

COHORT PROFILE

Cohort Profile: The Swiss National Cohort—a longitudinal study of 6.8 million people

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How did the study come about?

For many years research on socio-economic inequalities in health in Switzerland was based on cross-sectional data.^{1–3} Cross-sectional studies are problematic for several reasons. For example, results may be affected by numerator/denominator bias.⁴ Furthermore, occupational information from death certificates was used to describe the socio-economic position of individuals. However, this meant that those who do not work, older men and a substantial proportion of women, had to be excluded.

Decennial censuses, conducted at the beginning of December every 10 years, have been done in Switzerland since 1850 (exceptions were 1890 and 1940, which were replaced by a census in 1888 and 1941, respectively). Deaths and causes of death have been registered since 1876, with data stored electronically since 1969. Death registration is anonymous. However, the date of death and birth are available, as well as gender, marital status, place of residence, date of birth of spouse and other variables. The 1990 census for the first time included the exact date of birth, which opened the possibility of linking census and mortality data. Based on the promising results of

a pilot study that was done for one Canton at University of Zurich, the project was extended to cover the whole of Switzerland, linking the 1990 census with mortality records up to the end of 1997.⁵ The results indicated that linkage was less successful for foreign nationals and young adults, and led to the inclusion of additional data sources, including data on immigrants and emigrants and, importantly, the 2000 census.⁶ In 2005, an application by all five University Institutes of Social and Preventive Medicine (ISPMs) to obtain long-term funding for a Swiss National Cohort study (SNC) was successful within the framework of a Swiss National Science Foundation initiative to support longitudinal studies. Approval was obtained from the Ethics Committees of the Cantons of Zurich and Bern and a data centre was established at ISPM Bern.

What does the study cover?

The SNC is a national longitudinal research platform with an evolving, multi-faceted research programme. Ongoing research projects include examining to what extent variations in all-cause and cause-specific mortality across municipalities can be explained by differences in their socio-economic profile; developing an area-based indicator of socio-economic status for use in health research in Switzerland; a life-course approach to mortality differentials, using data from the 1970 and 1980 censuses; examining the socio-economic determinants of mortality in the old and very old; and the epidemiology of specific causes of death (e.g. road traffic accidents, suicides, perinatal deaths, lung cancer and coronary heart disease).

The SNC also provides support to other cohort studies, for example the Swiss HIV Cohort Study,⁷ the Swiss Hepatitis C Cohort Study,⁸ the Swiss Childhood Cancer Registry^{9,10} or the Swiss Cohort Study on Air Pollution and Lung Diseases in Adults (SAPALDIA).¹¹ This involves, for example, dedicated linkage studies to increase the completeness of follow-up for vital

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Table 1 Summary of key variables from 1990 census

Key variables	
Individual	Sex; date of birth; place of birth; nationality; marital status; religion; mother tongue; language used at home, work and school; place of residence; place of residence 5 years ago; educational level; current and learned profession(s); employment status; occupational status; place of work and type of transport to work.
Household and characteristics of dwelling	Household type; number of persons living in household; children and other relatives living in household; floor; number of rooms; surface area; type of kitchen; owned or rented accommodation and rent per month.
Building characteristics	Type of building; number of flats in same building; number of floors; age of building, renovations; ownership of building; type of hot water supply, sewerage and heating and geographical coordinates.

status and causes of death, or the provision of data on the representativeness of study populations enrolled in other cohorts. Finally, we are exploring the possibility of linking the SNC with the Swiss data of the Multinational MONITORing of trends and determinants in CARDIOvascular disease (MONICA) study¹² and other Swiss health surveys^{13,14} that include information on attitudes, behaviours, life styles, as well as self-reported health status, uptake of preventive interventions and utilization of health services.

What has been measured?

All variables from the 1990 census are available in the SNC, and additional questions were introduced in 2000. The census consists of three questionnaires: one for every individual living in the household (102 variables in 1990, 172 in 2000), a household questionnaire (161 variables in 1990, 204 in 2000), which also covers characteristics of the dwelling and a further questionnaire on the building (66 variables 1990, 48 in 2000). The questionnaires (in German, French, Italian and English) and variable lists (in German and French) are available from the SNC's website, at www.swissnationalcohort.ch. Table 1 gives an overview of the information collected in the 1990 census. Causes of death were coded according to the eighth revision of the International Classification of Diseases, Injuries and Causes of Death (ICD-8) until 1994. Since 1995 the 10th revision (ICD-10) has been used. In addition to the date and cause of death and socio-demographic data, information on the time and

place of death is included in the mortality file. Registration of deaths is near complete for people dying in Switzerland, but less complete for deaths among immigrants who returned to their countries after retirement.⁶

Who is in the sample?

