



ICHOM

International Consortium for
Health Outcomes Measurement

LUNG CANCER DATA COLLECTION REFERENCE GUIDE

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Measuring
results
that matter

Social
functioning

Lung Cancer



We are thrilled that you are interested in measuring outcomes for your lung cancer patients according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing this Set of Patient-Centered Outcome Measures and ensure collection of comparable data for global benchmarking and learning.

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Sets of Patient-Centered Outcome Measures, which are comprehensive yet parsimonious Sets of outcomes and case-mix variables we recommend all providers to track.

Each Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. We also include high-level treatment variables to allow stratification of outcomes by major treatment types. A comprehensive data dictionary is included in the appendix.

Working Group Members for Lung Cancer

The following individuals dedicated both time and expertise to develop the ICHOM Set for Lung Cancer in partnership with ICHOM, under the leadership of Dr. Mick Peake, Senior Lecturer in Respiratory Medicine at the University Hospitals of Leicester and Clinical Lead at the National Cancer Intelligence Network, Public Health, London.

| | | | |
|-------------------------------------|--|---|--|
| Australia Robert Stirling | Netherlands Franz Schramel Suresh Senan Michel Wouters | Diana Borthwick Jesme Fox Tom Haswell Mick Peake | Aileen Chen Marianna Koczywas Benjamin Kozower Kimberley Mak Reza Mehran |
| Belgium Jan van Meerbeeck | United Kingdom Matthew Baker David Baldwin | United States Janet Abrahm David Carbone | |
| Brazil Clarissa Baldotto | | | |

Supporting Organizations

The Lung Cancer Set is made possible only through the support of the Alliance of Dedicated Cancer Centers.

Thank you.



Conditions and Treatment Approaches Covered for Lung Cancer

For Lung Cancer, the following conditions and treatment approaches (or interventions) are covered by our Set.

| | |
|----------------------|--|
| Treatment Approaches | Surgery Radiotherapy Chemotherapy Targeted Therapy Immunotherapy Other |
| Conditions Covered | Small Cell and Non-Small Cell Lung Cancer |

ICHOM Set of Patient-Centered Outcome Measures for Lung Cancer

Case-Mix Variables

| Patient Population | Measure | Timing | Data Source | |
|---------------------------|--------------------------------|--|------------------|--------------------|
| Demographic Factors | | | | |
| All patients | Year of birth | Baseline | Clinical | |
| | Sex | | | |
| | Ethnicity/Race | | Patient-reported | |
| | Educational level | | | |
| Baseline Clinical Factors | | | | |
| All patients | Weight loss | Baseline | Patient-reported | |
| | Comorbidities | | | |
| | Patient-reported health status | Baseline; 3 months post initiation of treatment; 6 months post initiation of treatment; 1 year post initiation of treatment; Tracked ongoing annually for life | | |
| | | Smoking status | | Baseline |
| | | | | Performance status |
| | Patients undergoing surgery | Pulmonary function | | |
| Baseline Tumor Factors | | | | |
| All patients | Basis of diagnosis | Baseline | Clinical | |
| | Histology | | | |
| | ALK translocation | | | |
| | EGFR mutation | | | |
| | Clinical stage | | | |
| | Pathological stage | After biopsy/ surgery | | |
| Treatment Factors | | | | |
| All patients | Treatment intent | At time of treatment decision | Clinical | |
| | Completed treatment | After treatment | | |

ALK: Anaplastic Lymphoma Kinase; EGFR: Epidermal Growth Factor Receptor

Treatment Variables

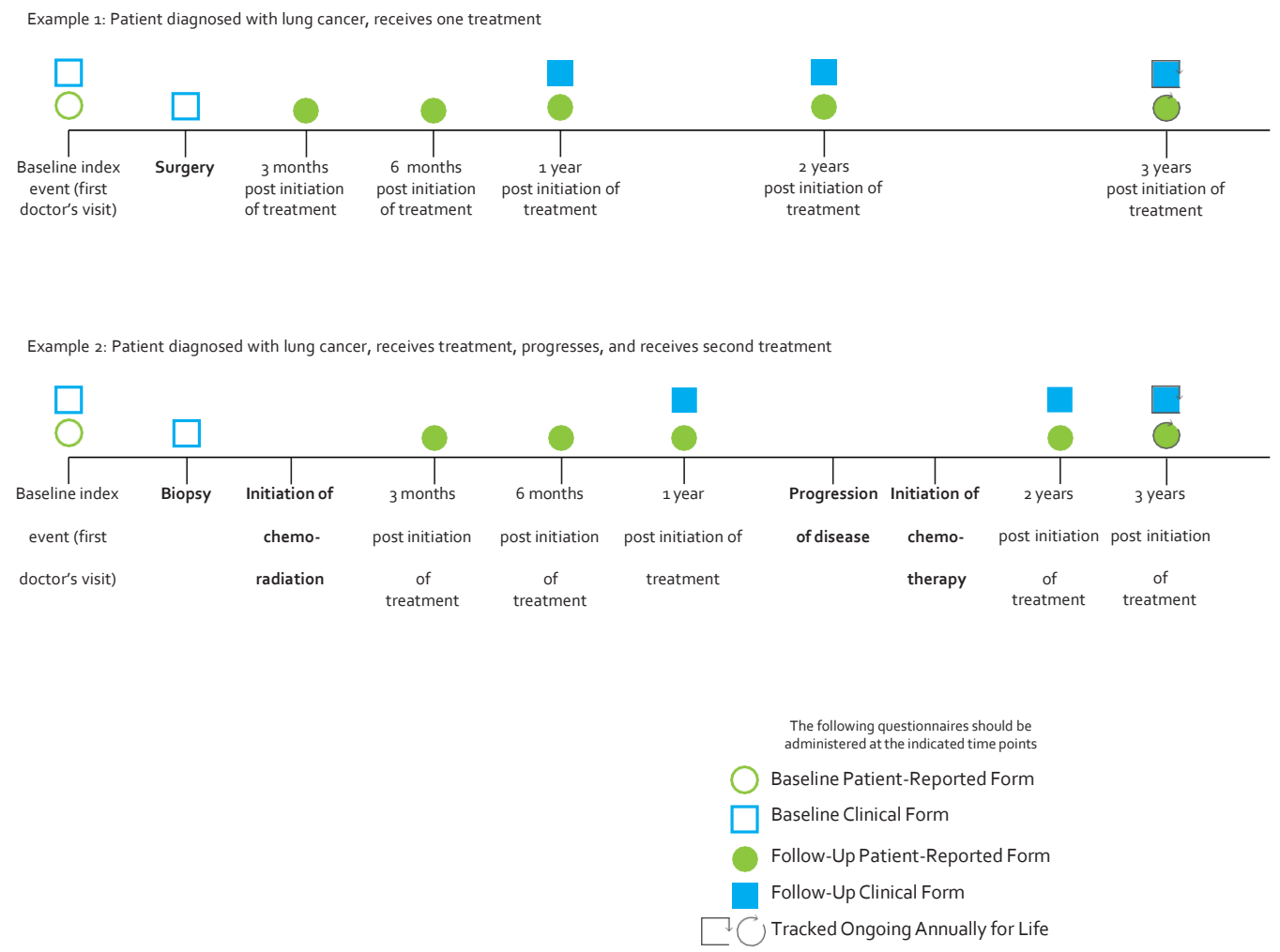
| Patient Population | Measure | Timing | Data Source |
|--------------------|------------------|--------------------------|-------------|
| All patients | Surgery | Update at least annually | Clinical |
| | Radiotherapy | | |
| | Chemotherapy | | |
| | Targeted therapy | | |
| | Immunotherapy | | |
| | Other | When treatment begins | |

Outcomes

| Patient Population | Measure | Timing | Data Source |
|--|---|--|------------------|
| Acute Complications of Treatment | | | |
| All patients receiving resectional surgery | Major surgical complications | | |
| Patients with radiation therapy | Major radiation complications | Update at least annually | Clinical |
| Patients with systemic therapy | Major systemic therapy complications | | |
| Degree of Health | | | |
| All patients | Performance status | Baseline; 1 year post initiation of treatment; Tracked ongoing annually for life (when hospital is able to track this ongoing) | Clinical |
| | Global health status/ Quality of life | Baseline; | |
| | Fatigue | 3 months post initiation of treatment; | |
| | Social function | Physical functioning | |
| | Emotional functioning | 6 months post initiation of treatment; | |
| | Cognitive function | 1 year post initiation of treatment; | Patient-reported |
| | Pain | Tracked ongoing annually for life | |
| | Shortness of breath | | |
| | Cough | | |
| Survival | | | |
| All patients | Cause of death | 1 year post initiation of treatment; | |
| | Overall survival | Tracked ongoing annually for life (when hospital is able to track this ongoing) | Clinical |
| | Treatment-related mortality | | |
| Quality of Death | | | |
| All patients | Place of death | 1 year post initiation of treatment; | |
| All patients with end-stage disease | Duration of time spent in hospital at end of life | Tracked ongoing annually for life (when hospital is able to track this ongoing) | Clinical |

Follow-Up Timeline

The following timeline illustrates when the Set variables should be collected from patients, clinicians, and administrative sources. Links to the sample questionnaires may be found in the legend below.



