

Table S1: Case finding methodology and SLE ascertainment in population-based Systemic Lupus Erythematosus cohorts

Study location (ref.)	Inclusion period	Population at risk, n	Age, yrs	Case definition	Chart review	Control group	Sources of Retrieval/Case Ascertainment	Capture recapture
<b>Tucumán, Argentina [1]</b>	2005 - 2012	1 011 188	>16	≥ 4 ACR 82/97 criteria	Yes	Non	1. List of in and outpatients from four public hospital. 2. Rheumatologist in private practice	No
<b>Barbados [2]</b>	2000 - 2009	268 792	All	≥ 4 ACR 97 criteria	Yes	Non	1. List of all SLE patients from the only public and private rheumatologist service on the island. 2. All medical practitioners were contacted. 3. Patient organization	No
<b>Manitoba, Canada [3]</b>	1980 - 1996	1 100 295	All	≥ 4 ACR 82 criteria	Yes	Non	1. All general internist, rheumatologist, nephrologist and one oncologist in Manitoba. 2. 20 % of the region 500 + family physicians.	No
<b>Hong Kong, China* [4,5]</b>	1991 - 2006	~ 1 000 000	All	≥ 4 ACR 97 criteria	Yes	General population	List of in and outpatients of one regional hospital with no private practitioners in the region and no other public hospital	No
<b>Curaçao [6]</b>	1980 - 1990	146 500	All	≥ 4 ACR 82 criteria	Yes	Non	1. List of patients discharged from the only hospital at the island. 2. All specialists were ask to provide information of patients. 3. Death certificate from the Public Health Department	No
<b>Denmark [7,8]</b>	1975 - 1995	NA	All	≥ 4 ACR 82 criteria	Yes	General population; age and sex matched	List of in and out patients from eight hospital	No
<b>Funen, Denmark* [9,10]</b>	1980 - 2010	NA	≥15	≥ 4 ACR 82 criteria/ Clinical diagnosis	Yes	General population	1. A registry covering all in patients. 2. A registry covering all out patients. 3. General practitioners and private specialists .4. Hospital laboratory (ANA, anti dsDNA).	Yes
<b>Northwest Greece [11]</b>	1982 - 2001	488 435	All	≥ 4 ACR 82 criteria	Yes	General population	1. In and outpatients referred to rheumatology clinic from the two rheumatology clinics in the area. 2. Patients refereed to all private rheumatologist in the area.	No
<b>Crete, Greece [12]</b>	1999 - 2013	~ 650 000	> 15	≥ 4 ACR 97 criteria	Yes	Non	1. In and out patients from only rheumatology clinic and all nephrology, dermatology hospital departments in the region. 2. Private rheumatologists (9/12). 3. Laboratory, general practitioners, patients association, hospitalizations. 4. The National Renal Data System for ESRD	No

