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## Using the ONS Longitudinal Study in epidemiological studies

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## What is the Longitudinal Study?

- a dynamic record linkage study with linked census records of $1 \%$ of the E\&W population
- started in 1971, so shortly will comprise of records spanning up to 30 years for >600,000 individuals
- complemented by event data


## Event data

- Live births and stillbirths to LS mothers
- Infant deaths to LS mothers
- Deaths of LS members and their spouses
- Embarkations
- all available to end of 2000
- Cancer registrations (to end 1997)


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## Person included from 1971 Census



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## Census data includes:

- age, sex, marital status
- family, household or communal establishment type
- housing, including tenure, rooms and amenities
- country of birth, and in 1971 parent's country of birth
- ethnicity (1991 \& 2001)
- educational qualifications (only higher level qualifications 1971 \& 1981; all levels 2001)
- economic activity
- occupation and social class
- migration and travel to work
- long-standing illness (1991 \& 2001) and self-rated health (2001)
- religion (2001)
- caregiving (2001)
- marriage and fertility history (1971)


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## Death registration data

(up to date to end 2000)
For deaths of LS members; spouses of LS members; stillbirths, neonatal \& postneonatal deaths to infants of female LS members (some for male); deaths of children < 16 to be added.

- Cause of death, main \& associated (up to 8)
- Certification type (1993_)
- Place of death, including type of communal establishment \& length of stay (1993_)
- Occupation/employment/social class of LS member \& husband/father


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## Cancer registration data

(up to date to end 1997)

- Age at registration
- Place of birth \& usual residence
- Registry Centre
- Occupation / employment / social class of LS member \& husband / father
- Basis of diagnosis
- Behaviour of neoplasm

From 1993:

- Age at diagnosis
- Marital status at registration
- Ethnic origin at registration
- Registered at screening indicator
- Tumour cell grading
- Treatment type


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# CeLSIUS (Centre for Longitudinal Study Information and User Support) 

Provides help to academic users of the LS Funded by ESRC and based at LSHTM
www.celsius.Ishtm.ac.uk

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## CeLSIUS and the ONS LS

- User support programme needed because, for confidentiality reasons, the data can only be accessed within a secure area at ONS
- Complexity of data set also means advice and training needed
- Only aggregated data can be supplied to researchers


## Data restrictions

- prevent identification of individuals
- no individual-level data released
- limits on complexity of data:
- categories, top coding
- care with geographical data
- data aggregated as frequency records


## Example of frequency record

| casessexagegpsclass | Itill9 | emiss | 411 | 11110021851 |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
|  |  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |  |

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## Research questions

- Cross-sectional (snapshot) at census point 1971, 1981 or 1991
- Change: investigating same people at two census points
- Duration: mortality, fertility, cancer incidence and survival
- need event data


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## Computing

- used to be primarily SPSS with some SAS support
- introduction of Stata some years ago when survival analysis of LS data became popular
- Celsius team now work almost exclusively in Stata


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- effectively get a person-years analysis


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## final aggregation

| cases | deaths | pyrs | period | yearfup | agegp | expected mortality |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| 3 | 0 | 3 | $1981-1985$ | 0 | $45-49$ | 0.00102 |
| 4 | 4 | 1.6425 | $1981-1985$ | 0 | $45-49$ | 0.00136 |
| 2 | 0 | 2 | $1981-1985$ | 0 | $50-54$ | 0.00068 |
| 1 | 1 | .01906 | $1981-1985$ | 0 | $50-54$ | 0.00072 |
| 2 | 0 | 2 | $1981-1985$ | 0 | $50-54$ | 0.00144 |

This data is OK to release and can form the basis of a Poisson model of crude survival or, by using a user defined link function in a glm model, relative survival can be modelled (year of follow up always included in model)

Details: Dickman P, Sloggett A, Hills M, Hakulinen T. Regression models for relative survival. Statistics in Medicine Accepted for publication 2003

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Table 1: Crude and relative survival at 1, 5 and 10 years: comparison with Cancer Survival Trends (CST)* data for breast cancer.

| Survival <br> Time | Crude survival (\%) |  |  | Relative survival (\%) |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
|  | This study <br> 1981-1997 <br> (95\% CIs) | CST <br> $\mathbf{1 9 8 1 -}$ <br> 85 | CST <br> $\mathbf{1 9 8 6 - 9 0}$ | This study <br> $\mathbf{1 9 8 1 - 1 9 9 7}$ <br> (95\%CIs) | CST <br> $\mathbf{1 9 8 1 - 8 5}$ | CST <br> $\mathbf{1 9 8 6 - 9 0}$ |
|  | $86.4(85.5-87.2)$ | 85 | 87 | $88.4(87.5-89.2)$ | 88 | 90 |
| $\mathbf{5}$ year | $58.4(57.0-59.8)$ | 54 | 59 | $66.1(64.5-67.6)$ | 63 | 68 |
| $\mathbf{1 0}$ year | $42.4(40.2-44.6)$ | 37 | - | $55.9(52.9-58.7)$ | 51 | - |

* (Coleman et al. 1999)


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## Using the LS

- Decide if the LS is a suitable source for the research project planned:
consult website; review publications (online list); consult CeLSIUS staff
- If yes, prepare project outline, consult CeLSIUS staff and submit proposal, including confidentiality undertaking
- Specify data extract needed using online resources (data dictionary) and help from assigned CeLSIUS support officer
- Specify analyses needed/aggregate tabulations
- Notify CeLSIUS of publications and presentations