Collecting Patient-Reported Outcome Measures

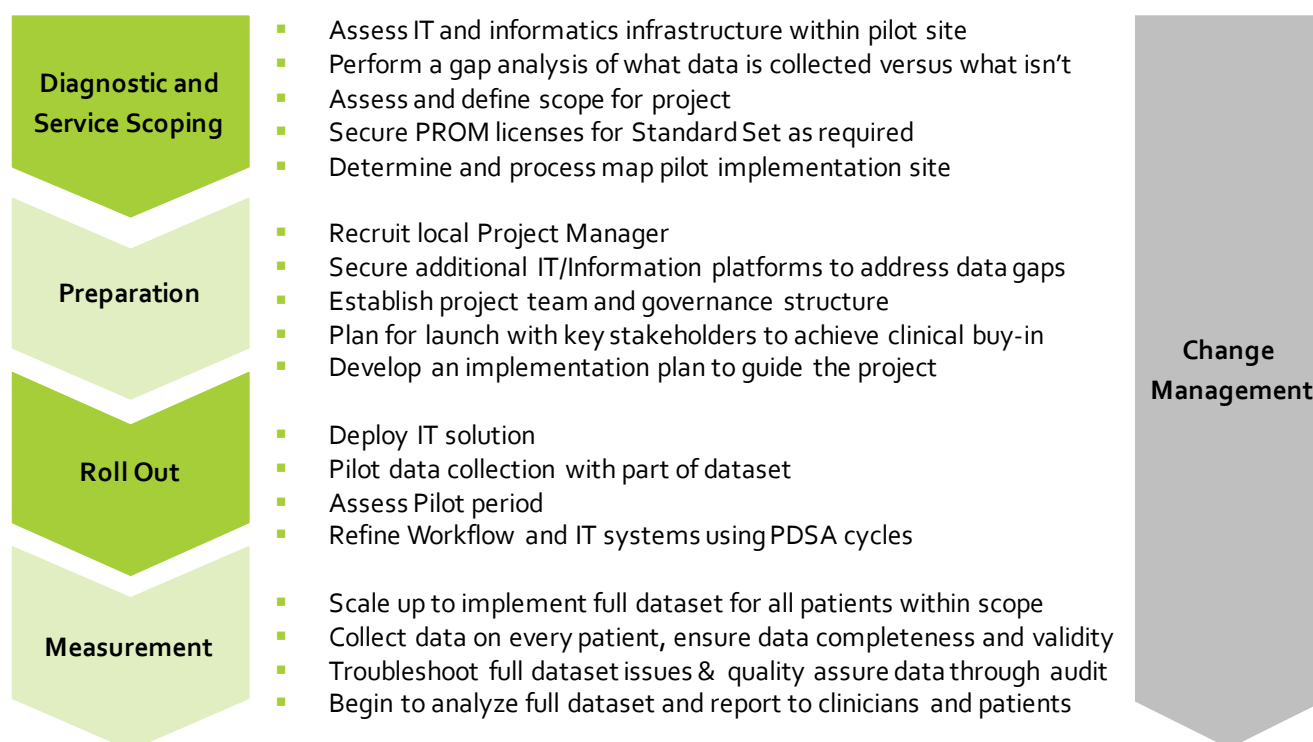
| Lung Cancer Survey Used | Licensing Information | Scoring Information |
|--|---|--|
| European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Core (EORTC QLQ-C30) | The EORTC QLQ-C30 is free for all health care organizations, but a license is needed for use. For more information, please visit: https://qol.eortc.org/questionnaire/eortc-qlq-c30/ | See link at left |
| European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Lung Cancer (EORTC QLQ-LC29) | The EORTC QLQ-C29 is free for all health care organizations, but a license is needed for use. For more information, please visit: https://qol.eortc.org/questionnaire/qlq-lc29/ | See link at left |
| Eastern Cooperative Oncology Group/ World Health Organization Scale for Performance Status (ECOG/WHO Performance Status) | The scale is freely available for public use without a license. It may be found at: https://ecog-acrin.org/resources/ecog-performance-status | See link at left |
| Self-Administered Comorbidity Questionnaire (SCQ) | The SCQ is not copyrighted and a license is not needed. It may be found at https://onlinelibrary.wiley.com/doi/full/10.1002/art.10993 | Sangha et al (2003) The self-administered comorbidity questionnaire: A new method to assess comorbidity for clinical and health services research. Arthritis Care & Research 49(2): 156-163. |

The Growing ICHOM Community

There is a growing community of healthcare providers implementing the Set. To support your organization in implementing the set and the measurement of outcomes data, we have outlined a framework to guide the implementation and reporting of patient-centered outcomes. All materials can be downloaded for free from ICHOM Connect, for further information or to enquire about implementation support offered by ICHOM Partners, please contact us: info@ichom.org.

Implementation framework:

The framework below, outlines the structured process to guide the implementation of an ICHOM Set at your organization. Typically, an implementation project takes 9 months to complete.



Implementation Study:

We are keen to find out if you have implemented or are implementing our Sets. Please fill in this survey: bit.ly/InitialImp or contact info@ichom.org for more information.

Translating the Set Tools:

PROMs within the ICHOM Sets are available in a number of languages. To check the availability of translations, we advise contacting the Tool authors directly to obtain and translate the PROM surveys into your desired language. To independently translate PROM surveys, if permitted by its license, we recommend following the 10 steps outlined below:^{*1}

| | | |
|---------|---|--|
| Step 1 | Preparation | Initial work carried out before the translation work begins |
| Step 2 | Forward Translation | Translation of the original language, also called source, version of the instrument into another language, often called the target language |
| Step 3 | Reconciliation | Comparing and merging more than one forward translation into a single forward translation |
| Step 4 | Back Translation | Translation of the new language version back into the original language |
| Step 5 | Back Translation Review | Comparison of the back-translated versions of the instrument with the original to highlight and investigate discrepancies between the original and the reconciled translation, which is then revised in the process of resolving the issues |
| Step 6 | Harmonization | Comparison of back translations of multiple language versions with each other and the original instrument to highlight discrepancies between the original and its derivative translations, as well as to achieve a consistent approach to translation problems |
| Step 7 | Cognitive Debriefing | Testing the instrument on a small group of relevant patients or lay people in order to test alternative wording and to check understandability, interpretation, and cultural relevance of the translation |
| Step 8 | Review of Cognitive Debriefing Results and Finalization | Comparison of the patients' or lay persons' interpretation of the translation with the original version to highlight and amend discrepancies |
| Step 9 | Proofreading | Final review of the translation to highlight and correct any typographic, grammatical or other errors |
| Step 10 | Final Report | Report written at the end of the process documenting the development of each translation |

*These ten steps follow the ISPOR Principles of Good Practice: The Cross-Cultural Adaptation Process for Patient-Reported Outcome Measures ¹ Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., et al. (2005). Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: Report of the ISPOR task force for translation and cultural adaptation. *Value in Health*, 8(2), 94–104. doi:10.1111/j.1524-4733.2005.04054.x.

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Lung Cancer Set as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. **Excel version of this data dictionary is also available for download on ICHOM Connect.** **Excel data dictionary is the most up-to-date version and it is the recommended document to plan data collection.**

Please timestamp all variables. Some Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

| | |
|-------------------------------|--|
| Variable ID: | N/A |
| Variable: | Patient ID |
| Definition: | Indicate the patient's medical record number |
| Supporting Definition: | This number will not be shared with ICHOM. In the case patient-level data is submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating institution |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| Timing: | On all forms |
| Data Source: | Administrative or clinical |
| Type: | Numerical |
| Value Domain: | N/A |
| Response Options: | According to institution |

Demographic Factors

| | |
|-------------------------------|-----------------------------|
| Variable ID: | YearOfBirth |
| Variable: | Year of Birth |
| Definition: | Year of birth |
| Supporting Definition: | None |
| Displayed Value: | In what year were you born? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline |
| Data Source: | Clinical |
| Type: | Date by YYYY |
| Value Domain: | Date |
| Response Options: | YYYY |

| | |
|-------------------------------|---|
| Variable ID: | Sex |
| Variable: | Sex |
| Definition: | The patient's sex at birth |
| Supporting Definition: | For statistical purposes, the following category codes, labels and definitions are preferred: CODE 1 Male: Persons who have male or predominantly masculine biological characteristics, or male sex assigned at birth. CODE 2 Female: Persons who have female or predominantly feminine biological characteristics, or female sex assigned at birth. CODE 3 Other: Persons who have mixed or non-binary biological characteristics (if known), or a non-binary sex assigned at birth |

The value meaning of 'Other' has been assigned to Code 3 for this value domain,

which replaces 'Intersex or indeterminate' for the superseded value domain Sex code N. Terms such as 'indeterminate,' 'intersex,' 'non-binary,' and 'unspecified' are variously used to describe the 'Other' category of sex. The label 'Other' is used because a more descriptive term has not been widely agreed within the general community.

