ICHOM

International Consortium for Health Outcomes Measurement

LUNG CANCER DATA COLLECTION REFERENCE GUIDE

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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.

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Reza Mehran

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	Baseline; 1 year post initiation of treatment; Tracked ongoing annually for life (when hospital is able to track this ongoing)	Clinical
Patients undergoing surgery	Pulmonary function	Baseline	
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	

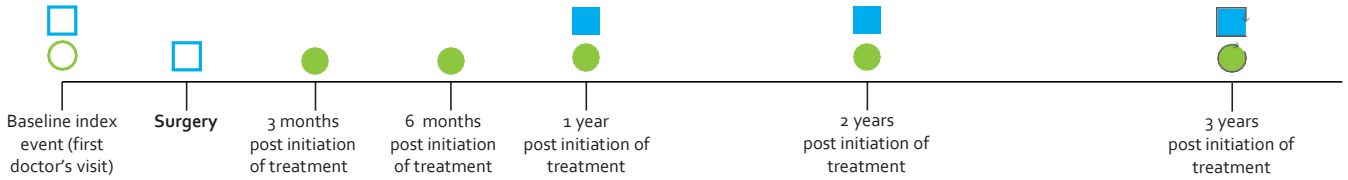
Outcomes

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

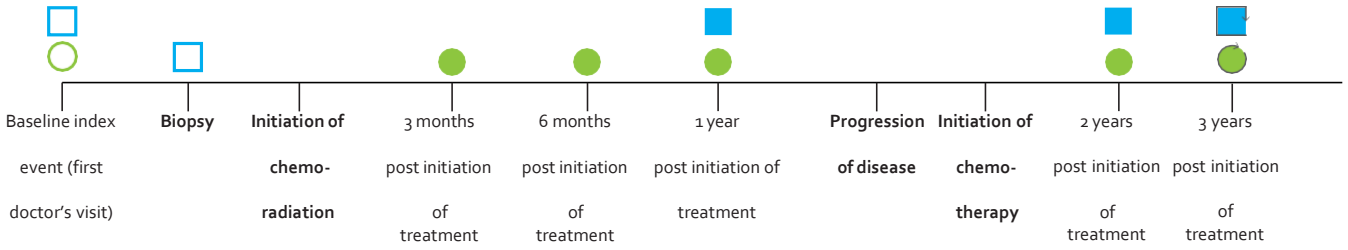
Follow-Up Timeline

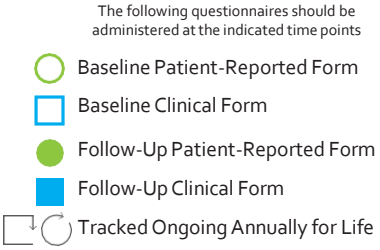
The following timeline illustrates when the Set variables should be collected from patients, clinicians, and administrative sources. Links to the sample questionnaires may be found in the legend below.

Example 1: Patient diagnosed with lung cancer, receives one treatment



Example 2: Patient diagnosed with lung cancer, receives treatment, progresses, and receives second treatment





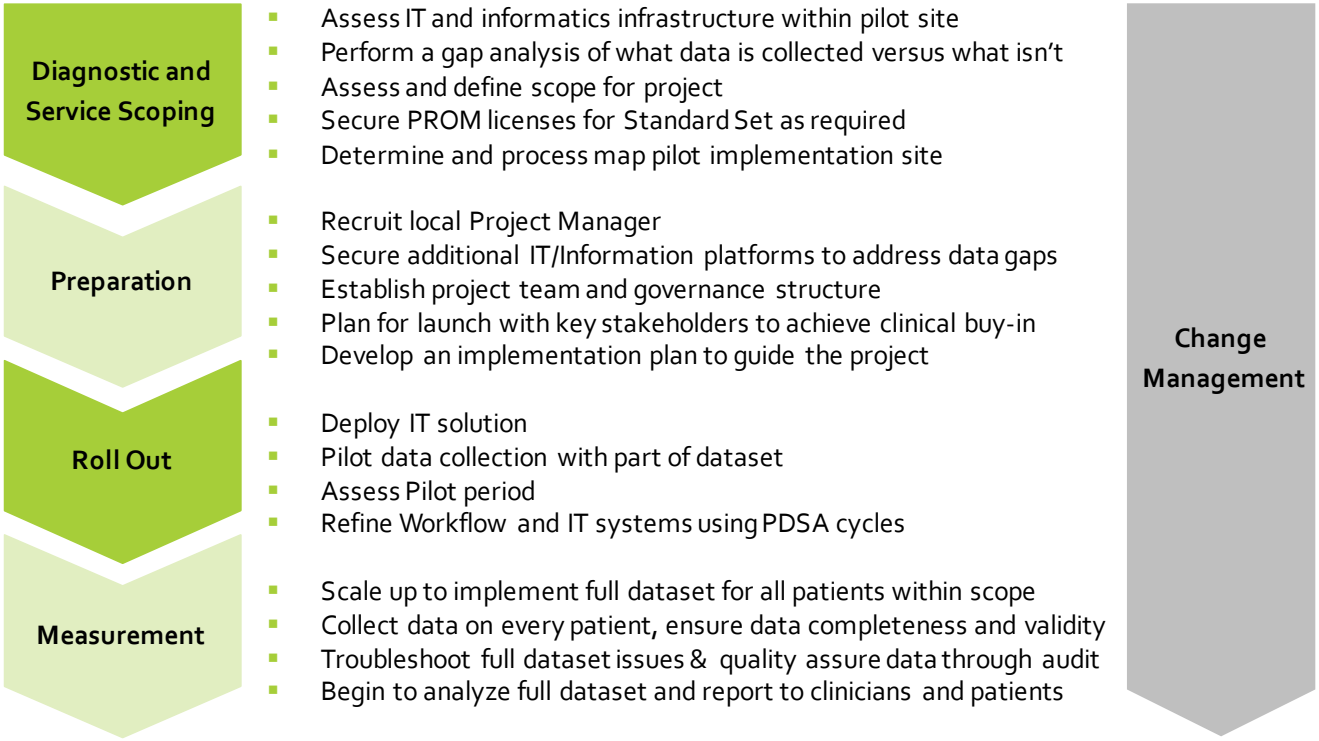
Collecting Patient-Reported Outcome Measures

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 neededfor 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 neededfor 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.

Appendix

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

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

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

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
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
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
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
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

	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

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

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

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:	PULMFUNCPER
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 adenocarcioma 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 cT0: 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 T0 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 cN0: 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 = cN0 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:	cM0: 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 = cM0 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 pT0: 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 = pT0 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 pN0: 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 = pN0 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:	pM0: 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 = pM0 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

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

	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

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_LUNGCA
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

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

Variable ID:	INCIDENDATE
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:	INCIDENDATEMETHOD
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

Variable ID:	COMPLSURG
Variable:	Clavien complication maximum grade

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 our 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

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

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:	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:	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:	COMPLSYSCYTODATE
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

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

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

	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_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?

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_Q03
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_Q04
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_Q05
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_Q06
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

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

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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

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