The anatomy of the SNC is shown in Figure 1. The core cohort consists of the 6.874 million residents who participated in the 1990 census. Participation in the census is mandatory in Switzerland and enumeration is virtually complete. The Federal Office of Statistics assessed non-participation in the 2000 census and estimated coverage at 98.6%.¹⁵ At the time of writing (September 2007), census data from 2000, mortality and migration files up to 2005 had been linked with the 1990 census, resulting in 96.7 million person-years of follow up during which 875 269 deaths occurred. The database is continuously updated with the latest mortality and migration files. Table 2 shows the characteristics of the study population: 82% were Swiss nationals, 51% were females, the mother tongue was German in 64% and 46% were aged 30–64 years. The largest religious group was catholic (46%). Among individuals aged ≥ 25 , vocational education was most common (45%).

How were records linked?

In the absence of a unique personal identifier, both deterministic and probabilistic methods of record linkage were used to link records from the 1990 census to a death record, a 2000 census record or an emigration record. In the first step, pairs of records that were matched on sex, date of birth, marital status, nationality, religion and place of residence were identified. In subsequent steps, probabilistic record linkage was used, which estimates the probability that a pair of records from different datasets relates to the same person.¹⁶ Additional variables, in particular information on the spouse and family structure were used in this process. Based on probability weights, possible matches were accepted or rejected. Linkage was recently automated using the Generalized Record Linkage System (GRLS) package developed by Statistics Canada.¹⁷ GRLS is an iterative procedure with predefined criteria for blocking and rules for how linkage variables are compared and weighted. GRLS is used each year to include the latest published mortality data.

Of 6 873 687 individuals registered in the 1990 census, 5 628 965 (81.9%) could be linked to a 2000 census record and, during the period 1990–2000, 175 929 (2.6%) to an emigration record and 591 979 (8.6%) to a mortality record (Figure 1). For the remaining 476 814 individuals with a 1990 census