Sex refers to the chromosomal, gonadal and anatomical characteristics associated with biological sex. Where there is an inconsistency between anatomical and chromosomal characteristics, sex is based on anatomical characteristics.

Displayed Value: Please indicate your sex at birth.
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = Male
 2 = Female
 3 = Other
 999 = Undisclosed

Variable ID: Ethnicity
Variable: Ethnicity
Definition: The cultural ethnicity of the person that they most closely identify with
Supporting Definition: This measure should be recorded based on local standards in the particular geographic region and should be self-reported by the patient. This is an optional question but ICHOM encourages that this information is collected and is as racially and ethnically inclusive as possible. This data will help to support combating health disparities based on ethnicity but all patient data regarding race and ethnicity will be kept confidential. The patient's response will then be coded based on LOINC's standards. All patients may choose not to answer as well.
Displayed Value: Please indicate the ethnicity that you identify with
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: Please report your ethnicity based on your geographic region's local standards

Variable ID: Race
Variable: Race
Definition: The biological race of the person
Supporting Definition: This measure should be recorded based on local standards in the particular geographic region and should be self-reported by the patient. This is an optional question but ICHOM encourages that this information is collected and is as racially and ethnically inclusive as possible. This data will help to support combating health disparities based on race but all patient data regarding race and ethnicity will be kept confidential. The patient's response will then be coded based on LOINC's standards. All patients may choose not to answer as well.
Displayed Value: Please indicate the biological race that you identify with.
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: Please report your race based on your geographic region's local standards.

Variable ID: EducationLevel
Variable: Level of education
Definition: Highest level of education completed based on local standard definitions of education levels
Supporting Definition: This measure may vary based on local standards for education levels so please

consult the International Standard Classification to select what level most closely relates to your education experience. Please follow this link here:

<http://uis.unesco.org/sites/default/files/documents/international-standard-classification-of-education-isced-2011-en.pdf>

Displayed Value: Please indicate your highest level of schooling.
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0= None
1= Primary
2= Secondary
3= Tertiary

Baseline Clinical Factors

Variable ID: WEIGHTL
Variable: Weight loss
Definition: Have you unintentionally lost weight?
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: ComorbiditiesSACQ
Variable: SACQ Comorbidities
Definition: Indicate whether the patient has a documented history of any of the following comorbidities
Supporting Definition: Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer.
Displayed Value: Have you been told by a doctor that you have any of the following?
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Patient-reported
Type: Multiple answer Separate multiple entries with ";"
Value Domain: Code
Response Options: 0 = I have no other diseases
1 = Heart disease (For example, angina, heart attack, or heart failure)
2 = High blood pressure
3 = Lung disease (For example, asthma, chronic bronchitis, or emphysema)
4 = Diabetes
5 = Ulcer or stomach disease
6 = Kidney disease
7 = Liver disease
8 = Anemia or other blood disease
9 = Cancer/Other cancer (within the last 5 years)
10 = Depression
11 = Osteoarthritis, degenerative arthritis
12 = Back pain
13 = Rheumatoid arthritis
14 = Other medical problems

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| Variable ID: | ComorbiditiesSACQ_HeartDiseaseFU1 |
| Variable: | SACQ comorbidities: Heart Disease: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for Heart disease (For example, angina, heart attack, or heart failure) |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for heart disease (For example, angina, heart failure, or heart attack)? |
| Inclusion Criteria: | If answered 1= Heart disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_HeartDiseaseFU2 |
| Variable: | SACQ comorbidities: Heart Disease: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's heart disease limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your heart disease limit your activities? |
| Inclusion Criteria: | If answered 1= Heart disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_HighBloodPressureFU1 |
| Variable: | SACQ comorbidities: High Blood Pressure: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for high blood pressure |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for high blood pressure? |
| Inclusion Criteria: | If answered 2= High blood pressure to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_HighBloodPressureFU2 |
| Variable: | SACQ comorbidities: High Blood Pressure: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's high blood pressure limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your high blood pressure limit your activities? |
| Inclusion Criteria: | If answered 2= High blood pressure to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |

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|-------------------------------|---|
| Variable ID: | ComorbiditiesSACQ_LungDiseaseFU1 |
| Variable: | SACQ comorbidities: Lung Disease: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for lung disease |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for lung disease? |
| Inclusion Criteria: | If answered 3= Lung disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_LungDiseaseFU2 |
| Variable: | SACQ comorbidities: Lung Disease: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's lung disease limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your lung disease limit your activities? |
| Inclusion Criteria: | If answered 3= Lung disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_DiabetesFU1 |
| Variable: | SACQ comorbidities: Diabetes: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for diabetes |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for diabetes? |
| Inclusion Criteria: | If answered 4= Diabetes to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_DiabetesFU2 |
| Variable: | SACQ comorbidities: Diabetes: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's diabetes limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your diabetes limit your activities? |
| Inclusion Criteria: | If answered 4= Diabetes to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_StomachDiseaseFU1 |
| Variable: | SACQ comorbidities: Stomach Disease: Follow-Up Question 1 |

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| Definition: | Please indicate if the patient receives treatment for an ulcer or stomach disease |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for an ulcer or stomach disease? |
| Inclusion Criteria: | If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
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| Variable ID: | ComorbiditiesSACQ_StomachDiseaseFU2 |
| Variable: | SACQ comorbidities: Stomach Disease: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's ulcer or stomach disease limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your ulcer or stomach disease limit your activities? |
| Inclusion Criteria: | If answered 5= Ulcer or stomach disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| <hr/> | |
| Variable ID: | ComorbiditiesSACQ_KidneyDiseaseFU1 |
| Variable: | SACQ comorbidities: Kidney Disease: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for kidney disease |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for kidney disease? |
| Inclusion Criteria: | If answered 6= Kidney disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| <hr/> | |
| Variable ID: | ComorbiditiesSACQ_KidneyDiseaseFU2 |
| Variable: | SACQ comorbidities: Kidney Disease: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's kidney disease limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your kidney disease limit your activities? |
| Inclusion Criteria: | If answered 6= Kidney disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| <hr/> | |
| Variable ID: | ComorbiditiesSACQ_LiverDiseaseFU1 |
| Variable: | SACQ comorbidities: Liver Disease: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for liver disease |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by |

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|-------------------------------|--|
| | other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for liver disease? |
| Inclusion Criteria: | If answered 7= Liver disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_LiverDiseaseFU2 |
| Variable: | SACQ comorbidities: Liver Disease: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's liver disease limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your liver disease limit your activities? |
| Inclusion Criteria: | If answered 7= Liver disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_BloodDiseaseFU1 |
| Variable: | SACQ comorbidities: Blood Disease: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for anemia or other blood disease |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for anemia or other blood disease? |
| Inclusion Criteria: | If answered 8= Anemia or other blood disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_BloodDiseaseFU2 |
| Variable: | SACQ comorbidities: Blood Disease: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's anemia or other blood disease limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your anemia or other blood disease limit your activities? |
| Inclusion Criteria: | If answered 8= Anemia or other blood disease to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_CancerFU1 |
| Variable: | SACQ comorbidities: Cancer: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for cancer/another cancer |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for cancer/another cancer? |
| Inclusion Criteria: | If answered 9= Cancer/Other cancer to ComorbiditiesSACQ |

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| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_CancerFU2 |
| Variable: | SACQ comorbidities: Cancer: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's cancer/other cancer limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your cancer/other cancer limit your activities? |
| Inclusion Criteria: | If answered 9= Cancer/Other cancer to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_DepressionFU1 |
| Variable: | SACQ comorbidities: Depression: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for depression |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for depression? |
| Inclusion Criteria: | If answered 10= Depression to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_DepressionFU2 |
| Variable: | SACQ comorbidities: Depression: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's depression limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your depression limit your activities? |
| Inclusion Criteria: | If answered 10= Depression to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_OsteoarthritisFU1 |
| Variable: | SACQ comorbidities: Osteoarthritis: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for osteoarthritis/degenerative arthritis |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for osteoarthritis/degenerative arthritis? |
| Inclusion Criteria: | If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |

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| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_OsteoarthritisFU2 |
| Variable: | SACQ comorbidities: Osteoarthritis: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's osteoarthritis/degenerative arthritis limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your osteoarthritis/degenerative arthritis limit your activities? |
| Inclusion Criteria: | If answered 11= Osteoarthritis, degenerative arthritis to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_BackPainFU1 |
| Variable: | SACQ comorbidities: Back Pain: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for back pain |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for back pain? |
| Inclusion Criteria: | If answered 12= Back pain to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_BackPainFU2 |
| Variable: | SACQ comorbidities: Back Pain: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's back pain limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your back pain limit your activities? |
| Inclusion Criteria: | If answered 12= Back pain to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_RheumatoidArthritisFU1 |
| Variable: | SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 1 |
| Definition: | Please indicate if the patient receives treatment for rheumatoid arthritis |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Do you receive treatment for rheumatoid arthritis? |
| Inclusion Criteria: | If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |

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| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_RheumatoidArthritisFU2 |
| Variable: | SACQ comorbidities: Rheumatoid Arthritis: Follow-Up Question 2 |
| Definition: | Please indicate if the patient's rheumatoid arthritis limits their function |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | Does your rheumatoid arthritis limit your activities? |
| Inclusion Criteria: | If answered 13= Rheumatoid arthritis to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes |
| Variable ID: | ComorbiditiesSACQ_Other |
| Variable: | SACQ comorbidities: Other Medical Problems |
| Definition: | Please indicate what other medical problems the patient is experiencing |
| Supporting Definition: | Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003). Phrased as a patient-reported measure, but information can be abstracted by other means if patient is unable to answer. |
| Displayed Value: | What other medical problems are you experiencing? |
| Inclusion Criteria: | If answered 14= Other medical problems to ComorbiditiesSACQ |
| Timing: | Baseline |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | String |
| Response Options: | None |
| Variable ID: | ComorbiditiesSACQ_Score |
| Variable: | Score of the SACQ comorbidities questionnaire |
| Definition: | Please indicate the summed score for all of the patient's comorbidities |
| Supporting Definition: | An individual can receive a max of 3 points for each medical condition: 1 point for the presence of the problem, another point if he/she receives treatment for it, and an additional point if the problem causes a limitation in function. The Max score a patient can receive is 45 points |
| Displayed Value: | What is the total summed score of the patient's SACQ responses? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline |
| Data Source: | Clinical |
| Type: | Numerical value |
| Value Domain: | Quantity |
| Response Options: | Total summed score |
| Variable ID: | SmokingStatus |
| Variable: | Smoking status |
| Definition: | A person's current and past smoking behavior |
| Supporting Definition: | Daily smoker: A person who smokes daily Weekly smoker: A person who smokes at least weekly but not daily Former smoker: A person who does not smoke at all now, but has smoked at least 100 cigarettes or a similar amount of other tobacco products in his/her lifetime Never-smoker: A person who does not smoke now and has smoked fewer than 100 cigarettes or similar amount of other tobacco products in his/her lifetime |
| Displayed Value: | Please indicate your smoking behavior. More detailed definitions are as follows: Daily smoker: A person who smokes daily Weekly smoker: A person who smokes at least weekly but not daily Former smoker: A person who does not smoke at all now, but has smoked at least 100 cigarettes or a similar amount of other tobacco products in his/her lifetime Never-smoker: A person who does not smoke now and has smoked fewer than 100 |

cigarettes or similar amount of other tobacco products in his/her lifetime

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 0 = Current every day smoker
1 = Current weekly smoker
2 = Former smoker
3 = Never smoker
4 = Others
999 = Unknown if ever smoked

Variable ID: PULMFUNCAB

Variable: Pulmonary function at lung cancer diagnosis: Absolute value FEV-1

Definition: Indicate the absolute value of FEV-1 at time of lung cancer diagnosis

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: Patients undergoing surgery

Timing: Baseline

Data Source: Clinical

Type: Numerical value

Value Domain: Quantity

Response Options: Numerical value in liters
999 = Unknown

Variable ID: PULMFUNCPEP

Variable: Pulmonary function at lung cancer diagnosis: Percent predicted normal value

Definition: Indicate the percentage predicted value of FEV-1 at time of lung cancer diagnosis

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: Patients undergoing surgery

Timing: Baseline

Data Source: Clinical

Type: Numerical value

Value Domain: Quantity

Response Options: Numerical value of 0-100
999 = Unknown

Baseline Tumor Factors

Variable ID: BASISDIAGN

Variable: Method of diagnosis (clinical or pathologic)

Definition: Indicate how lung cancer was diagnosed

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1 = Clinical assessment
2 = Histological assessment
3 = Cytological assessment
999 = Unknown

Variable ID: HISTOL_LUNGCA

Variable: Histology

Definition: Indicate the lung cancer histology

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = Adenocarcinoma
 2 = Adenocarcinoma with lepidic pattern
 3 = Invasive mucinous adenocarcinoma
 4 = Squamous cell carcinoma
 5 = Small-cell carcinoma
 6 = Non-small cell lung cancer (NSCLC) – favor adenocarcinoma
 7 = NSCLC – favor squamous cell carcinoma
 8 = NSCLC with neuroendocrine (NE) morphology and positive NE markers;
 possible large-cell neuroendocrine carcinoma
 9 = NSCLC with NE morphology (negative NE markers)
 10 = NSCLC with spindle and/or giant cell carcinoma
 11 = NSCLC-not otherwise specified
 12 = Atypical adenomatous hyperplasia
 13 = Adenocarcinoma in situ
 14 = Minimally invasive adenocarcinoma
 15 = Carcinoid typical (NET grade 1)
 16 = Carcinoid atypical (NET grade 2)
 999 = Unknown

Variable ID: ALK
Variable: Mutation status: ALK translocation
Definition: Indicate presence of ALK translocation
Supporting Definition: If the test is not performed, unknown can be answered.
Displayed Value: None
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
 1 = Yes
 2 = Failed analysis
 999 = Unknown

Variable ID: EGFR
Variable: Mutation status: Activating EGFR
Definition: Indicate presence of activating EGFR mutation
Supporting Definition: If the test is not performed, unknown can be answered.
Displayed Value: None
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
 1 = Yes
 2 = Failed analysis
 999 = Unknown

Variable ID: TNMCT_LUNGCA
Variable: Clinical tumor stage
Definition: Indicate the clinical tumor stage (per UICC / IASLC / AJCC 7th)
Supporting Definition: Pathologic staging preferred, if available
 cTo: no primary tumor
 cT1: if not able to select T1a or T1b: Tumor ≤3 cm diameter, surrounded by lung or visceral pleura, without invasion more proximal than lobar bronchus
 cT1a: Tumor ≤2 cm in diameter

cT1b: Tumor >2 cm but ≤3 cm in diameter
 cT2: if not able to select T2a or T2b: Tumor >3 cm but ≤7 cm, or tumor with any of the following features: Involves main bronchus, ≥2 cm distal to carina. Invades visceral pleura. Associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung
 cT2a: Tumor >3 cm but ≤5 cm
 cT2b: Tumor >5 cm but ≤7 cm
 cT3: Tumor >7 cm or any of the following: Directly invades any of the following: chest wall, diaphragm, phrenic nerve, mediastinal pleura, parietal pericardium, main bronchus <2 cm from carina (without involvement of carina), Atelectasis or obstructive pneumonitis of the entire lung. Separate tumor nodules in the same lobe
 cT4: Tumor of any size that invades the mediastinum, heart, great vessels, trachea, recurrent laryngeal nerve, esophagus, vertebral body, carina, or with separate tumor nodules in a different ipsilateral lobe
 cTX: Primary tumor cannot be assessed

Displayed Value: None
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = c To

1 = cT1
 2 = cT1a
 3 = cT1b
 4 = cT2
 5 = cT2a
 6 = cT2b
 7 = cT3
 8 = cT4
 9 = cTX
 999 = Unknown

Variable ID: TNMCN_LUNGCA

Variable: Clinical nodal stage

Definition: Indicate the clinical nodal stage (per UICC / IASLC / AJCC 7th)

Supporting Definition: Pathologic staging preferred, if available

cNo: No regional lymph node metastases
 cN1: Metastasis in ipsilateral peribronchial and/or ipsilateral hilar lymph nodes and intrapulmonary nodes, including involvement by direct extension
 cN2: Metastasis in ipsilateral mediastinal and/or subcarinal lymph node(s)
 cN3: Metastasis in contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene, or supraclavicular lymph node(s)
 cNX: Regional lymph nodes were not assessed

Displayed Value: None
Inclusion Criteria: All patients
Timing: Baseline
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = cNo

1 = cN1
 2 = cN2
 3 = cN3
 4 = cNX
 999 = Unknown

Variable ID: TNMCM_LUNGCA

Variable: Clinical metastatic stage

Definition: Indicate clinical metastatic stage (per UICC / IASLC / AJCC 7th)

Supporting Definition: cMo: No distant metastasis
cM1: Distant metastasis
cM1a: Separate tumor nodule(s) in a contralateral lobe; tumor with pleural nodules or malignant pleural or pericardial effusion
cM1b: Distant metastasis (in extrathoracic organs)
cMX: Distant metastasis cannot be evaluated

Displayed Value: None

Inclusion Criteria: All patients

Timing: Baseline

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = cMo
1 = cM1
2 = cM1a
3 = cM1b
4 = cMX
999 = Unknown

Variable ID: TNMPT_LUNGCA

Variable: Pathological tumor stage

Definition: Indicate the pathological tumor stage (per UICC / IASLC / AJCC 7th)

