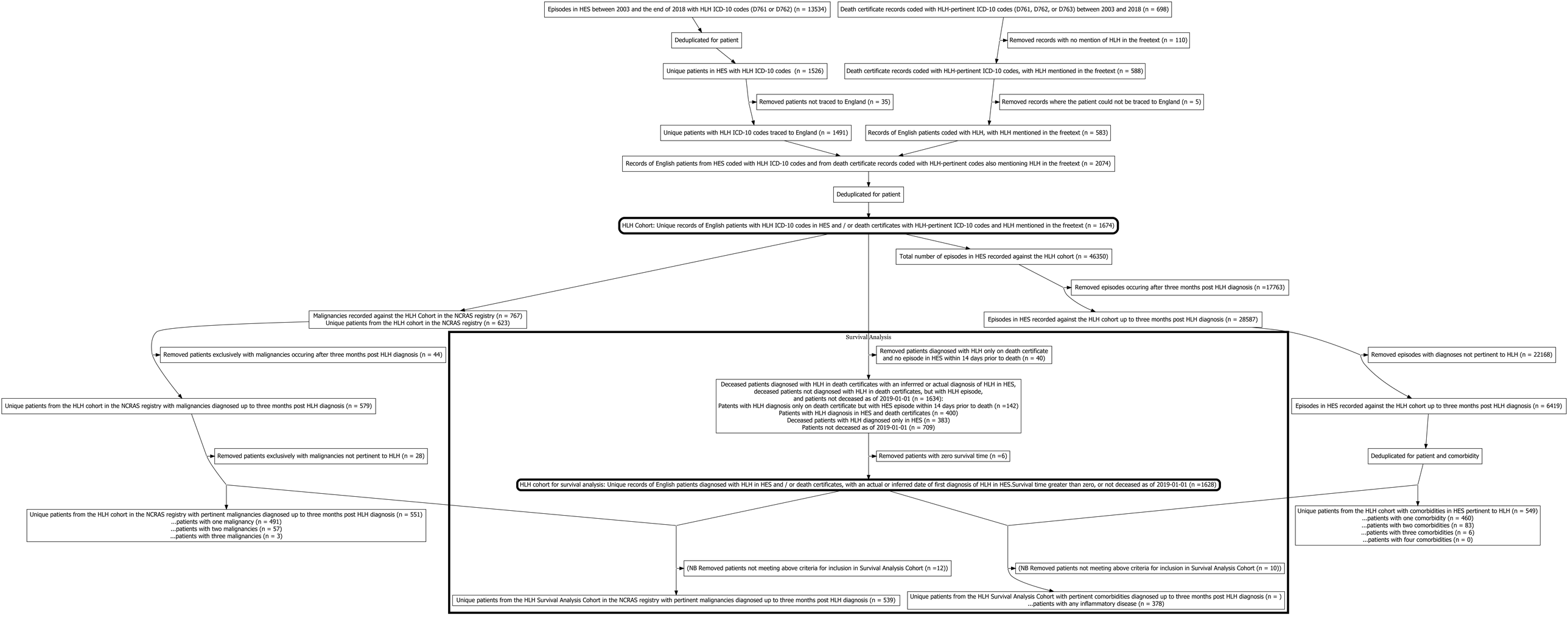
Episodes in HES between 2003 and the end of 2018 with HLH ICD-10 codes (D761 or D762) (n = 13534)
Death certificate records coded with HLH-pertinent ICD-10 codes (D761, D762, or D763) between 2003 and 2018 (n = 698)
Deduplicated for patient
Removed records with no mention of HLH in the freetext (n = 110)
Unique patients in HES with HLH ICD-10 codes (n = 1526)
Death certificate records coded with HLH-pertinent ICD-10 codes, with HLH mentioned in the freetext (n = 588)
Removed patients not traced to England (n = 35)
Removed records where the patient could not be traced to England (n = 5)
Unique patients with HLH ICD-10 codes traced to England (n = 1491)
Records of English patients coded with HLH, with HLH mentioned in the freetext (n = 583)
Records of English patients from HES coded with HLH ICD-10 codes and from death certificate records coded with HLH-pertinent codes also mentioning HLH in the freetext (n = 2074)
Deduplicated for patient
HLH Cohort: Unique records of English patients with HLH ICD-10 codes in HES and / or death certificates with HLH-pertinent ICD-10 codes and HLH mentioned in the freetext (n = 1674)
Total number of episodes in HES recorded against the HLH cohort (n = 46350)
Removed episodes occuring after three months post HLH diagnosis (n =17763)
Malignancies recorded against the HLH Cohort in the NCRAS registry (n = 767)
Unique patients from the HLH cohort in the NCRAS registry (n = 623)
Episodes in HES recorded against the HLH cohort up to three months post HLH diagnosis (n = 28587)
Survival Analysis
Removed patients exclusively with malignancies occuring after three months post HLH diagnosis (n = 44)
Removed patients diagnosed with HLH only on death certificate and no episode in HES within 14 days prior to death (n = 40)
Removed episodes with diagnoses not pertinent to HLH (n = 22168)
Deceased patients diagnosed with HLH in death certificates with an inferrred or actual diagnosis of HLH in HES, deceased patients not diagnosed with HLH in death certificates, but with HLH episode, and patients not deceased as of 2019-01-01 (n = 1634):
Patents with HLH diagnosis only on death certificate but with HES episode within 14 days prior to death (n =142)
Patients with HLH diagnosis in HES and death certificates (n = 400)
Deceased patients with HLH diagnosed only in HES (n = 383)
Patients not deceased as of 2019-01-01 (n = 709)
Unique patients from the HLH cohort in the NCRAS registry with malignancies diagnosed up to three months post HLH diagnosis (n = 579)
Episodes in HES recorded against the HLH cohort up to three months post HLH diagnosis (n = 6419)
Removed patients with zero survival time (n =6)
Removed patients exclusively with malignancies not pertinent to HLH (n = 28)
Deduplicated for patient and comorbidity
HLH cohort for survival analysis: Unique records of English patients diagnosed with HLH in HES and / or death certificates, with an actual or inferred date of first diagnosis of HLH in HES.Survival time greater than zero, or not deceased as of 2019-01-01 (n =1628)
Unique patients from the HLH cohort in the NCRAS registry with pertinent malignancies diagnosed up to three months post HLH diagnosis (n = 551)
...patients with one malignancy (n = 491)
...patients with two malignancies (n = 57)
...patients with three malignancies (n = 3)
Unique patients from the HLH cohort with comorbidities in HES pertinent to HLH (n = 549)
...patients with one comorbidity (n = 460)
...patients with two comorbidities (n = 83)
...patients with three comorbidities (n = 6)
...patients with four comorbidities (n = 0)
(NB Removed patients not meeting above criteria for inclusion in Survival Analysis Cohort (n =12))
(NB Removed patients not meeting above criteria for inclusion in Survival Analysis Cohort (n = 10))
Unique patients from the HLH Survival Analysis Cohort in the NCRAS registry with pertinent malignancies diagnosed up to three months post HLH diagnosis (n = 539)
Unique patients from the HLH Survival Analysis Cohort with pertinent comorbidities diagnosed up to three months post HLH diagnosis (n = )
...patients with any inflammatory disease (n = 378)