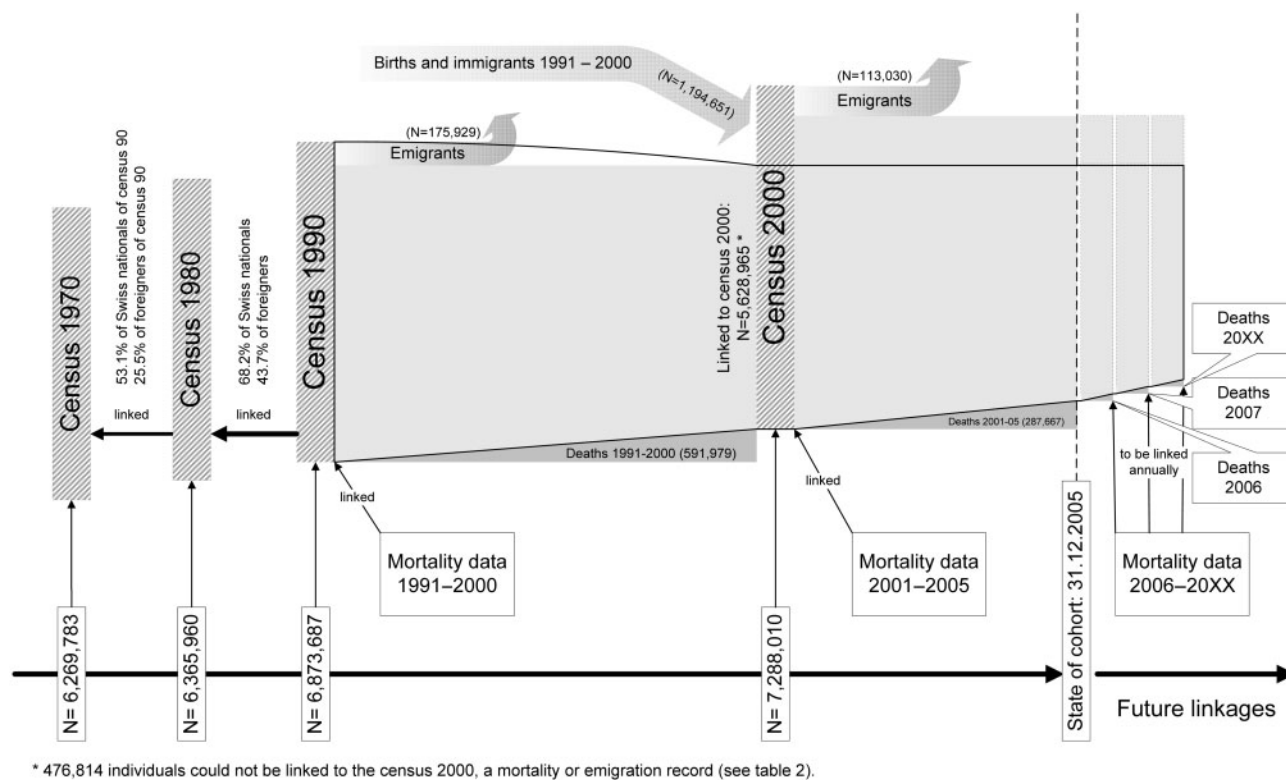


Figure 1 Structure of the Swiss National Cohort

records (6.9%) no satisfactory link could be found. Table 2 compares unlinked census records with all records from census 1990. The majority of unlinked records related to individuals aged 10–29 years. The lower linkage rates among young adults are probably due to their high mobility and residence in larger cities, which makes linkage more difficult. Also, a large proportion of young adults live in single households, which precludes the use of information on the spouse and family as additional linkage variables.

Of the 937 637 deaths recorded from December 5, 1990 (the day after the census) to the end of 2005, 875 269 (93.3%) could be linked to a 1990 census record. Table 3 compares the characteristics of all deaths from the census 1990 up to 2005 with those, which could be reasonably linked to a census record. Deaths that could not be linked were younger at death, less likely to be Swiss nationals and more likely to be women and single. Injury and poisoning, ill-defined causes and other causes were more common among unlinked deaths, and malignancies and cardiovascular causes more common among linked deaths.

Of note, people recorded in the 1990 census were also traced back to the censuses of 1980 and 1970. Despite the fact that in the earlier censuses only the year of birth, rather than exact birth dates are available, a substantial proportion of records could be linked: 82.2% of individuals born before 1940 could be found in the 1980 census and 74.3% also in the

1970 census (Figure 1). Similar results were obtained for the 2000 census.

What has the Swiss National cohort found?

Recent analyses of SNC data focused on mortality differentials by level of education among men and women of Swiss nationality, based on mortality data up to 1997.¹⁸ Standardized mortality ratios for men aged 25–39 were 61 (95% confidence interval 54–70) among men with university education, compared with 196 (184–209) among men with compulsory schooling or less. Gradients in women were less pronounced. When expressed as differentials in life expectancy,¹⁹ men with university education aged 30, 50, 65 and 80 years lived 7.1, 5.4, 3.5 and 1.6 years, respectively longer than their counterparts with compulsory education only. In women the corresponding differences were 3.6, 3.1, 2.7 and 2.2 years, respectively. During the years leading to the establishment of the SNC, mortality data from the German-speaking part of Switzerland were included in several analyses of the SEDHA project (Socio-Economic Determinants of Healthy Aging), which studied socio-economic differences in morbidity and mortality in adults in different European countries. Swiss data contributed to analyses of educational gradients in all-cause mortality²⁰

Table 2 Socio-demographic characteristics of entire study population from 1990 census and persons not linked to either the 2000 census or a mortality or emigration record 1990–2000: Swiss National Cohort