Study location (ref.)	Inclusion period	Population at risk, n	Age, yrs	Case definition	Chart review	Control group	Sources of Retrieval/Case Ascertainment	Capture recapture
Iceland* [13,14]	1957 - 2001	239 498	All	≥ 4 ACR 82 criteria	Yes	General population; life tables	1. Computerized search in all hospitals in Iceland. 2. Questionnaire sent to all private practitioners, district medical officers, internists, neurologists, pediatricians, dermatologists, nephrologists, rheumatologists	No
Okinawa, Japan [15]	1972 - 1991	NA	All	≥ 4 ACR 82 criteria	Yes	General population	1. Forty-five hospitals and seven clinics in the area, including all dialysis unit. 2. The Okinawa Medical Association. 3. A dialysis registry covering all chronic dialysis patients who survive more than 1 month	No
Northern Norway* [16-18]	1978 - 2006	224 724/226 898	≥16	≥ 4 ACR 82/97 criteria	Yes	General population; 5:1, matched for age, sex, municipality	In and out patients from all department in four hospitals, no private rheumatologist in the area	No
Oslo, Norway [19,20]	1999 - 2009	580 000	≥16	≥ 4 ACR 97 criteria	Yes	General population; 5:1, matched for age, gender and parents ethnicity	1. List of in and out patients from six hospitals. 2. The National Connective Tissue registry. 3. A earlier local cohort. 4. The only two private rheumatologists in the area. 5. Norway's Cause of Death Registry	No
Oman [21]	2006 - 2020	~ 4 500 000	All	≥ 4 ACR 97 or SLICC criteria	Yes	Non	Patient from the Royal Hospital and all regional hospitals of the Ministry of Health (MOH), as well as the Sultan Qaboos University Hospital.	No
Lugo, Spain [22]	1987 - 2006	NA	≥15	≥ 4 ACR 82 criteria	Yes	Non	In and out patient list of only referral center in the region	No
Lund, Sweden* [23-26]	1981 - 2014	~ 200 000	> 15	Clinical diagnosis	Yes	General population; matched age, sex	1. Computerized diagnosis registry at only hospital serving the region 2. Diagnosis registry in primary health care and private practitioners 3. Hospital laboratory (ANA, complement)	Yes
Taiwan* [27-31]	1997 - 2011	~ 22 600 000	All	≥ 4 ACR 97 criteria	Yes	General population, age matched	ICD code in The National Health Insurance Research Database that covers more than 96 - 99 % of all residents	No
Thrace, Turkey [32]	2003 - 2014	620 447	≥16	≥ 4 ACR 82 criteria	Yes	Non	1. List of in and out patient from one hospital. 2. All state hospital in the region were screened for ICD code. 3. Hospital laboratory (ANA) and pathology department (LN)	No

Study location (ref.)	Inclusion period	Population at risk, n	Age, yrs	Case definition	Chart review	Control group	Sources of Retrieval/Case Ascertainment	Capture recapture
Georgia, USA [33,34]	2002 - 2004	NA	All	≥ 4 ACR 82/97 criteria	Yes	General population; life tables; matched age, gender and race	1. Hospitals; rheumatologists, dermatologist - and nephrologists groups in the area. 2. Commercial and hospital-based laboratories (ANA, complement, anti-cardiolipin antibody). 3. Regional pathology laboratories (LN or cutaneous lupus). 5. Lupus research databases. 6. USRDS. 7. Veterans Affairs data. 8. Medicaid claims data. 9. State mortality and hospital discharge data.	Yes
Michigan, USA [35]	2002 - 2004	~ 2 400 000	All	≥ 4 ACR 97 criteria	Yes	Non	1. Hospitals/health systems in the area. 2. Private rheumatologists and nephrologists. 3. Commercial laboratories. 4. Medicaid claims. 5. USRDS. 6. Random sample of primary care practices.	Yes
Minnesota, USA [36]	1950 - 1992	NA	All	≥ 4 ACR 82 criteria	Yes	General population; life tables	Community diagnostic retrieval system (SLE, Ana, LE cell, false positive syphilis test)	No
Minnesota, USA [37]	1993 - 2005	124 277	All	≥ 4 ACR 82 criteria	Yes	General population; life tables; matched age, time of SLE diagnosis, sex	Computerized search in all local providers (Mayo Clinic, Olmsted medical center, local nursing homes and few private practitioner)	No
Wisconsin, USA [38,39]	1991 - 2008	77 280	All	≥ 4 ACR 82 criteria	Yes	Non	Community diagnostic retrieval system (SLE); covering all hospital and regional healthcare centers in the region	No
Ref.: References, n: Numbers, ACR: American College of Rheumatology SLE classification criteria, SLICC: The 2012 Systemic Lupus International Collaborating Clinics classification criteria. SLE: Systemic Lupus Erythematosus, ANA: Antinuclear antibody, LE cell: Lupus erythematosus cell test, dsDNA: Anti-double stranded DNA antibody, USRDS: United States Renal Data System, LN: Lupus Nephritis, ICD: International Statistical Classification of Diseases and Related Health Problems, ESRD: End-stage Renal Disease, NA: Not available. * Patient retrieval at different time periods								

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## Supplementary Materials S2

