Supplementary Material

# Supplementary Tables

Supplementary table 1. Literature review characteristics.

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| Database | Pubmed/Medline |
| Search Period  | 01/01/2015- 31/12/2017 |
| Search Strategy  | ("lung neoplasms"[MeSH Terms] AND (randomized controlled trial[All Fields] OR randomized controlled trials[All Fields] OR randomized controlled trial[All Fields] OR randomised controlled trials[All Fields] OR randomized controlled trial[Publication Type] OR Review[ptyp] OR systematic[sb]) AND ("Quality of Life"[Mesh] OR "Quality Indicators, Health Care"[Mesh] OR "Patient Outcome Assessment"[Mesh] OR patient reported outcome\*[tiab] OR patient related outcome\*[tiab] OR patient-reported outcome\*[tiab] OR patient-related outcome\*[tiab] OR patient reported outcome\*[ot] OR patient related outcome\*[ot] OR patient-reported outcome\*[ot] OR patient-related outcome\*[ot] OR "Treatment Outcome"[Mesh])  |
| Filters | English [Lang]; Clinical Trials |

Supplementary table 2. Case mix variables proposed during the scientific committee and nominal group meetings.

Legend:

ALK: Anaplastic lymphoma kinase; BMI: body mass index; BRAF: v-raf murine sarcoma viral oncogene homolog B1; EGFR: Epidermal Growth Factor Receptor; FEV-1: forced expiratory volume; CV: Cardiovascular; PD-L1: Programmed Death-ligand 1; ROS-1: Reactive Oxygen Species.

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| --- | --- | --- | --- | --- |
| **Scientific Committee meeting** | **Nominal group 1** | **Nominal group 2** | **Nominal group 3** | **Nominal group 4** |
| **Demographic factors** |
| * Age
* Gender
* Ethnicity
* Educational level
 | * Age
* Gender
* Ethnicity
* Height and weight
* Family status
* Occupational exposure
 | * Age
* Gender
* Ethnicity
* Family support
* Employment status
 | * Age
* Gender
* Ethnicity
* Educational level
* Occupational exposure
 | * Age
* Gender
* BMI
* Occupational exposure to asbestos
* Employment status
* Socio-economic status
* Presence of a caregiver
 |
| **Baseline clinical factors** |
| * Unintentional weight loss
* Smoking status (pack-year index)
* Pulmonary function (FEV1)
* Comorbidities (Modified Self-administered Comorbidity Questionnaire)
 | * Unintentional weight loss
* Smoking status (pack-year index)
* Pulmonary function (FEV1)
* Comorbidities (according to clinical record: CV disease, pulmonary, renal or liver disease, endocrine disorders, immunological disease, recent surgery)
 | * Unintentional weight loss
* Smoking status
* Pulmonary function (FEV1)

Comorbidities (according to clinical record: CV disease, pulmonary, renal or liver disease, auto-immune disease, diabetes, recent surgery, hearing impairment).  | * Unintentional weight loss
* Smoking status (pack-year index)
* Comorbidities (Modified Self-administered Comorbidity Questionnaire)
* Health-related quality of life (any validated instrument)
 | * Unintentional weight loss
* Smoking status (pack-year index + classification as smoker, non-smoker, ex-smoker)
* Comorbidities
 |
| Baseline tumor factors |
| * Clinical stage (TNM)
* Pathological stage (TNM)
* Histology
* EGFR mutation
* ALK translocation
* ROS-1 rearrangement
* PD-L1 expression
 | * Clinical stage (TNM)
* Pathological stage (TNM)
* Histology
* EGFR mutation
* ALK translocation
* ROS-1 rearrangement
* PD-L1 expression
 | * Clinical stage (TNM)
* Pathological stage (TNM)
* Histology
* EGFR mutation
* ALK translocation
* ROS-1 rearrangement
* PD-L1 expression
* BRAF
* % of diagnosis based on biopsy/cytology
 | * Clinical stage (TNM)
* Pathological stage (TNM)
* Histology
* EGFR mutation
* ALK translocation
* ROS-1 rearrangement
* PD-L1 expression
 | * Clinical stage (TNM)
* Pathological stage (TNM)
* Histology
* EGFR mutation
* ALK translocation
* ROS-1 rearrangement
* PD-L1 expression
* BRAF
* Number of metastases
* Brain metastases
 |
| **Treatment Factors** |
| * Treatment intent (curative/palliative)
* Completed treatment (w/o dose reduction)
 | * Treatment intent (curative/palliative)
* Completed treatment (w/o dose reduction)
* Allergies
* Treatment withdrawal (with reasons)
 | * Treatment intent (curative/palliative)
* Completed treatment
* Treatment withdrawal
* Dose reduction
 | * Treatment intent (curative/palliative)
 | * Treatment intent (curative/palliative)
* Completed treatment (w/o dose reduction)
* First line of treatment
* Administration route (oral, intravenous, subcutaneous)
* Local treatment received (type)
 |

Supplementary table 3. Outcomes variables proposed during the scientific committee and nominal group meetings.