	Census 1990	
	All (%)	Not linked ^a (%)
Total	6 873 687 (100)	476 814 (100)
Nationality		
Swiss	5 628 255 (82)	390 785 (82)
Other	1 245 432 (18)	86 029 (18)
Sex		
Females	3 483 475 (51)	226 104 (47)
Males	3 390 212 (49)	250 710 (53)
Linguistic region		
German	4 949 434 (72)	327 762 (69)
French	1 604 372 (24)	127 986 (27)
Italian	294 862 (4)	19 517 (4)
Rumantsch	25 019 (0)	1549 (0)
Mother tongue		
German	4 374 694 (64)	282 707 (59)
French	1 321 695 (19)	99 745 (21)
Italian	524 116 (8)	27 785 (6)
Other	653 182 (9)	66 577 (14)
Age groups		
0–9 years	787 649 (11)	37 006 (8)
10–29 years	1 942 256 (28)	254 269 (53)
30–64 years	3 159 020 (46)	144 571 (30)
65–84 years	880 772 (13)	33 733 (7)
85 years and over	103 990 (2)	7235 (2)
Marital status		
Never married	2 895 681 (42)	303 022 (64)
Married	3 266 943 (48)	124 543 (26)
Widowed	415 544 (6)	24 092 (5)
Divorced	295 519 (4)	25 157 (5)
Educational level (aged ≥ 25)		
College and tertiary	843 781 (18)	43 827 (18)
Vocational education	2 140 479 (45)	88 020 (36)
Compulsory schooling	1 536 334 (32)	86 905 (36)
None/not stated	228 034 (5)	23 311 (10)
Religious denomination		
Catholic	3 172 321 (46)	219 354 (46)
Protestant	2 747 821 (40)	189 136 (40)
Other denomination	340 719 (5)	34 034 (7)
No denomination	510 927 (7)	25 009 (5)
Not stated	101 899 (2)	9281 (2)
Area of residence		
Urban	2 106 775 (31)	144 090 (30)
Periurban	2 972 999 (43)	209 634 (44)
Rural	1 793 913 (26)	123 090 (26)

^aNot linked to census 2000 or a death or emigration record 1990–2000.

Table 3 Socio-demographic characteristics of all deaths 1990–2005 and unlinked deaths: Swiss National Cohort

	Deaths 1990 to 2005	
	All ^a (%)	Not linked ^b (%)
Total	930 247 (100)	56 640 (100)
Nationality		
Swiss	869 300 (93)	49 744 (88)
Other	60 947 (7)	6896 (12)
Sex		
Females	472 271 (51)	33 112 (58)
Males	457 976 (49)	23 528 (42)
Linguistic region		
German	668 253 (72)	36 697 (65)
French	214 180 (23)	16 289 (29)
Italian	43 462 (5)	3333 (6)
Rumantsch	4352 (0)	321 (0)
Age groups		
0–9 years	1344 (0)	579 (1)
10–29 years	14 692 (2)	2383 (4)
30–64 years	151 254 (16)	10 830 (19)
65–84 years	443 505 (48)	21 528 (38)
≥ 85 years	319 452 (34)	21 320 (38)
Marital status		
Never married	134 996 (15)	13 995 (25)
Married	375 927 (40)	11 123 (20)
Widowed	356 515 (38)	25 560 (45)
Divorced	62 809 (7)	5962 (10)
Religious denomination		
Catholic	366 924 (39)	21 331 (38)
Protestant	473 119 (51)	23 997 (42)
Other denomination	35 735 (4)	5346 (9)
No denomination	31 338 (3)	3167 (6)
Not stated	23 131 (3)	2799 (5)
Area of residence		
Urban	330 751 (35)	20 311 (36)
Periurban	349 478 (38)	21 314 (38)
Rural	250 016 (27)	15 015 (26)
Cause of death		
Malignant neoplasm	234 610 (25)	11 122 (20)
CVD	380 951 (41)	21 584 (38)
Ill-defined	28 956 (3)	2847 (5)
Injury and poisoning	59 389 (7)	5161 (9)
Other	226 341 (24)	15 926 (28)

^aOnly death records eligible for linkage, i.e. without individuals born or immigrated after the 1990 census.

^bNot linked to census 1990 record.

and cause-specific mortality,²¹ including mortality from cancer,^{22,23} cardiovascular disease,^{24,25} traffic accidents²⁶ and suicide.²⁷ Another study examined the influence of marital status on suicide risk.²⁸ The results showed that despite a comparatively low overall mortality, Swiss men, and particularly young men, tended to show steeper educational mortality gradients than men in other European countries. In contrast, gradients in Swiss women were below average. More recently, the SNC contributed data to the EUROTHINE project (Tackling Health Inequalities in Europe: an integrated approach). A recent analysis of alcohol related cancer mortality showed that gradients in Swiss men were among the steepest in Western European populations.²⁹

What are the main strengths and weaknesses?

Based on the entire Swiss population in 1990, i.e. 6.8 million men, women and children and a follow-up of currently 15 years, the SNC is one of the largest longitudinal datasets worldwide. Value is added by the fact that Switzerland includes several distinct cultural, linguistic and geographical regions and populations within the same country and health system. We believe the SNC has considerable potential, considering the wealth of data that is available from the census, which included separate and detailed questionnaires at the level of the person, household and dwelling, with information that is not generally available in longitudinal studies. Because each building is geo-referenced, the SNC also allows the study of environmental exposures, for example electromagnetic fields from power lines. Finally, the linkage of the census with other existing databases means that the SNC is very cost-effective.

