo-adjuvant treatment', answer question 3c)
- c. Other neo-adjuvant ACC treatment [Free text; string]
- d. Pre-surgical treatment with alpha blockers for pheochromocytoma performed: [Radio button, one selection]
 No
 Yes
 Unknown
- e. Previous treatment metastasis performed (including treatment of primary tumour): [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 3f)
- f. Type of previous treatment: [Checkbox, multiple selection]
 Chemotherapy
 Radiotherapy
 Immunotherapy
 Angiogenesis inhibitors
 Tyrosine kinase inhibitors (TKIs)
 Hormonal treatment (prostate cancer)
 Surgery for primary tumour
 Other previous treatment
 Unknown
(If not 'Unknown', a date field for last date treatment will appear)
(If 'Radiotherapy', answer question 3g)
(If 'Surgery on primary tumour', answer question 3i, 3j, 3k)
(If 'Other previous treatment', answer question 3l)
- g. Type of radiotherapy [Radio button, one selection]
 Stereotactic radiation therapy (SBRT)
 Proton radiotherapy
 Other type of radiotherapy
 Unknown
(If 'Other type of radiotherapy', answer question 3h)
- h. Other type of radiotherapy [Free text; string]
- i. Number of operations for primary tumour [Number, integer]
- j. Date of 1st surgery [Date, dd/mm/yy format; on/after DoB]
- k. Type of surgery [Free text; string]
- l. Other previous treatment [Free text; string]
- m. Date of last ... treatment *(appears for each selected previous treatment selected for question 3f)* [Date, dd/mm/yy format; on/after DoB]
4. Preoperative care:
- a. Discussed in multidisciplinary team: [Radio button, one selection]
 Yes No Unknown

- b. Preoperative imaging performed: [Checkbox, multiple selection]
- MRI
 - CT
 - PET CT
 - Other
 - Unknown
- (If 'Other', answer question 4c)
- c. Other preoperative imaging [Free text; string]
-
- d. Was a biopsy performed? [Radio button, one selection]
- Yes
 - No
 - Unknown
- (If 'Yes', answer question 4e, 4f, 4g, 4i)
- e. Date of biopsy [Date, dd/mm/yy format; on/after DoB]
-
- f. Was the biopsy conclusive or inconclusive? [Radio button, one selection]
- Conclusive
 - Inconclusive
 - Unknown
- g. Pathologic diagnosis [Radio button, one selection]
- ACC
 - Pheochromocytoma
 - Metastasis
 - Adenoma
 - Other
- (If 'Other', answer question 4h)
- h. Other pathologic diagnosis biopsy [Free text; string]
-
- i. Did any complications occur during/after the biopsy? [Radio button, one selection]
- Yes
 - No
 - Unknown

5. 1st surgery for current disease of the adrenal tumour:
- a. 1st surgery date: [Date, dd/mm/yy format; on/after DoB]
-
- b. Type surgery: [Radio button, one selection]
- Laparoscopy
 - Retroperitoneoscopy
 - Robot-assisted
 - Open
 - Other
 - Unknown
- (If 'Other', answer questions 5c)
- c. Other type of surgery: [Free text; string]
-
- d. Lymph node dissection performed? [Radio button, one selection]
- Yes
 - No
 - Unknown
 - Not applicable
- (If 'Yes', answer question 5e and 5f)
- e. Which lymph node template was removed? [Free text; string]
-
- f. Number of resected lymph nodes in pathology report [Numeric, integer]
-
- g. Status after surgery for malignant tumours [Radio button, one selection]
- R0 (Negative resection margins)
 - R+ (Positive resection margins)
 - RX (Unclear resection margin)
 - Unknown
- (If 'Positive resection margins', answer question 5h)
- h. Specification positive resection margins [Radio button, one selection]
- R1 (Microscopic positive resection margins)
 - R2 (Macroscopic positive resection margins)
 - Unknown
- i. Ki67 score [Numeric, %, integer]
- 0-9%
 - 10% – 19%
 - ≥ 20%
 - Unknown
- j. ENSAT tumour classification [Radio button, one selection]
- Stage I
 - Stage II
 - Stage III
 - Stage IV
 - Unknown
- k. S-GRAS score [Automatic calculation]
- l. Weiss score [Numeric, integer, between 0-9]

-
- m. Status after surgery when tumour was hormonally active pre-surgery: [Radio button, one selection]
- Cured
- Not cured
- Not applicable, tumour was not hormonally active pre-surgery
- Unknown