Legend:

CTCAE: Common Terminology Criteria for Adverse events; ECOG: Eastern Cooperative Oncology Group; EORTC: European Organisation for Research and Treatment of Cancer; EQ-5D: EuroQol; ER: emergency room; HRQoL: Health related quality of life; LCSS: Lung Cancer Symptoms Scale; PRO-CTCAE: Patient-Reported Outcomes version of the CTCAE; QLQ- LC13:Lung Cancer-specific quality of life questionnaire; SERMAS: Servicio Madrileño de Salud

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Scientific Committee meeting** | **Nominal group 1** | **Nominal group 2** | **Nominal group 3** | **Nominal group 4** |
| **Degree of health** |
| * Performance status (ECOG)
* Patient-reported health status: Global health status, physical and emotional function; fatigue, vitality, pain, cough, difficulty breathing, hemoptysis, loss of appetite, insomnia, constipation, diarrhea, weight loss (measured with a specific and a general HRQoL questionnaire)
 | * Performance status (ECOG)
* Patient-reported health status: Global health status, physical and emotional function; fatigue, vitality, pain, cough, difficulty breathing, hemoptysis, loss of appetite, (measured with LCSS + EQ-5D)
 | * Performance status (ECOG)
* Patient-reported health status: Global health status, physical and emotional function; fatigue, vitality, pain, cough, difficulty breathing, hemoptysis, loss of appetite, (measured with LCSS + EQ-5D) or Global health status, physical and emotional function; pain, cough, difficulty breathing, hemoptysis, weight loss, (measured with EORT-QLQ-LC-13 + EQ-5D)
 | * Performance status (ECOG)
 | * Performance status (ECOG)
* Patient-reported health status: Global health status, physical and emotional function; fatigue, vitality, pain, cough, difficulty breathing, hemoptysis, loss of appetite, (measured with LCSS + EQ-5D)
 |
| **Survival** |
| * Overall survival
* Cause of death
 | * Overall survival
* Cause of death
* Number of treatment lines
* Progression-free survival
* Progression-free survival (1st treatment line)
 | * Overall survival
* Cause of death
 | * Overall survival
* Cause of death
* Number of treatment lines
* Progression-free survival (clinical evaluation and/or radiographic progression)
 | * Overall survival
* Cause of death
* Progression-free survival
* Clinical benefit (time)
* Time to treatment failure
* Time to next treatment
 |
| **Quality of death** |
| * Place of death
* Length of hospital stay during end of life period
* Aggressive intervention and palliative care (Earle criteria)
* Existence or doctor´s knowledge about the living will of patients
 | * Place of death
* Length of hospital stay during end of life period
* Aggressive intervention and palliative care (Earle criteria 1, 2, 5 and 6)
* Doctor´s knowledge about the living will of patients
* Access to palliative care (y/n)
 | * Place of death
* Aggressive intervention and palliative care (Earle criteria 1-3)
* Existence or doctor´s knowledge about the living will of patients
 | * Place of death
* Therapeutic aggressiveness in the end of life (antineoplastic treatment in the last 14 days) and access to palliative care (at least 3 months before death).
* Existence or doctor´s knowledge about the living will of patients
 | * Place of death
* Length of hospital stay during end of life period
* Administration of active treatment in the last month (y/n)
* Change of treatment in the last month (y/n)
* ICU admission in the last month (y/n)
* ER admission in the last month
* Access to palliative care in the last month
 |
| **Acute complications of treatment** |
| * Major surgical complications (Indicators of the SERMAS observatory)
* Major systemic therapy or/and radiotherapy complications (CTCAE and PRO-CTCAE)
 | * Major surgical complications (surgical complications and post-operative mortality)
* Major systemic therapy or/and radiotherapy complications (CTCAE and PRO-CTCAE)
 | * Major surgical complications (surgical complications and post-operative mortality)
* Major systemic therapy or/and radiotherapy complications (CTCAE and PRO-CTCAE)
 | * Major surgical complications (Indicators of the SERMAS observatory)
* Major systemic therapy or/and radiotherapy complications (CTCAE and PRO-CTCAE)
 | * Major surgical complications (surgical complications, re-admission due to surgical complications and post-operative mortality)
* Major systemic therapy or/and radiotherapy complications (list of the 5 most relevant complications according to treatment type)
* Treatment withdrawal due to toxicity
* Patient wish to withdraw the treatment due to toxicity
 |
| **Others** |
| * Date of diagnosis
* Productivity loss of the patient and caregiver (sick leave)
* resource use (ER admission, unscheduled specialist visits, hospitalizations)
 | * Date of diagnosis
* Productivity loss of the patient and caregiver (sick leave)
* resource use (ER admission, unscheduled specialist visits, hospitalizations)
* Treatment start date
* Patients’ preferences
 | * Date of diagnosis
* Productivity loss of the patient and caregiver (sick leave)
* resource use (ER admission, unscheduled specialist visits, hospitalizations, nurse visit)
* Treatment start date
 | * Date of diagnosis
* Independence in activities

of daily living | * Date of diagnosis
* Adherence to treatment
* Time to diagnosis
* Time to first treatment
 |