An important limitation is the SNC's reliance on routine mortality data for outcomes, and the lack of information on lifestyle and other exposures. Swiss mortality records are virtually complete for deaths that occurred in Switzerland. However, deaths among immigrants are under ascertained, particularly in older individuals who tend to return to their countries after retirement.⁶ The accuracy of death certificates was estimated in a comparison of information on cause of death from hospital discharge records with the data available from the routine mortality statistics in Switzerland in 1989.³⁰ There was good concordance (>85%) for most of the malignant neoplasms, cerebrovascular diseases, ischaemic heart disease and accidents, but low concordance (<65%) for diseases of nervous system, chronic respiratory diseases and other forms of heart diseases. More recent international studies support these results: routine cause of death information is generally accurate for clearly defined diagnoses including, for example, malignant neoplasms, but less accurate for less well defined

conditions such as chronic obstructive pulmonary disease (COPD).^{31–33}

Can I get hold of the data and where can I find out more?

The SNC database is open to collaborations with national and international researchers. Access to raw and tabulated data has to be approved by Swiss Federal Statistical Office, who owns the data. We invite interested parties to contact the study team (snc_info@ispm.unibe.ch.) in order to discuss project ideas, data access and the submission of a concept to the study's Scientific Board. Templates for concept sheets and further information on the study are available at www.swissnationalcohort.ch.

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References

- Minder CE. Socio-economic factors and mortality in Switzerland. *Soz Präventivmed* 1993;**38**:313–28.
- Beer V, Bisig B, Gutzwiller F. Social class gradients in years of potential life lost in Switzerland. *Soc Sci Med* 1993;**37**:1011–18.
- Egger M, Minder CE, Davey Smith G. Health inequalities and migrant workers in Switzerland. *Lancet* 1990;**336**:816.
- Kunst AE, Groenhof F, Borgan JK *et al.* Socio-economic inequalities in mortality. Methodological problems illustrated with three examples from Europe. *Rev Epidemiol Sante Publique* 1998;**46**:467–79.
- Bopp M, Gutzwiller F. *Record Linkage von Volkszählung 1990 und Todesursachenstatistik 1990–97 in der Schweiz*. 2000. *Forschung und Dokumentation No. 23*. Zürich: Institut für Sozial- und Präventivmedizin der Universität, 2000.
- Bopp M, Gutzwiller F. *Die Swiss National Cohort 1990–2000 – eine soziodemografische Datenbasis für longitudinale Gesundheitsanalysen*. *Swiss National Cohort Report Nr. 5*. *Forschung und Dokumentation 28*. Zürich: Institut für Sozial- und Präventivmedizin, 2007.
- Egger M, Hirschel B, Francioli P *et al.* Impact of new antiretroviral combination therapies in HIV infected patients in Switzerland: prospective multicentre study. *Br Med J* 1997;**315**:1194–99.
- Prasad L, Spicher VM, Zwahlen M, Rickenbach M, Helbling B, Negro F. Cohort Profile: the Swiss Hepatitis C Cohort Study (SCCS). *Int J Epidemiol* 2007;**36**:731–37.
- Michel G, von der Weid NX, Zwahlen M, Redmond S, Strippoli MP, Kuehni CE. Incidence of childhood cancer