Supporting Definition: Pathologic staging preferred, if available
pTo: no primary tumor
pT1: if not able to select T1a or T1b: Tumor ≤ 3 cm diameter, surrounded by lung or visceral pleura, without invasion more proximal than lobar bronchus
pT1a: Tumor ≤ 2 cm in diameter
pT1b: Tumor > 2 cm but ≤ 3 cm in diameter
pT2: if not able to select T2a or T2b: Tumor > 3 cm but ≤ 7 cm, or tumor with any of the following features:
Involves main bronchus, ≥ 2 cm distal to carina. Invades visceral pleura. Associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung
pT2a: Tumor > 3 cm but ≤ 5 cm
pT2b: Tumor > 5 cm but ≤ 7 cm
pT3: Tumor > 7 cm or any of the following: Directly invades any of the following: chest wall, diaphragm, phrenic nerve, mediastinal pleura, parietal pericardium, main bronchus < 2 cm from carina (without involvement of carina), Atelectasis or obstructive pneumonitis of the entire lung. Separate tumor nodules in the same lobe
pT4: Tumor of any size that invades the mediastinum, heart, great vessels, trachea, recurrent laryngeal nerve, esophagus, vertebral body, carina, or with separate tumor nodules in a different ipsilateral lobe
pTX: Primary tumor cannot be assessed

Displayed Value: None

Inclusion Criteria: All patients

Timing: After biopsy/surgery

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = pTo
1 = pT1
2 = pT1a
3 = pT1b
4 = pT2
5 = pT2a
6 = pT2b
7 = pT3
8 = pT4
9 = pTX

999 = Unknown

Variable ID: TNMPN_LUNGCA
Variable: Pathological nodal stage
Definition: Indicate the pathological nodal stage (per UICC / IASLC / AJCC 7th)
Supporting Definition: Pathologic staging preferred, if available
pNo: No regional lymph node metastases
pN1: Metastasis in ipsilateral peribronchial and/or ipsilateral hilar lymph nodes and intrapulmonary nodes, including involvement by direct extension
pN2: Metastasis in ipsilateral mediastinal and/or subcarinal lymph node(s)
pN3: Metastasis in contralateral mediastinal, contralateral hilar, ipsilateral or contralateral scalene, or supraclavicular lymph node(s)
pNX: Regional lymph nodes were not assessed
Displayed Value: None
Inclusion Criteria: All patients
Timing: After biopsy/surgery
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = pNo
1 = pN1
2 = pN2
3 = pN3
4 = pNX
999 = Unknown

Variable ID: TNMPM_LUNGCA
Variable: Pathological metastatic stage
Definition: Indicate pathological metastatic stage (per UICC / IASLC / AJCC 7th)
Supporting Definition: pMo: No distant metastasis
pM1: Distant metastasis
pM1a: Separate tumor nodule(s) in a contralateral lobe; tumor with pleural nodules or malignant pleural or pericardial effusion
pM1b: Distant metastasis (in extrathoracic organs)
pMX: Distant metastasis cannot be evaluated
Displayed Value: None
Inclusion Criteria: All patients
Timing: After biopsy/surgery
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = pMo
1 = pM1
2 = pM1a
3 = pM1b
4 = pMX
999 = Unknown

Treatment Factors

Variable ID: TREATINT
Variable: Intent of treatment
Definition: Indicate intent of treatment
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: All patients
Timing: At time of treatment decision
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = Curative/Radical

2 = Palliative (includes ablative treatment for oligometastatic disease)
999 = Unknown

Variable ID: TREATCOMPL
Variable: Completed treatment
Definition: Indicate if the patient completed treatment
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: All patients
Timing: After treatment
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 1 = Yes
2 = Yes but with chemotherapy dose reduction
3 = Yes but with radiotherapy dose reduction
4 = No, patient choice
5 = No, due to toxicity
6 = No, due to patient death
999 = Unknown

Treatment Variables

Variable ID: SURGERY_LUNGCA
Variable: Treatments received during the last year: Surgery
Definition: Indicate if the patient received surgery
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: All patients
Timing: Update at least annually
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = No
1 = Yes, primary tumor
2 = Yes, any metastatic site except brain
3 = Yes, brain metastasis

Variable ID: SurgeryDate
Variable: Surgery date
Definition: Provide the date of surgery:
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: All patients
If answered '1-3' on SURGERY
Timing: Update at least annually
Data Source: Clinical
Type: Date by DD/MM/YYYY
Value Domain: Date
Response Options: DD/MM/YYYY

Variable ID: TARGETTX_LUNGCA
Variable: Treatments received during the last year: Targeted therapy
Definition: Indicate if the patient received targeted therapy over the past 12 months
Supporting Definition: None
Displayed Value: None
Inclusion Criteria: All patients
Timing: Update at least annually
Data Source: Clinical
Type: Single answer
Value Domain: Code

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| Response Options: | 0 = No 1 = Yes |
| Variable ID: | TargetTxStartDate |
| Variable: | Targeted therapy start date |
| Definition: | Please provide the start date of targeted therapy, if applicable |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered "1= Yes" to TARGETTX_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | TargetTxStopDate |
| Variable: | Targeted therapy stop date |
| Definition: | Please provide the stop date of targeted therapy, if applicable |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered "1= Yes" to TARGETTX_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | TARGETTXONGOING |
| Variable: | Ongoing targeted therapy |
| Definition: | Indicate if targeted therapy is ongoing |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered "1= Yes" to TARGETTX_LUNGCA and no end date is entered on TargetTxStopDate |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No 1= Yes, ongoing |
| Variable ID: | CHEMOTXLASTY |
| Variable: | Treatments received during the last year: Chemotherapy |
| Definition: | Indicate if the patient received chemotherapy over the past 12 months |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0 = No 1 = Yes |
| Variable ID: | ChemoTxStartDate |
| Variable: | Chemotherapy start date |
| Definition: | Indicate date patient started with chemotherapy |
| Supporting Definition: | Refers to start of first cycle, in case of multiple cycles |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |

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| | If answered "1= Yes" to CHEMOTXLASTY |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | ChemoTxStopDate |
| Variable: | Chemotherapy stop date |
| Definition: | Indicate date patient stopped with chemotherapy |
| Supporting Definition: | Refers to stop of last cycle, in case of multiple cycles |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| | If answered "1= Yes" to CHEMOTXLASTY |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | CHEMOTXONGOING |
| Variable: | Ongoing chemotherapy |
| Definition: | Indicate if chemotherapy is ongoing |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| | If answered "1= Yes" to CHEMOTXLASTY and no end date is entered on ChemoTxStopDate |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0= No |
| | 1= Yes, ongoing |
| Variable ID: | IMMUNOTX |
| Variable: | Treatments received during the last year: Immunotherapy |
| Definition: | Indicate if the patient received immunotherapy |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0 = No |
| | 1 = Yes |
| | 999 = Unknown |
| Variable ID: | IMMUNOTXSTARTDATE |
| Variable: | Start of immunotherapy |
| Definition: | Indicate date patient started with immunotherapy |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| | If answered "1= Yes" to IMMUNOTX |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | IMMUNOTXSTOPDATE |

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| Variable: | Stop of immunotherapy |
| Definition: | Indicate date patient stopped immunotherapy |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered "1= Yes" to IMMUNOTX |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | IMMUNOTXONGOING |
| Variable: | Ongoing immunotherapy |
| Definition: | Indicate if immunotherapy is ongoing |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered "1= Yes" to IMMUNOTX, and no end date is entered on IMMUNOTXSTOPDATE |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0 = No 1= Yes, ongoing |
| Variable ID: | RADIOTX_LUNCA |
| Variable: | Treatments received during the last year: Radiotherapy |
| Definition: | Indicate if the patient received radiotherapy |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0 = No 1 = Yes, primary tumor 2 = Yes, any metastatic site except brain 3 = Yes, brain metastasis |
| Variable ID: | RadioTxStartDate |
| Variable: | Radiotherapy start date |
| Definition: | Please provide the start date of radiotherapy: |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered '1-3' on RADIOTX |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | RadioTxStopDate |
| Variable: | Radiotherapy stop date |
| Definition: | Please provide the stop date of radiotherapy: |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered '1-3' on RADIOTX |

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| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | RADIOTXONGOING |
| Variable: | Ongoing radiotherapy |
| Definition: | Indicate if radiotherapy is ongoing |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| | If answered '1-3' on RADIOTX, and no end date is entered on RadioTxStopDate |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0 = No |
| | 1= Yes, ongoing |