### Search strings MEDLINE

- 1 lupus erythematosus, systemic/ or (systemic lupus or SLE).tw,kf.
- 2 ((SLICC\* or Systemic Lupus International Collaborating Clinics or ACR\* or American College of Rheumatology or American Rheumatism Association or ARA\* or European League Against Rheumatism or EULAR\* or lupus or lupusnephritis or SLE) adj4 (criteria or classification\*)).tw,kf.
- 3 ((systemic lupus or SLE) adj2 diagnos\*).tw,kf.
- 4 2 or 3
- 5 mortality/ or "cause of death"/ or fatal outcome/ or hospital mortality/ or survival rate/ or mortality.fs. or (mortalit\* or death\* or fatal or fatalit\* or surviv\*).tw,kf.
- 6 exp Neoplasms/ or (neoplas\* or cancer\* or oncol\* or malign\* or carcinom\* or adenocarcinom\* or metasta\* or leukemia\* or myeloma\*).tw,kf.
- 7 5 or 6
- 8 incidence/ or prevalence/ or (incidence\* or prevalence\* or population based or ((unselected or un-selected) adj3 cohort\*)).tw,kf.
- 9 (observational study/ or cohort studies/ or follow-up studies/ or longitudinal studies/ or prospective studies/ or retrospective studies/) and (unselected or un-selected).tw,kf.
- 10 8 or 9
- 11 1 and 4 and 7 and 10
- 12 limit 11 to english language
- 13 Lupus Nephritis/ or (lupusnephritis or ((lupus or lupoid or systemic lupus or SLE) adj2 (nephritis or glomerulonephritis or kidney\* or nephropath\* or nephro-path\*))).tw,kf.
- 14 exp Renal Replacement Therapy/ or exp Renal Dialysis/ or Kidney Transplantation/ or (dialysis or hemodiafiltration\* or hemo-diafiltration\* or hemodialysis or ((renal or kidney) adj replacement therap\*) or ESRD or end stage renal disease\* or end stage kidney disease\* or ((kidney or renal) adj2 (transplant\* or graft\*))).tw,kf.
- 15 10 and 13 and 14
- 16 limit 15 to english language
- 17 12 or 16

### Search strings EMBASE

- 1 systemic lupus erythematosus/ or (systemic lupus or SLE).tw,kw.
- 2 ((SLICC\* or Systemic Lupus International Collaborating Clinics or ACR\* or American College of Rheumatology or American Rheumatism Association or ARA\* or European League Against Rheumatism or EULAR\* or lupus or lupusnephritis or SLE) adj4 (criteria or classification\*)).tw,kw.
- 3 ((systemic lupus or SLE) adj2 diagnos\*).tw,kw.
- 4 2 or 3
- 5 exp mortality/ or exp survival/ or death/ or "cause of death"/ or (mortalit\* or death\* or fatal or fatalit\* or surviv\*).tw,kw.
- 6 exp malignant neoplasm/ or (neoplas\* or cancer\* or oncol\* or malign\* or carcinom\* or adenocarcinom\* or metasta\* or leukemia\* or myeloma\*).tw,kw.
- 7 5 or 6
- 8 incidence/ or prevalence/ or population research/ or population based case control study/ or (incidence\* or prevalence\* or population based or ((unselected or un-selected) adj3 cohort\*)).tw,kw.

9 (observational study/ or cohort analysis/ or follow up/ or longitudinal study/ or prospective  
 study/ or retrospective study/) and (unselected or un-selected).tw,kw.  
 10 8 or 9  
 11 1 and 4 and 7 and 10  
 12 limit 11 to conference abstracts  
 13 11 not 12  
 14 limit 13 to english language  
 15 lupus erythematosus nephritis/ or (lupusnephritis or ((lupus or lupoid or systemic lupus or  
 SLE) adj2 (nephritis or glomerulonephritis or kidney\* or nephropath\* or nephro-path\*))).tw,kw.  
 16 exp renal replacement therapy/ or end stage renal disease/ or kidney graft/ or kidney  
 transplantation/ or (dialysis or hemodiafiltration\* or hemo-diafiltration\* or hemodialysis or ((renal or  
 kidney) adj replacement therap\*) or ESRD or end stage renal disease\* or end stage kidney disease\* or  
 ((kidney or renal) adj2 (transplant\* or graft\*))).tw,kw.  
 17 10 and 15 and 16  
 18 limit 17 to conference abstracts  
 19 17 not 18  
 20 limit 19 to english language  
 21 14 or 20