6. Possible complications after surgery:

- a. Did any intraoperative complications occur? [Radio button, one selection]
- Yes No Unknown
- (If 'Yes', answer question 6b)*
- b. Which complications occurred? Free text; string]
-
- c. Did any postoperative complications occur (within 30 days after surgery): [Radio button, one selection]
- Yes No Unknown
- (If 'Yes', answer question 6d and 6e)*
- d. Which complications occurred? [Free text; string]
- e. Clavien-Dindo classification of this complication? [Radio button, one selection]
- Grade 1
- Grade 2
- Grade 3a
- Grade 3b
- Grade 4
- Grade 5
- Unknown

7. Follow-up within a year from the start date of treatment (question 2.5 in the Common Data Elements):

- a. Date last follow-up: [Date, dd/mm/yy format; after DoB]
-
- b. Further treatment needed after the 1st surgery for adrenal tumour? [Radio button, one selection]
- Yes No Unknown
- (If 'Yes', answer question 7c)*
- c. Specification further (adjuvant) treatment (excluding recurrence) [Checkbox, multiple selection]
- Mitotane Chemotherapy Immunotherapy Other
- Radiation therapy Additional surgery Angiogenesis inhibitors Unknown
- (If 'Additional surgery' answer question 7d, 7e, 7f)*
- (If 'Other', answer question 7g)*
- d. Number of additional operations [Numeric, integer]
-
- (A date field and reason of surgery will appear per additional surgery)*
- e. Reason of additional surgery [Date, dd/mm/yy format; on/after FS]
-
- f. Date of additional surgery [Date, dd/mm/yy format; on/after FS]
-
- g. Specification other (adjuvant) treatment: [Free text; string]
- h. *For pheochromocytoma:* Biochemical recurrence (elevated metanephrine levels in blood/urine)? [Radio button, one selection]
- Yes No Unknown
- i. *For pheochromocytoma:* Follow-up imaging performed? [Radio button, one selection]
- Yes No Unknown
- (If 'Yes', answer question 7j)*
- j. Recurrence confirmed on follow-up imaging? [Radio button, one selection]
- No
- Yes, local recurrence
- Yes, metastasized recurrence
- Unknown
- (If 'Yes, metastasized recurrence', answer question 7k)*
- (If any 'Yes', answer question 7s and 7u)*
- k. Location of metastasized recurrence [Free text, string]
-
- l. *For metastasis:* Did adrenal cortex insufficiency occur? [Radio button, one selection]
- Yes No Unknown
- m. *For ACC:* Biochemical recurrence? [Radio button, one selection]

- No
- Yes, hypercortisolism
- Yes, other biochemical marker (17-hydroxy progesterone, DHEA-S, 11-deoxycortisol etc.)
- Unknown

(If 'Yes, other biochemical marker, answer question 7n)

- n. Biomarker(s) indicating recurrence [Free text, string]
- o. For ACC: Date last CT (thorax/abdomen) within the first year of the start date of treatment (question 2.5 in the Common Data Elements) [Date, dd/mm/yy format; on/after FS]
- p. For ACC: Progression of tumour based on last scan following RECIST scoring? [Radio button, one selection]
 Yes No Unknown
- q. For ACC/metastasis: Was there a recurrence of the tumour? [Radio button, one selection]
 No
 Yes, local recurrence
 Yes, metastasized recurrence
 Unknown
(If 'Yes, metastasized recurrence', answer question 7q)
(If any 'Yes', answer question 7s)
- r. Location of metastasized recurrence [Free text, string]
- s. Date of recurrence diagnosis [Date, dd/mm/yy format; on/after FS]
- t. Was further treatment for recurrence of the adrenal tumour performed? [Radio button, one selection]
 Yes No Unknown
(If 'Yes', answer question 7u)
- u. Specification further treatment for recurrence [Checkbox, multiple selection]
 Mitotane Chemotherapy Immunotherapy Other
 Radiation therapy Additional surgery Targeted therapy Unknown
(If 'Additional surgery' answer question 7v and 7w)
(If 'Other', answer question 7x)
- v. Number of additional surgeries [Numeric, integer]

(A date field will appear per additional surgery)
- w. Date of additional surgery [Date, dd/mm/yy format; on/after FS]
- x. Specification other treatment for recurrence: [Free text; string]



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