Outcomes

Other

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| Variable ID: | INCIDENTATE |
| Variable: | Date of pathologic or clinical diagnosis |
| Definition: | Indicate when patient was diagnosed by pathology |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| Timing: | When treatment begins |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | INCIDENTATEMETHOD |
| Variable: | Method of pathologic or clinical diagnosis |
| Definition: | Indicate how pathologic or clinical diagnosis was made |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| Timing: | When treatment begins |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | Pathologic (preferred if available, indicate earliest recorded method) |
| | 1 = Date specimen taken |
| | 2 = Date specimen received |
| | 3 = Date of pathology report |
| | Clinical diagnosis (if pathologic diagnosis unavailable) |
| | 4 = Date of admission to hospital because of this malignancy |
| | 5 = Date of first consultation at the outpatient clinic because of this malignancy (if only outpatient data available) |
| | 888 = Other |

Acute Complications of Treatment

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| Variable ID: | COMPLSURG |
| Variable: | Clavien complication maximum grade |

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| Definition: | Indicate if patient experienced a Clavien-Dindo grade III-IV complication within 6 months after initiating treatment |
| Supporting Definition: | Grade III: Requiring surgical, endoscopic, or radiological intervention, with or without general anesthesia Grade IV: Life-threatening complication (including CNS complications) requiring IC/ICU management; includes single organ dysfunction and multi-organ dysfunction Source: Annals of Surgery. 250(2):187-196, August 2009. |
| Displayed Value: | None |
| Inclusion Criteria: | All patients receiving resectional surgery If answered '1-3' on SURGERY |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0 = No 1 = Yes, grade 3 2 = Yes, grade 4 |
| Variable ID: | COMPLRAD_LUNGCA |
| Variable: | CTCAE grade III-IV complications due to radiotherapy |
| Definition: | Indicate if patient experienced a CTCAE v 4.0 grade III-IV complication while on therapy and within 6 months after initiating treatment |
| Supporting Definition: | A CTCAE v 4 grade III complication or higher means that the patient had to be admitted to the hospital. See http://evs.nci.nih.gov/ftp1/CTCAE/CTCAE_4.03_2010-06-14_QuickReference_5x7.pdf for a list of domains and grades of complications |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered '1-3' on RADIOTX |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Multiple answer |
| Value Domain: | Code |
| Response Options: | 0 = No grade III-IV toxicity 1 = Cytopenias (anemia, febrile neutropenia, thrombocytopenia) 2 = Infection, any primary site 3 = Skin reaction (rash, dermatitis radiation) 4 = Pneumonitis, cough, dyspnea, other lung toxicity 5 = Oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, other GI toxicity 6 = Neuropathy, tinnitus, hearing impaired, other neurologic toxicity 7 = Acute kidney injury 888 = Other |
| Variable ID: | COMPLRADOTHER |
| Variable: | CTCAE grade III-IV complication due to radiotherapy other than those explicitly listed |
| Definition: | Indicate the CTCAE v 4.0 grade III-IV complication the patient experienced |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "888= Other" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Free text |
| Value Domain: | String |
| Response Options: | CTCAE grade III-IV complication due to radiotherapy |
| Variable ID: | COMPLSYSCYTODATE |
| Variable: | Date of cytopenias |

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| Definition: | Indicate date when the cytopenic complication was first diagnosed |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "1= Cytopenias" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSINFDATE |
| Variable: | Date of infection |
| Definition: | Indicate date when the infectious complication was first diagnosed |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "2= Infection" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLRADSKIDATE |
| Variable: | Date of skin reaction |
| Definition: | Indicate date of skin reaction |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "3= Skin reaction" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLRADPNEDATE |
| Variable: | Date of pneumonitis, cough, dyspnea, or other lung toxicity |
| Definition: | Indicate date of pneumonitis, cough, dyspnea, or other lung toxicity |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "4= Pneumonitis, cough, dyspnea, other lung toxicity" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLRADOESDATE |
| Variable: | Date of oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, or other GI toxicity |
| Definition: | Indicate date of oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, or other GI toxicity |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "5= Oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, other GI toxicity" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |

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| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLRADNEURODATE |
| Variable: | Date of neuropathy, tinnitus, hearing impaired, or other neurologic toxicity |
| Definition: | Indicate date of neuropathy, tinnitus, hearing impaired, or other neurologic toxicity |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "6= Neuropathy, tinnitus, hearing impaired, other neurologic toxicity" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLRADKIDDATE |
| Variable: | Date of acute kidney injury |
| Definition: | Indicate date of acute kidney injury |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "7= Acute kidney injury" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSOTHERDATE |
| Variable: | Date of other complication |
| Definition: | Indicate date when other complication was first diagnosed |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with radiotherapy If answered "888= Other" to COMPLRAD_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYS_LUNGCA |
| Variable: | CTCAE grade III-IV complications due to systemic therapy |
| Definition: | Indicate if patient experienced a CTCAE v 4.0 grade III-V complication while on therapy and within 6 months after initiating treatment |
| Supporting Definition: | A CTCAE v 4 grade III complication or higher means that the patient had to be admitted to the hospital. See http://evs.nci.nih.gov/ftp1/CTCAE/CTCAE_4.03_2010-06-14_QuickReference_5x7.pdf for a list of domains and grades of complications |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "1= Yes" to CHEMOTXLASTY or IMMUNOTX |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Multiple answer |
| Value Domain: | Code |
| Response Options: | o = No grade III-IV toxicity |

- 1 = Cytopenias (anemia, febrile neutropenia, thrombocytopenia)
- 2 = Infection, any primary site
- 3 = Skin reaction (rash, dermatitis radiation)
- 4 = Pneumonitis, cough, dyspnea, other lung toxicity
- 5 = Oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, other GI toxicity
- 6 = Neuropathy, tinnitus, hearing impaired, other neurologic toxicity
- 7 = Acute kidney injury
- 888 = Other

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| Variable ID: | COMPLSYSOTHER_LUNGCA |
| Variable: | CTCAE grade III-IV complication due to systemic therapy other than those explicitly listed |
| Definition: | Indicate the CTCAE v 4.0 grade III-IV complication the patient experienced |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "888= Other" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Free text |
| Value Domain: | String |
| Response Options: | CTCAE grade III-IV complication due to systemic therapy |
| Variable ID: | COMPLSYSCYTO DATE |
| Variable: | Date of cytopenias |
| Definition: | Indicate date of cytopenias |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "1= Cytopenias" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSINFDATE |
| Variable: | Date of infection |
| Definition: | Indicate date of infection |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "2= Infection" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSSKIDATE |
| Variable: | Date of skin reaction |
| Definition: | Indicate date of skin reaction |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "3= Skin reaction" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |

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| Variable ID: | COMPLSYSPNEDATE |
| Variable: | Date of pneumonitis, cough, dyspnea, or other lung toxicity |
| Definition: | Indicate date of pneumonitis, cough, dyspnea, or other lung toxicity |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "4= Pneumonitis, cough, dyspnea, other lung toxicity" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSOESDATE |
| Variable: | Date of oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, or other GI toxicity |
| Definition: | Indicate date of oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, or other GI toxicity |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "5= Oesophagitis, mucositis oral, nausea, vomiting, diarrhea, constipation, other GI toxicity" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSNEURODATE |
| Variable: | Date of neuropathy, tinnitus, hearing impaired, or other neurologic toxicity |
| Definition: | Indicate date of neuropathy, tinnitus, hearing impaired, or other neurologic toxicity |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "6= Neuropathy, tinnitus, hearing impaired, other neurologic toxicity" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSKIDDATE |
| Variable: | Date of acute kidney injury |
| Definition: | Indicate date of acute kidney injury |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | Patients with systemic therapy If answered "7= Acute kidney injury" to COMPLSYS_LUNGCA |
| Timing: | Update at least annually |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | COMPLSYSOTHERDATE |
| Variable: | Date of other complication |
| Definition: | Indicate date of other complication |

Supporting Definition: None
Displayed Value: None
Inclusion Criteria: Patients with systemic therapy
 If answered "888= Other" to COMPLSYS_LUNGCA
Timing: Update at least annually
Data Source: Clinical
Type: Date by DD/MM/YYYY
Value Domain: Date
Response Options: DD/MM/YYYY

Degree of Health

Variable ID: PERFORM
Variable: ECOG/WHO performance status
Definition: Indicate the ECOG/WHO performance status
Supporting Definition: 0 = PS 0 - normal activity level;
 1 = PS 1 - restricted with strenuous activity, but can do light activity;
 2 = PS 2 - active >= 50% of day;
 3 = PS 3 - spends >50% of day in chair or bed;
 4 = PS 4 - totally confined to bed
Displayed Value: None
Inclusion Criteria: All patients
Timing: Baseline
 1 year post initiation of treatment
 Tracked ongoing annually for life
 (when hospital is able to track this ongoing)
Data Source: Clinical
Type: Single answer
Value Domain: Code
Response Options: 0 = 0
 1 = 1
 2 = 2
 3 = 3
 4 = 4
 999 = Unknown

Variable ID: EORTCQLQC30_Q01
Variable: Question 1 of EORTC-QLQ-C30
Definition: We are interested in some things about you and your health. Please answer all of the questions yourself by selecting the answer that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.
 1: Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?
Supporting Definition: None
Displayed Value: We are interested in some things about you and your health. Please answer all of the questions yourself by selecting the answer that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.
 1: Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code

Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q02
Variable: Question 2 of EORTC-QLQ-C30
Definition: 2: Do you have any trouble taking a long walk?
Supporting Definition: None
Displayed Value: 2: Do you have any trouble taking a long walk?
Inclusion Criteria: All patients
Timing: Baseline

3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q03
Variable: Question 3 of EORTC-QLQ-C30
Definition: 3: Do you have any trouble taking a short walk outside of the house?
Supporting Definition: None
Displayed Value: 3: Do you have any trouble taking a short walk outside of the house?
Inclusion Criteria: All patients
Timing: Baseline

3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q04
Variable: Question 4 of EORTC-QLQ-C30
Definition: 4: Do you need to stay in bed or a chair during the day?
Supporting Definition: None
Displayed Value: 4: Do you need to stay in bed or a chair during the day?
Inclusion Criteria: All patients
Timing: Baseline

3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life

Data Source: Patient-reported

Type: Single answer

Value Domain: Code

Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

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| Variable ID: | EORTCQLQC30_Q05 |
| Variable: | Question 5 of EORTC-QLQ-C30 |
| Definition: | 5: Do you need help with eating, dressing, washing yourself or using the toilet? |
| Supporting Definition: | None |
| Displayed Value: | 5: Do you need help with eating, dressing, washing yourself or using the toilet? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit 4 = Very much |
| Variable ID: | EORTCQLQC30_Q06 |
| Variable: | Question 6 of EORTC-QLQ-C30 |
| Definition: | During the past week: 6: Were you limited in doing either your work or other daily activities? |
| Supporting Definition: | None |
| Displayed Value: | During the past week: 6: Were you limited in doing either your work or other daily activities? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit 4 = Very much |
| Variable ID: | EORTCQLQC30_Q07 |
| Variable: | Question 7 of EORTC-QLQ-C30 |
| Definition: | 7: Were you limited in pursuing your hobbies or other leisure time activities? |
| Supporting Definition: | None |
| Displayed Value: | 7: Were you limited in pursuing your hobbies or other leisure time activities? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit 4 = Very much |
| Variable ID: | EORTCQLQC30_Q08 |
| Variable: | Question 8 of EORTC-QLQ-C30 |

Definition: 8: Were you short of breath?
Supporting Definition: None
Displayed Value: 8: Were you short of breath?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q09
Variable: Question 9 of EORTC-QLQ-C30
Definition: 9: Have you had pain?
Supporting Definition: None
Displayed Value: 9: Have you had pain?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q10
Variable: Question 10 of EORTC-QLQ-C30
Definition: 10: Did you need to rest?
Supporting Definition: None
Displayed Value: 10: Did you need to rest?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q11
Variable: Question 11 of EORTC-QLQ-C30
Definition: 11: Have you had trouble sleeping?
Supporting Definition: None
Displayed Value: 11: Have you had trouble sleeping?
Inclusion Criteria: All patients

Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q12
Variable: Question 12 of EORTC-QLQ-C30
Definition: 12: Have you felt weak?
Supporting Definition: None
Displayed Value: 12: Have you felt weak?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q13
Variable: Question 13 of EORTC-QLQ-C30
Definition: 13: Have you lacked appetite?
Supporting Definition: None
Displayed Value: 13: Have you lacked appetite?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q14
Variable: Question 14 of EORTC-QLQ-C30
Definition: 14: Have you felt nauseated?
Supporting Definition: None
Displayed Value: 14: Have you felt nauseated?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment

Data Source: Tracked ongoing annually for life
Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q15
Variable: Question 15 of EORTC-QLQ-C30
Definition: 15: Have you vomited?
Supporting Definition: None
Displayed Value: 15: Have you vomited?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q16
Variable: Question 16 of EORTC-QLQ-C30
Definition: 16: Have you been constipated?
Supporting Definition: None
Displayed Value: 16: Have you been constipated?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q17
Variable: Question 17 of EORTC-QLQ-C30
Definition: 17: Have you had diarrhea?
Supporting Definition: None
Displayed Value: 17: Have you had diarrhea?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code

Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q18
Variable: Question 18 of EORTC-QLQ-C30
Definition: 18: Were you tired?
Supporting Definition: None
Displayed Value: 18: Were you tired?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q19
Variable: Question 19 of EORTC-QLQ-C30
Definition: 19: Did pain interfere with your daily activities?
Supporting Definition: None
Displayed Value: 19: Did pain interfere with your daily activities?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q20
Variable: Question 20 of EORTC-QLQ-C30
Definition: 20: Have you had difficulty in concentrating on things, like reading a newspaper or watching television?
Supporting Definition: None
Displayed Value: 20: Have you had difficulty in concentrating on things, like reading a newspaper or watching television?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little

3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q21
Variable: Question 21 of EORTC-QLQ-C30
Definition: 21: Did you feel tense?
Supporting Definition: None
Displayed Value: 21: Did you feel tense?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q22
Variable: Question 22 of EORTC-QLQ-C30
Definition: 22: Did you worry?
Supporting Definition: none
Displayed Value: 22: Did you worry?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q23
Variable: Question 23 of EORTC-QLQ-C30
Definition: 23: Did you feel irritable?
Supporting Definition: None
Displayed Value: 23: Did you feel irritable?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q24
Variable: Question 24 of EORTC-QLQ-C30

Definition: 24: Did you feel depressed?
Supporting Definition: None
Displayed Value: 24: Did you feel depressed?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q25
Variable: Question 25 of EORTC-QLQ-C30
Definition: 25: Have you had difficulty remembering things?
Supporting Definition: None
Displayed Value: 25: Have you had difficulty remembering things?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q26
Variable: Question 26 of EORTC-QLQ-C30
Definition: 26: Has your physical condition or medical treatment interfered with your family life?
Supporting Definition: None
Displayed Value: 26: Has your physical condition or medical treatment interfered with your family life?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQC30_Q27
Variable: Question 27 of EORTC-QLQ-C30
Definition: 27: Has your physical condition or medical treatment interfered with your social activities?

Supporting Definition: None
Displayed Value: 27: Has your physical condition or medical treatment interfered with your social activities?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q28
Variable: Question 28 of EORTC-QLQ-C30
Definition: 28: Has your physical condition or medical treatment caused you financial difficulties?

Supporting Definition: None
Displayed Value: 28: Has your physical condition or medical treatment caused you financial difficulties?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQC30_Q29
Variable: Question 29 of EORTC-QLQ-C30
Definition: For the following questions please select the number between 1 and 7 that best applies to you
29: How would you rate your overall health during the past week?

Supporting Definition: Range from 1 to 7, with 1 = Very poor and 7 = Excellent
1-7 denotes 1-7 correspondingly
Displayed Value: For the following questions please select the number between 1 and 7 that best applies to you
29: How would you rate your overall health during the past week?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Quantity
Response Options: Numerical value of 1 – 7

Variable ID: EORTCQLQC30_Q30
Variable: Question 30 of EORTC-QLQ-C30
Definition: 30: How would you rate your overall quality of life during the past week?

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| Supporting Definition: | Range from 1 to 7, with 1 = Very poor and 7 = Excellent 1-7 denotes 1-7 correspondingly |
| Displayed Value: | 30: How would you rate your overall quality of life during the past week? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Quantity |
| Response Options: | Numerical value of 1 – 7 |
| Variable ID: | EORTCQLQLC13_Q01 |
| Variable: | Question 1 of EORTC-QLQ-LC13 |
| Definition: | Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by selecting the answer that best applies to you. During the past week: 31: How much did you cough? |
| Supporting Definition: | None |
| Displayed Value: | Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by selecting the answer that best applies to you. During the past week: 31: How much did you cough? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit 4 = Very much |
| Variable ID: | EORTCQLQLC13_Q02 |
| Variable: | Question 2 of EORTC-QLQ-LC13 |
| Definition: | 32: Did you cough up blood? |
| Supporting Definition: | None |
| Displayed Value: | 32: Did you cough up blood? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit |

4 = Very much

Variable ID: EORTCQLQLC13_Qo3
Variable: Question 3 of EORTC-QLQ-LC13
Definition: 33: Were you short of breath when you rested?
Supporting Definition: None
Displayed Value: 33: Were you short of breath when you rested?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQLC13_Qo4
Variable: Question 4 of EORTC-QLQ-LC13
Definition: 34: Were you short of breath when you walked?
Supporting Definition: None
Displayed Value: 34: Were you short of breath when you walked?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQLC13_Qo5
Variable: Question 5 of EORTC-QLQ-LC13
Definition: 35: Were you short of breath when you climbed stairs?
Supporting Definition: None
Displayed Value: 35: Were you short of breath when you climbed stairs?
Inclusion Criteria: All patients
Timing: Baseline
3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQLC13_Qo6
Variable: Question 6 of EORTC-QLQ-LC13
Definition: 36: Have you had a sore mouth or tongue?