- in Switzerland: the Swiss Childhood Cancer Registry. *Pediatr Blood Cancer* 2008;**50**:46–51.
- ¹⁰ Michel G, von der Weid NX, Zwahlen M, Adam M, Rebholz CE, Kuehni CE. The Swiss Childhood Cancer Registry: rationale, organisation and results for the years 2001–2005. *Swiss Med Wkly* 2007;**137**:502–9.
- ¹¹ Ackermann-Lieblich U, Kuna-Dibbert B, Probst-Hensch NM *et al.* Follow-up of the Swiss Cohort Study on Air Pollution and Lung Diseases in Adults (SAPALDIA 2) 1991–2003: methods and characterization of participants. *Soz Präventivmed* 2005;**50**:245–63.
- ¹² Rickenbach M, Gutzwiller F, Wietlisbach V, Martin J, Epstein FH. Switzerland's participation in MONICA. *Soz Präventivmed* 1985;**30**:95–99.
- ¹³ Gutzwiller F, La Vecchia C, Levi F, Negri E, Wietlisbach V. Education, disease prevalence and health service utilization in the Swiss National Health Survey "SOMIPOPS". *Prev Med* 1989;**18**:452–59.
- ¹⁴ Eichholzer M, Bisig B. Daily consumption of (red) meat or meat products in Switzerland: results of the 1992/93 Swiss Health Survey. *Eur J Clin Nutr* 2000;**54**:136–42.
- ¹⁵ Bundesamt für Statistik. *Eidgenössische Volkszählung 2000. Abschlussbericht zur Volkszählung 2000.* Neuchâtel: Bundesamt für Statistik, 2005.
- ¹⁶ Fellegi IP, Sunter AB. A theory of record linkage. *J Am Stat Assoc* 1969;**64**:1183–210.
- ¹⁷ Fair M. Generalized record linkage system - Statistics Canada's record linkage software. *Austrian J Stat* 2004;**33**:37–53.
- ¹⁸ Bopp M, Minder CE. Mortality by education in German speaking Switzerland, 1990–1997: results from the Swiss National Cohort. *Int J Epidemiol* 2003;**32**:346–54.
- ¹⁹ Spoerri A, Zwahlen M, Egger M, Gutzwiller F, Minder C, Bopp M. Educational inequalities in life expectancy in German speaking part of Switzerland 1990–1997: Swiss National Cohort. *Swiss Med Wkly* 2006;**136**:145–48.
- ²⁰ Huisman M, Kunst AE, Andersen O *et al.* Socioeconomic inequalities in mortality among elderly people in 11 European populations. *J Epidemiol Community Health* 2004;**58**:468–75.
- ²¹ Huisman M, Kunst AE, Bopp M *et al.* Educational inequalities in cause-specific mortality in middle-aged and older men and women in eight western European populations. *Lancet* 2005;**365**:493–500.
- ²² Mackenbach JP, Huisman M, Andersen O *et al.* Inequalities in lung cancer mortality by the educational level in 10 European populations. *Eur J Cancer* 2004;**40**:126–35.
- ²³ Strand BH, Kunst A, Huisman M *et al.* The reversed social gradient: higher breast cancer mortality in the higher educated compared to lower educated. A comparison of 11 European populations during the 1990s. *Eur J Cancer* 2007;**43**:1200–7.
- ²⁴ Avendano M, Kunst AE, Huisman M *et al.* Socioeconomic status and ischaemic heart disease mortality in 10 western European populations during the 1990s. *Heart* 2006;**92**:461–67.
- ²⁵ Avendano M, Kunst AE, Huisman M *et al.* Educational level and stroke mortality: a comparison of 10 European populations during the 1990s. *Stroke* 2004;**35**:432–37.
- ²⁶ Borrell C, Plasencia A, Huisman M *et al.* Education level inequalities and transportation injury mortality in the middle aged and elderly in European settings. *Inj Prev* 2005;**11**:138–42.
- ²⁷ Lorant V, Kunst AE, Huisman M, Costa G, Mackenbach J. Socio-economic inequalities in suicide: a European comparative study. *Br J Psychiatry* 2005;**187**:49–54.
- ²⁸ Lorant V, Kunst AE, Huisman M, Bopp M, Mackenbach J. A European comparative study of marital status and socio-economic inequalities in suicide. *Soc Sci Med* 2005;**60**:2431–41.
- ²⁹ Menvielle G, Kunst AE, Stirbu I *et al.* Socioeconomic inequalities in alcohol related cancer mortality among men: to what extent do they differ between Western European populations? *Int J Cancer* 2007;**121**:649–55.
- ³⁰ Minder, C, Zingg W. *Die Sterblichkeitsstatistik in der Schweiz. Amtliche Statistik der Schweiz No. 155.* Bern: Bundesamt für Statistik, 1989.
- ³¹ Weinstock MA, Reynes JF. Validation of cause-of-death certification for outpatient cancers: the contrasting cases of melanoma and mycosis fungoides. *Am J Epidemiol* 1998;**148**:1184–86.
- ³² Lahti RA, Penttilä A. Cause-of-death query in validation of death certification by expert panel; effects on mortality statistics in Finland, 1995. *Forensic Sci Int* 2003;**131**:113–24.
- ³³ Jensen HH, Godtfredsen NS, Lange P, Vestbo J. Potential misclassification of causes of death from COPD. *Eur Respir J* 2006;**28**:781–85.