Supporting Definition: None
Displayed Value: 36: Have you had a sore mouth or tongue?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQLC13_Q07
Variable: Question 7 of EORTC-QLQ-LC13
Definition: 37: Have you had trouble swallowing?
Supporting Definition: None
Displayed Value: 37: Have you had trouble swallowing?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQLC13_Q08
Variable: Question 8 of EORTC-QLQ-LC13
Definition: 38: Have you had tingling hands or feet?
Supporting Definition: None
Displayed Value: 38: Have you had tingling hands or feet?
Inclusion Criteria: All patients
Timing: Baseline
 3 months post initiation of treatment
 6 months post initiation of treatment
 1 year post initiation of treatment
 Tracked ongoing annually for life
Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
 2 = A little
 3 = Quite a bit
 4 = Very much

Variable ID: EORTCQLQLC13_Q09
Variable: Question 9 of EORTC-QLQ-LC13
Definition: 39: Have you had hair loss?
Supporting Definition: None
Displayed Value: 39: Have you had hair loss?
Inclusion Criteria: All patients
Timing: Baseline

3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life

Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQLC13_Q10
Variable: Question 10 of EORTC-QLQ-LC13
Definition: 40: Have you had pain in your chest?
Supporting Definition: None
Displayed Value: 40: Have you had pain in your chest?
Inclusion Criteria: All patients
Timing: Baseline

3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life

Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQLC13_Q11
Variable: Question 11 of EORTC-QLQ-LC13
Definition: 41: Have you had pain in your arm or shoulder?
Supporting Definition: None
Displayed Value: 41: Have you had pain in your arm or shoulder?
Inclusion Criteria: All patients
Timing: Baseline

3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life

Data Source: Patient-reported
Type: Single answer
Value Domain: Code
Response Options: 1 = Not at all
2 = A little
3 = Quite a bit
4 = Very much

Variable ID: EORTCQLQLC13_Q12
Variable: Question 12 of EORTC-QLQ-LC13
Definition: 42: Have you had pain in other parts of your body?
Supporting Definition: None
Displayed Value: 42: Have you had pain in other parts of your body?
Inclusion Criteria: All patients
Timing: Baseline

3 months post initiation of treatment
6 months post initiation of treatment
1 year post initiation of treatment
Tracked ongoing annually for life

Data Source: Patient-reported

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|-------------------------------|--|
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit 4 = Very much |
| Variable ID: | EORTCQLQLC13_Q12SUB |
| Variable: | Question 12sub of EORTC-QLQ-LC13 |
| Definition: | If yes, where |
| Supporting Definition: | None |
| Displayed Value: | If yes, where |
| Inclusion Criteria: | Only if answered '2-4' on EORTCQLQLC13-Q12 |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Free text |
| Value Domain: | String |
| Response Options: | Location of pain in free text |
| Variable ID: | EORTCQLQLC13_Q13 |
| Variable: | Question 13 of EORTC-QLQ-LC13 |
| Definition: | 43: Did you take any medicine for pain? |
| Supporting Definition: | None |
| Displayed Value: | 43: Did you take any medicine for pain? |
| Inclusion Criteria: | All patients |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit 4 = Very much |
| Variable ID: | EORTCQLQLC13_Q13SUB |
| Variable: | Question 13sub of EORTC-QLQ-LC13 |
| Definition: | If yes, how much did it help? |
| Supporting Definition: | None |
| Displayed Value: | If yes, how much did it help? |
| Inclusion Criteria: | Only if answered '2-4' on EORTCQLQLC13-Q13 |
| Timing: | Baseline 3 months post initiation of treatment 6 months post initiation of treatment 1 year post initiation of treatment Tracked ongoing annually for life |
| Data Source: | Patient-reported |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 1 = Not at all 2 = A little 3 = Quite a bit 4 = Very much |

Survival

| | |
|-------------------------------|---|
| Variable ID: | VitalStatus |
| Variable: | Vital status |
| Definition: | Indicate if the person has deceased, regardless of cause |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients |
| Timing: | 1 year post initiation of treatment Tracked ongoing annually for life (when hospital is able to track this ongoing) |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |
| Response Options: | 0 = No 1 = Yes 999 = Unknown |
| Variable ID: | DeceasedDate |
| Variable: | Date of death |
| Definition: | The date of death of the person |
| Supporting Definition: | It is recommended that in cases where all components of the date of death are not known or where an estimate is arrived at from age, a valid date be used together with a flag to indicate that it is an estimate. For record identification and/or the derivation of other metadata items that require accurate date of death information, estimated dates of death should be identified by a date accuracy indicator to prevent inappropriate use of date of death data. The linking of client records from diverse sources, the sharing of patient data, and data analysis for research and planning all rely heavily on the accuracy and integrity of the collected data. In order to maintain data integrity and the greatest possible accuracy an indication of the accuracy of the date collected is critical. The collection of Date accuracy indicator may be essential in confirming or refuting the positive identification of a person. For this reason it is strongly recommended that the data element Date accuracy indicator also be recorded at the time of record creation to flag the accuracy of the data. |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered "1= Yes" to VitalStatus |
| Timing: | 1 year post initiation of treatment Tracked ongoing annually for life (when hospital is able to track this ongoing) |
| Data Source: | Clinical |
| Type: | Date by DD/MM/YYYY |
| Value Domain: | Date |
| Response Options: | DD/MM/YYYY |
| Variable ID: | DEATHLC |
| Variable: | Cause of death: Death attributable to lung cancer |
| Definition: | Indicate if death is noted to be directly attributable to lung cancer as indicated on certificate of death |
| Supporting Definition: | None |
| Displayed Value: | None |
| Inclusion Criteria: | All patients If answered "1= Yes" to VitalStatus |
| Timing: | 1 year post initiation of treatment Tracked ongoing annually for life (when hospital is able to track this ongoing) |
| Data Source: | Clinical |
| Type: | Single answer |
| Value Domain: | Code |

Response Options: 0 = No
1 = Yes
999 = Unknown

Variable ID: DEATHLCTX

Variable: Cause of death: Death attributable to lung cancer treatment

Definition: Indicate if death was directly attributable to lung cancer treatment

Supporting Definition: This is needed to calculate the 30 and 90 day treatment-related mortality

Displayed Value: None

Inclusion Criteria: All patients receiving treatment
If answered "1= Yes" to VitalStatus

Timing: 1 year post initiation of treatment
Tracked ongoing annually for life
(when hospital is able to track this ongoing)

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 0 = No
1 = Yes
999 = Unknown

Quality of Death

Variable ID: DeathLocation

Variable: Location of death

Definition: The location of death for a deceased person

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: All patients
If answered "1= Yes" to VitalStatus

Timing: 1 year post initiation of treatment
Tracked ongoing annually for life (when hospital is able to track this ongoing)

Data Source: Clinical

Type: Single answer

Value Domain: Code

Response Options: 1=At home
2=Hospital
3=Nursing home/Non-hospice Long term care facility
4=Hospice
888=Other
999=Unknown

Variable ID: INHOSPITAL

Variable: Days spent in hospital in the last 30 days of life

Definition: Indicate how long patient spent time in the hospital (in hospital includes ICU) at end of life, meaning last 30 days

Supporting Definition: None

Displayed Value: None

Inclusion Criteria: All patients with end-stage disease
If answered "1= Yes" to VitalStatus

Timing: 1 year post initiation of treatment
Tracked ongoing annually for life
(when hospital is able to track this ongoing)

Data Source: Clinical

Type: Numerical value

Value Domain: Quantity

Response Options: Numerical value of number of days

ICHOM Contact Information

| | |
|------------------|--|
| Website | http://www.ichom.org |
| Business Address | 399 Boylston St. 6th floor, Boston MA, 02116, United States of America |

Reference Guide

| Reference Guide Version | Location within Reference Guide | Content Change |
|-------------------------|-------------------------------------|--|
| 2.1 | The Growing ICHOM Community | Removed map and updated information |
| 2.1 | Introduction to the Data Dictionary | Modifications to introductory paragraph |
| 2.1 | Data Dictionary | Modified Item of [COMPLRAD], [COMPLRADOTHER], [COMPLSYS], and [COMPLSYSOTHER] |
| 2.2 | Data Dictionary | Modified Variable ID and Item of [DOB]. Modified Inclusion Criteria and Response Options of [COMPLRAD], [COMPLRADOTHER], [COMPLSYS], and [COMPLSYSOTHER]. Modified Definition and Reporting Source of [DEATH], [DEATHDATE], [DEATHLC], and [DEATHPLACE]. |
| 2.3 | Data Dictionary | Modified Inclusion Criteria for [DEATHDATE], [DEATHLC], [DEATHCTX], [DEATHPLACE], and [INHOSPITAL] . |
| 2.3.1 | Contact Information | Removed inactive email address: ichomteam@ichom.org |
| 4.0.0 | Data Dictionary | Harmonisation update |
| 4.0.0 | Whole Document | Wording change. Replacing 'Standard Sets' to 'Sets of Patient-Centered Outcome Measures' |

Notes

